

**Functioning, disability and health in people living with
HIV on antiretroviral therapy in Rwanda**

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ABSTRACT

Many people living with the Human Immunodeficiency Virus (HIV) (PLWH) experience functional limitations caused by either the HIV infection itself and/or the antiretroviral treatment. In Rwanda, many PLWH have access to antiretroviral treatment; however, there is no information about the extent of disability or functional limitations present among PLWH which might be caused by either the HIV infection or the antiretroviral treatment. In addition, the service delivery model may well be based on the medical model, rather than the bio-psycho-social model. As a consequence, PLWH may be receiving medical treatment, but we do not know whether they need or are receiving rehabilitation within the hospital environment and support within the community. This study used the bio-psycho-social model with the International Classification of Functioning, Disability and Health (ICF) as a theoretical framework.

The study aimed to explore the need for and nature of care that PLWH living in Rwanda receive from their health care providers using a bio-psycho-social framework. A further aim was to determine if the Kinyarwanda version of the World Health Organisation Disability Assessment Schedule 2.0 (WHODAS 2.0), which was used to gather the functional data, was valid within the Rwandan context. A mixed methods approach was used.

A quantitative survey was used to determine the profile and the prevalence of disability among PLWH, by measuring impairment, activity limitation and participation restriction amongst PLWH who are also on antiretroviral treatment. In addition the relationship between functioning and medication was explored. A Kinyarwanda version of the ICF core set of questions and the WHODAS 2.0 outcome instrument was used. Face-to-face interviews were conducted among PLWH at 15 selected hospitals representing all provinces in the country. The final sample size included 502 PLWH. Participants' health status showed that the longer they had HIV and had been on antiretroviral treatment, the more likely they were to have impairments. Pain (69%) and fatigue (83%) were more prevalent than any other problems found in all domains measured under impairments. Problems with mobility function (57%) scored the highest prevalence under activity limitations, and problems in participation/social functions had the highest prevalence in comparison to the other domains. The mean score of the different domains were significantly different with participation scoring the highest (46%, with 100% the worst score rate). Participants experienced problems for approximately half

the days in every month. Various impairments of body function predicted functional limitations with regard to activities and the participation/social restriction domains. Energy and drive and memory functions were predictive of the means scores of all the domains.

The qualitative component used focus group discussions among PLWH on antiretroviral treatment with associated disabilities, to explore the relationship between the impairments, functional limitations, participation restrictions and personal and environmental factors. Two focus group discussions consisting of a total of 16 PLWH with associated disabilities (10 females, six males), were conducted at two hospitals, and purposively selected from among the fifteen hospitals involved in the survey. The impairments experienced every day, including a lack of energy, pain, paraesthesia, breathlessness and loss of memory corroborated the findings of the quantitative survey. These impairments affected their performance of daily activities and their participation in social life. Participants described the personal factors that facilitated functioning (such as spiritual beliefs, and positive thinking about disclosure as a strategy to improve psychological well-being, to overcome internalized stigma and to create awareness about HIV), or limited functioning (for example internalized stigma and age), and the social relationship environmental factors that facilitated functioning, or limited functioning, which included participants' relationships with their families, and with their communities. Participants discussed the influence of the hospital environment and services (either as a facilitator or a barrier) on their functioning. This included the ARV (Antiretroviral) clinic and services in the hospital outside the ARV clinic. Participants made recommendations that could improve service delivery provided to PLWH with associated disabilities or functional limitations, such as increase in the number of health care providers including rehabilitation care using a multidisciplinary approach and the establishment of counselling programmes.

The process of translating the English version of the ICF core set of questions and the WHODAS 2.0 outcome instrument into Kinyarwanda is documented; it highlights the problems encountered, whether related to linguistic meaning or to cultural influence. Despite challenges, particularly with regard to words used for disability and impairment, the translated versions were found to have appropriate linguistic and cultural meanings, and used clear and understandable expressions. Additionally, impairments, activity limitations and participation restrictions that were identified by participants in the focus group discussions were used to determine content validity. The translated instruments demonstrated good

content validity. One way ANOVA was used to establish convergent validity of the WHODAS 2.0 and Cronbach's Alpha was calculated to test for internal consistency of the Impairments Questionnaire and the WHODAS 2.0. The translated instruments demonstrated good construct validity and good reliability.

In conclusion, the prevalence of disability in PLWH on antiretroviral therapy in Rwanda is considerable. There were a large range of functional limitations among PLWH associated with a variety of impairments which cannot be addressed simply by pharmacological medical management. There is a need to establish interdisciplinary collaboration by a multidisciplinary team, based on a bio-psychosocial approach, to reinforce referral within the hospital system. In addition, the use of a bio-psychosocial model, such as that of the ICF framework, might lead to more holistic assessment and management of these patients.



DECLARATION

I declare that Functioning, Disability, and health in people living with HIV on antiretroviral therapy in Rwanda, is my own work, that it has not been submitted for any degree or examination in any other University, and that all the sources I have used or quoted have been indicated and acknowledged by means of complete references.

Name:

Date:

Signed:



DEDICATION

To my husband Kasongo Wa-Kutuma and our children Kabedi Malaika and Kalala Musomba for your unwavering support, love, understanding, and above all, your patience.

To my dearest nephews Malo Shingiro Kahamaile and Maxime Nkiko Kahamaile, for the cherished memory of your father, my brother, Justin Murego Kahamaile. He will always be present among us.



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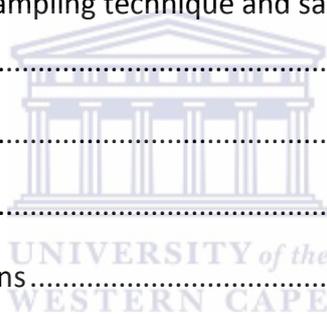
Many thanks to all who have assisted with data collection. Last but not least, my sincere thanks to all the participants in this study for accepting to share your life experience.

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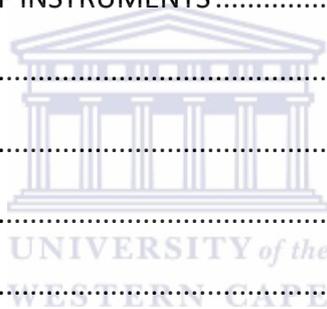
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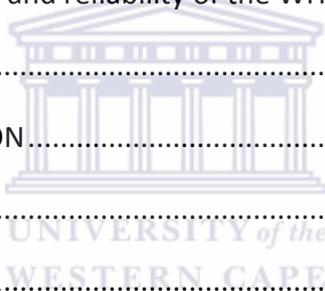
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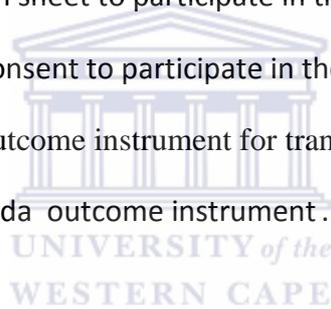


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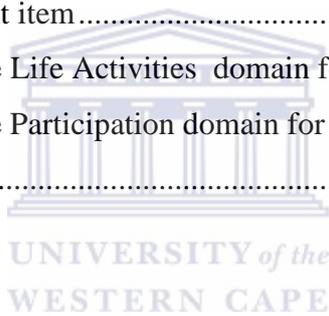
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ABBREVIATIONS

| | |
|----------|--|
| ABC | Abacavir |
| AIDS | Acquired Immunodeficiency Syndrome |
| ARV | Antiretroviral |
| AZT | Zidovudine |
| CBHI | Community Based Health Insurance |
| CDC | Centers for Disease Control and Prevention |
| CD4 | Cluster definition 4 |
| CHUK | <i>Centre Hospitalier Universitaire de Kigali</i> |
| CNLS | <i>Commission Nationale de Lutte contre le SIDA/National AIDS Control Commission</i> |
| CNS | Central nervous system |
| DNA | Deoxyribonucleic acid |
| d 4T | Stavudine |
| EFV | Efavirenz |
| EQ-5D | The European Quality of Life 5-dimensions |
| FGD | Focus Group Discussion |
| FIM | Function Independence Measure |
| FTC | Emtricitabine |
| HDL | Higher density lipoprotein |
| HIV | Human Immunodeficiency Virus |
| HIV/AIDS | Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome |
| HOOS | Hip disability and Osteoarthritis Outcome Score |
| HRQoL | Health- related quality of life |
| ICF | International Classification of Function |
| IRIS | Immune reconstitution inflammatory syndrome |
| K-DASH | Korean version of the disability of arms, shoulder, and hand outcome questionnaire |
| KHI | Kigali Health Institute |
| KHI IRB | Kigali Health Institute Institution Review Board |
| LDL | Lower density lipoprotein |
| MMI | Military Medical Insurance |

| | |
|------------------|---|
| NGOs | Non-Governmental Organisations |
| NNRTIs | None Nucleoside Reverse Transcriptase Inhibitors |
| NRTIs | Nucleoside Reverse Transcriptase Inhibitors |
| NVP | Nevirapine |
| PCP | Pneumocystis Cariini pneumonia |
| Pis | Protease Inhibitors |
| PLWH | People living with HIV |
| PMTCT | Prevention of mother to child transmission of HIV |
| RAMA | <i>Regime d'Assurance Maladie des Agents de l'etat</i> /Rwanda Medical Insurance Scheme |
| RBC/HIV division | Rwanda Biomedical Centre/HIV division |
| RDHS | Rwanda Demographic and Health Survey |
| RNA | Ribonucleic Acid |
| STI | Sexually transmitted infections |
| TB | Tuberculosis |
| TDF | Tenofovir |
| 3TC | Lamivudine |
| Trac Plus | Treatment and Research AIDS Centre Plus |
| UWC | University of the Western Cape |
| WHO | World Health Organisation |
| WHODAS 2.0 | The World Health Organisation Disability Assessment Schedule 2.0 |
| WHOQOL-BREF | World Health Organisation Quality of Life instrument |
| WHOQOL-HIV BREF | World Health Organisation Quality of Life HIV instrument |



1 CHAPTER ONE: INTRODUCTION

1.1 Background

Worldwide, there were an estimated of 34 million people living with HIV¹ (PLWH) in 2011, and sub-Saharan Africa continues to be the region the most severely affected , accounting for 69% of all PLWH globally (UNAIDS, 2012a). The United Nations joint programme on Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome (HIV/AIDS) reported that new Human Immunodeficiency Virus (HIV) infection rates have decreased considerably in many countries, especially in the sub-Saharan Africa region (UNAIDS, 2012a, 2012b), and the number of the people who have died from Acquired Immunodeficiency Syndrome (AIDS) related illnesses declined drastically in 2011 compared to the figure for six years previously (UNAIDS, 2012b). This decline has largely been achieved through investment in, and the scaling up of, antiretroviral treatment². It has been indicated that in sub-Saharan Africa, approximately 56% of PLWH who are eligible have had access to antiretroviral treatment (UNAIDS, 2012a).

1.1.1 HIV in Rwanda

Rwanda is among the ten countries in sub-Saharan Africa most severely affected by the pandemic of HIV/AIDS (World Health Organisation (WHO), 2005b), and HIV infection is one of the two diseases which cause the most significant burden on Rwanda's health system (Ministry of Health (MoH) of Rwanda, 2009) . The most recent Rwanda Demographic and Health Survey (RDHS) conducted in 2010 indicated that the HIV prevalence rate was 3% in the general population (National Institute of Statistics Rwanda, Ministry of Health Rwanda, & ICF International US, 2012).

Enrolment into antiretroviral treatment programmes increased from 35% of PLWH who were eligible in 2005 to 76% in 2008. There was a significant reduction in the real cost of accessing antiretroviral treatment services by PLWH as a result of the introduction of the community based health insurance (CBHI); *Mutuelle de Santé*³, which covers the cost of

¹The term People living with HIV (PLWH) is used, referring to the document published by UNAIDS on terminology guidelines. This was suggested as it signifies that an infected person may continue living a normal life for a long period (UNAIDS, 2011b).

² Antiretroviral treatment is used, referring to the document published by UNAIDS on terminology guidelines. It was recommended that it is preferable to spell out "antiretroviral treatment" or "antiretroviral therapy", instead of using an abbreviation, so as to avoid confusion with other similar terms such as AZT (UNAIDS, 2011b).

³ Mutuelle de Santé is a French term and it is commonly used to mean community based health insurance.

antiretroviral treatment. In addition the treatment of opportunistic infections was included in other service packages offered by *Mutuelle de Sante* (Ministry of Health (MoH) of Rwanda, 2009). In the year 2011, antiretroviral treatment reached 93% of the national coverage (Ministry of Health (MoH) Rwanda, 2012b).

1.1.2 PLWH and disability

There is an accumulation of evidence that suggests that the provision of antiretroviral treatment has changed the profile of the HIV infection from being a terminal illness to being a chronic, manageable disease: PLWH can expect to live normal lives (Fillipas, Oldmeadow, Bailey, & Cherry, 2006; Mahungu, Rodger, & Johnson, 2009; Rusch et al., 2004a). However, numerous impairments are also experienced; these are caused by the HIV infection itself, its related pathologies and the side effects of antiretroviral treatment (Hanass-Hancock & Nixon, 2009a; O'Brien, Bayoumi, Strike, Young, & Davis, 2008; Rusch, et al., 2004a).

The disability or functional limitations experienced by PLWH are more severe than in the general population (Worthington, Myers, O'Brien, Nixon, & Cockerill, 2005). These impairments can affect the individual's physical, psychological and social functioning (Myezwa, Stewart, Musenge, & Nesara, 2009; Rusch, et al., 2004a; Van As, Myezwa, Stewart, Maleka, & Musenge, 2009). This can have an impact on the individual's health related quality of life (HRQoL) (Lorenz, Cunningham, Spritzer, & Hays, 2006). The manifestation of these impairments and functional limitations may be episodic, multidimensional, and unpredictable (Hanass-Hancock & Nixon, 2009a; O'Brien, et al., 2008), or they may be permanent (Hanass-Hancock & Nixon, 2009a). These are influenced by environmental and personal contextual factors which can hinder or facilitate functioning. This experience of disability can be accompanied by uncertainty as PLWH struggle to readjust to their new situation of living with long-term chronic illness (O'Brien, et al., 2008).

1.1.3 PLWH and Health service delivery

Based on a public health perspective, there are four major strategies which health care and service providers should consider as essential to deliver comprehensive care: prevention, curative care, support and rehabilitation. Curative care refers to a secondary prevention whereas rehabilitation sometimes refers to as tertiary prevention. The goal of prevention is to maintain the health of the population. Curative care aims to control the disease process. Supportive care aims at improving quality of life through the palliation of symptoms and by

providing assistance. Rehabilitation aims to optimise functioning (Stucki, Cieza, & Melvin, 2007).

“Rehabilitation care achieves its goal by applying and integrating approaches to optimize a person’s capacity, approaches which build on and strengthen the resources of the person, which provide a facilitating environment, and which develop performance in the interaction with the environment” (Stucki, et al., 2007, p. 280).

Primary health care provides comprehensive health care to people also includes the health care strategies highlighted above: preventive care, curative care, rehabilitative care and in addition, promotive care (Hall & Taylor, 2003; Walton et al., 2004). It is characterised by equity and the universal provision of basic health care services, by affordable and appropriate health care services, , and by accessible health care services with community participation (Hall & Taylor, 2003; Walley et al., 2008). It includes all levels of the health system, such as clinics and health centres in the community, as well as hospitals (Hall & Taylor, 2003).

There has been a considerable increase in the incidence of chronic illnesses, particularly in developing countries; these include cardio-vascular diseases and diabetes in addition to tuberculosis and HIV infection. These conditions require continuous care over a number of years rather than months (Goudge, Gilson, Russell, Gumede, & Mills, 2009; Walley, et al., 2008), and many countries, especially those in Africa, are not prepared to face the challenges of these diseases because of poverty and/or weak health systems (Goudge, et al., 2009).

The majority of HIV programs in Africa, even though these are managed by government institutions, are supported by donor funding (Schneider, Blaauw, Gilson, Chabikuli, & Goudge, 2006). Management of HIV infection can be integrated within the primary health care system. Despite being a burden, if well planned, its improvement can reinforce the goals of the primary health care system (Price, Leslie, Welsh, & Binagwaho, 2009; Walton, et al., 2004). However, some of the barriers to accessing HIV care, particularly antiretroviral treatment, include: the challenge of reorienting service delivery towards chronic disease care and the shortage of skilled and motivated health care providers (this is mostly due to poor remuneration and lack of motivation, to national and international immigration and to poor distribution (Schneider, et al., 2006).

Comprehensive primary health care requires team spirit or multidisciplinary/interdisciplinary collaboration (especially interdisciplinary collaboration) among health-care providers

(Sicotte, D'Amour, & Moreault, 2002). It has been found that, even more than other chronic diseases, because of its multifaceted nature; the management of HIV infection requires health care providers from different disciplines to come together and to share their responsibilities as providers of care: by sharing their knowledge and skills they are better able to respond to the complex health needs of the patient. It is also recommended that the patient become involved in his or her health management (Van Manen, Laschinger, Stevenson, & Fothergill-Bourbonnais, 2005).

The ICF is a globally recognised classification framework to be used in different health care situations by health care providers in multidisciplinary teams (Finger, Cieza, Stoll, Stucki, & Huber, 2006). Furthermore it could assist in multi-professional patient assessment, goal setting, and intervention management and evaluation; it could be a new way of communicating, thereby assisting in the continuum of care, and it could serve to communicate a comprehensive view of the patient's health status by emphasizing the role of rehabilitation, especially when transferring the patient from one health care setting to another (Stucki, Ewert, & Cieza, 2003).

1.1.3.1 PLWH and health service delivery in Rwanda.

In 1994, Rwanda went through genocide. Many people were killed, especially men (Jones, 2002; Newbury & Baldwin, 2000). Also, since rape was used as a weapon by the perpetrators, it has been reported that a great number of women and girls experienced sexual violence (Cohen et al., 2009; Donovan, 2002; Mukamana & Brysiewicz, 2008; Nowrojee, 1996; Sharlach, 2000), and children were born from raped women (Donovan, 2002; Mukamana & Brysiewicz, 2008). This could have contributed to the spread of HIV infection (Donovan, 2002; Nowrojee, 1996), particularly among women (Mukamana & Brysiewicz, 2008). Perpetrators also used HIV as a weapon to destroy and to cause pain and suffering to the victims (Donovan, 2002). Thus, it is possible that 1994 genocide has contributed to the high prevalence of PLWH (Donovan, 2002). Furthermore, it has destroyed many health care infrastructures and contributed to a huge loss in the number of health care professionals; this has disrupted the health system and resulted in a weakening of health service delivery. (Rusa, Schneidman, Fritsche, & Musango, 2009).

Despite the aftermath of the genocide, it has recently been observed that the country has introduced significant innovations to its health system and to health service delivery (Logie, Rowson, & Ndagije, 2008). During the year 2000, Rwanda developed a vision for what

should be achieved by 2020; the vision 2020 relates to policies, laws and regulations and helps the government to identify priorities for all sectors that should assist in transforming Rwanda from a low-developing country to a middle-developing country by the year 2020. With regard to the health sector, Vision 2020 suggests that health-care programmes should prioritize the following factors; high population growth rate (3.2% per year), maternal health, malaria and HIV/AIDS (Ministry of Health (MoH) Rwanda, 2012b).

Rwanda's health system has integrated primary health care and the Ministry of Health is responsible for setting policies and for overall health sector planning (Ministry of Health (MoH) of Rwanda, 2009; USAID, 2007). All components of a comprehensive primary health care system, preventive, promotive, curative and rehabilitative, are offered by the various health services and are integrated in all programmes, including HIV programmes (Ministry of Health (MoH) Rwanda, 2012b).

Services are provided at different levels of the health care system: at the community level; there are community-based projects, and also health posts that provide very basic care at the lowest community administrative level (village level) (Ministry of Health (MoH) Rwanda, 2012b; Wyman, 2008). Regarding HIV programmes; the community level is broader in scope than other programmes as it can include and target specific public locations, such as markets and bars. Activities carried out at the community level may include the prevention of HIV infection, reducing mortality and morbidity, and mitigating the impact of HIV (Ministry of Health (MoH) of Rwanda, 2009).

From community level, there are health centres which provide basic primary care of a higher standard than that found at village level (Ministry of Health (MoH) Rwanda, 2012b; Wyman, 2008). The services are provided by qualified health-care providers, the majority of whom are only nurses (Wyman, 2008). Health centres supervise community-based projects and health posts (Ministry of Health (MoH) Rwanda, 2012b). Health centres make referrals directly to district hospitals where patients are provided with more general care. Majority of health conditions are treated at district hospitals. However, difficult cases that require more specialised care are referred to referral hospitals, which provide this kind of care (Ministry of Health (MoH) Rwanda, 2012a; Wyman, 2008).

HIV programmes offered at these levels, particularly at health centres and district hospitals, may include HIV testing, treatment, care and support, as well as the prevention of new HIV infections. These include programmes related to the prevention of mother-to-child

transmission of HIV (PMTCT), male circumcision, sexually transmission infections (STI) treatment and sexual and reproductive health service provision (Ministry of Health (MoH) of Rwanda, 2009). It has been indicated that, in developing countries, the best way to understand the problems of PLWH from their perspective is to reach these people at the district hospitals, which they attend regularly to get treatment, and to spend time interacting with health care providers (Streefland, 2005).

1.2 Conceptual framework: The International Classification of Functioning, Disability and Health and PLWH

In 2001, the World Health Organisation (WHO) published a new and universal model of understanding disability; the International Classification of Functioning Disability and Health (ICF), which is a classification system able to capture the full range of human functioning (World Health Organisation (WHO), 2001). It is based on a bio-psychosocial approach and offers a broader multidimensional view, and a comprehensive conception of health, functioning and disability (Reed et al., 2005; Shaw & MacKinnon, 2004). It considers the impact of a health condition on human functioning (this could result in disability); it does this from the biological, individual and societal perspectives rather than from the biological alone (Reed, et al., 2005; World Health Organisation (WHO), 2001). Thus, the interaction between the health condition and the health of an individual is looked at from a perspective that goes beyond mortality and disease and focusses on how people live with their condition in society (Kirchberger, Glaessel, Stucki, & Cieza, 2007). The concept of disability within the ICF framework is an umbrella term for impairments, activity limitations and participation restrictions (Reinhardt, Cieza, Stamm, & Stucki, 2006; Vanleit, 2008; World Health Organisation (WHO), 2001).

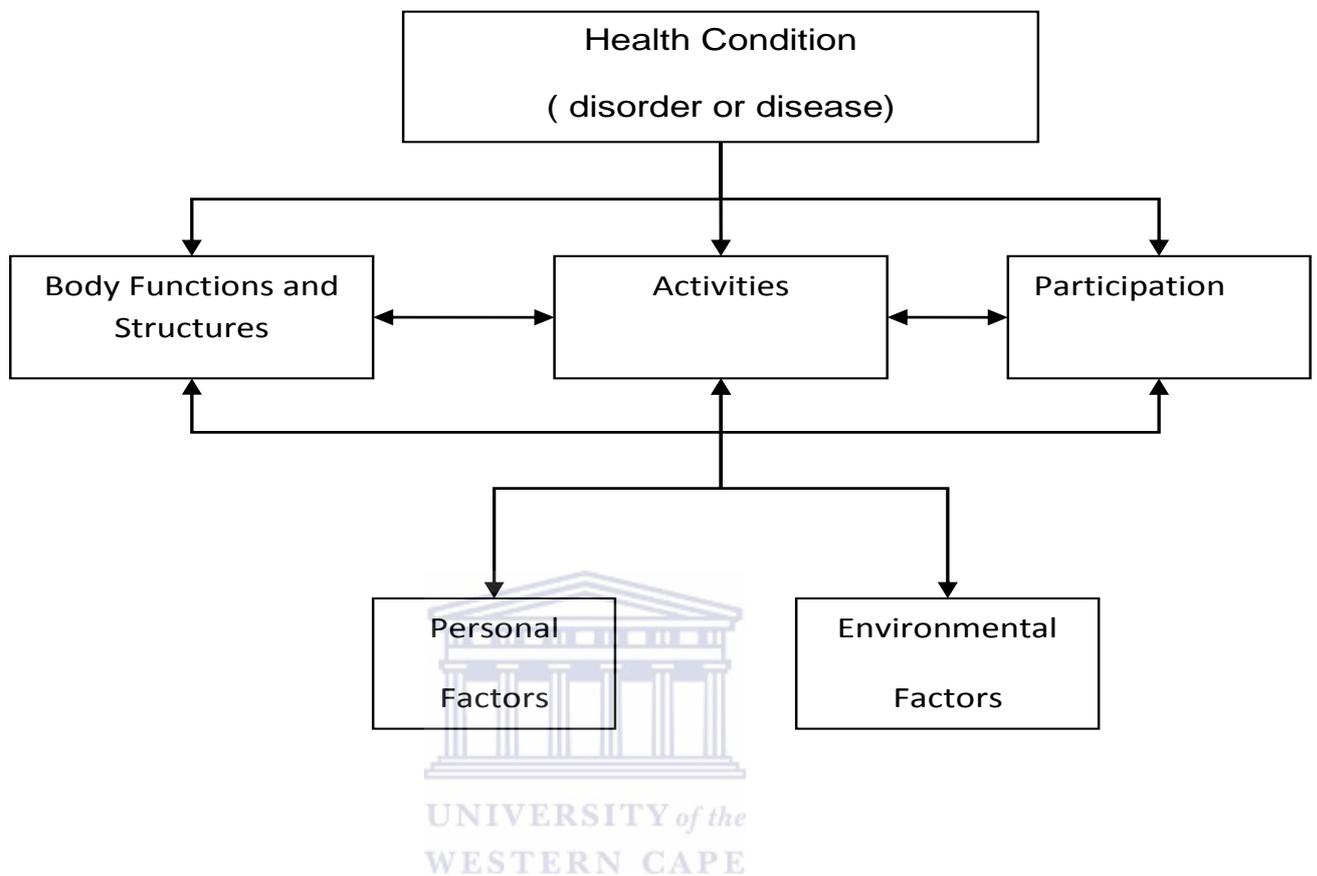


Figure 1: Interaction between the components of ICF

(World Health Organisation (WHO), 2001, p. 26).

Understanding the complex, multifaceted presentation of the HIV infection requires a holistic approach. Disability resulting from the HIV infection itself, its associated pathologies and also from antiretroviral treatment varies from individual to individual and may include various types of disability (Worthington, et al., 2005). ICF has the potential to provide a holistic classification and framework that is able to highlight and to document all the types of challenge related to living with HIV. It does this at the level of body structure and function, at the level of the individual and at the level of the individual's involvement with the society (Hanass-Hancock & Nixon, 2009a; Myezwa, et al., 2009; Van As, et al., 2009).

The researcher has drawn on the ICF framework to develop a conceptual framework for this thesis. It is suggested that currently the medical model of management is the dominant

approach to intervention in PLWH. This is outlined below in figure 2 **Error! Reference source not found.** In this model the causation is linear, the primary problem is the infectious disease and the primary intervention is to resolve the medical condition.

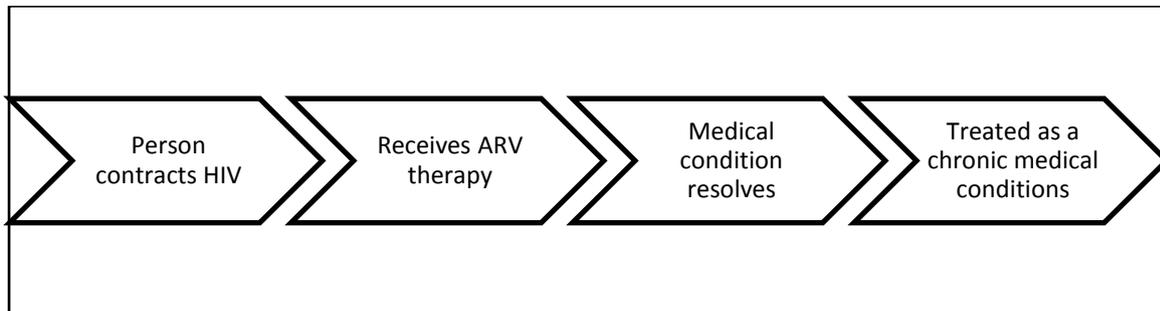


Figure 2: The Medical Model of management as applied to PLWH in Rwanda.

In contrast we propose that the bio-psychosocial model based on the ICF framework and as graphically represented in figure 3 **Error! Reference source not found.** is a better representation of the experience of living with HIV in Rwanda. In this model, the person living with HIV, his/her personal factors and his/her health condition are central to their experience. There is interaction between the personal factors, health condition, impairments, functional limitation and the hospital environment and community environment. The relationship between the above is not linear as the health condition and functional limitations both modify and in turn are modified by the environment (which includes hospital provision of medication). It is suggested that although the bio-psychosocial model might result in a better approach to intervention, it is not currently being implemented to plan and manage health related support given to PLWH.

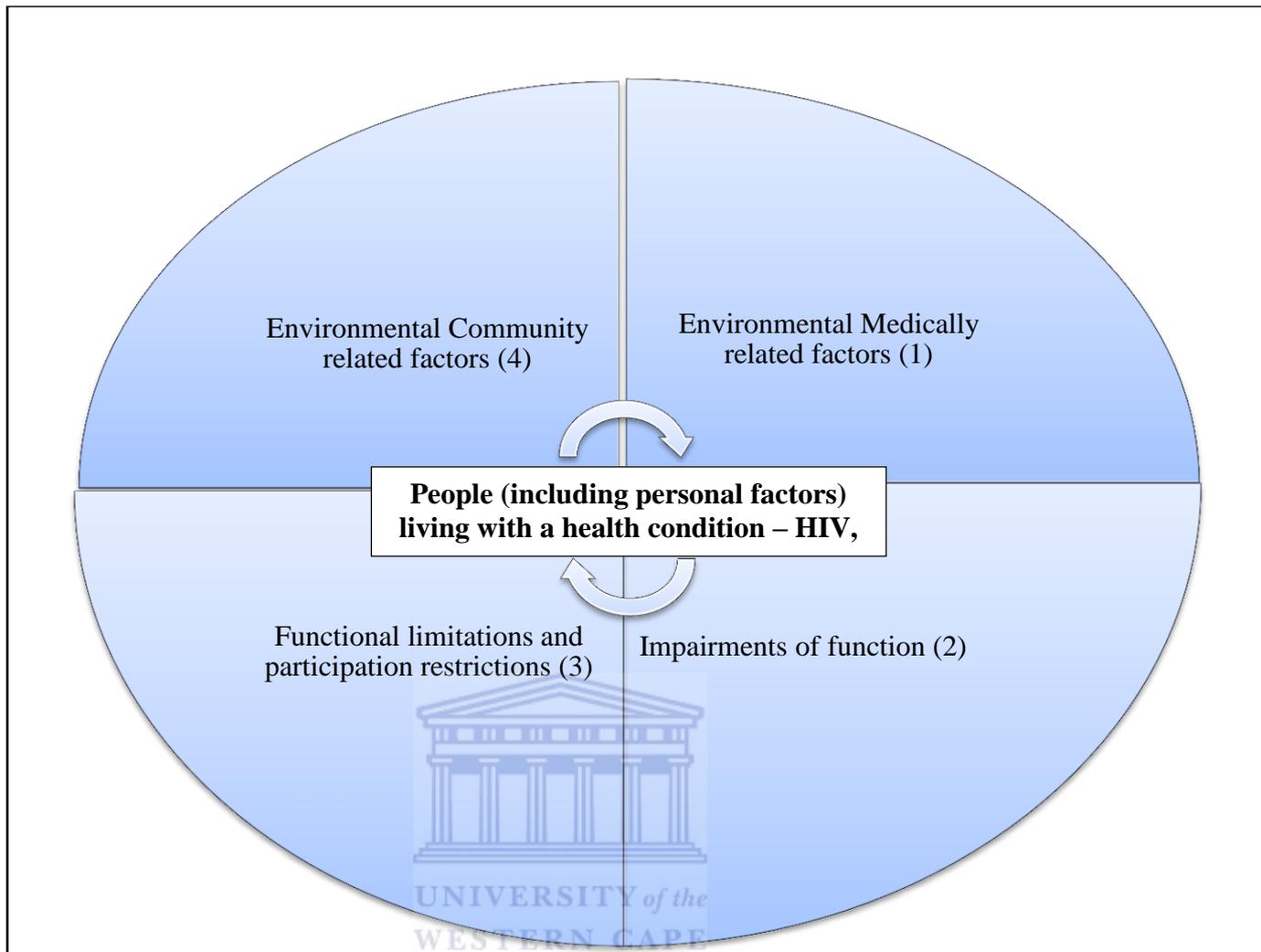


Figure 3: The proposed bio-psycho-social model of management applied to PLWH in Rwanda

This thesis aims to explore the extent to which the bio-psycho-social model correctly reflects the experience of PLWH in Rwanda. There are certain questions which need to be answered in order to determine whether the bio-psycho-social model is appropriate and whether the bio-psycho-social model is utilised to any extent.

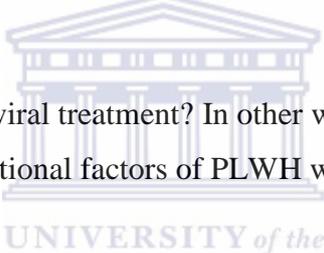
1.3 Statement of the problem

HIV infection manifests as a multi-systemic disease with multiple complications that affect the person's physical, psychological and the social functioning as a result of the HIV infection itself and its related pathologies and the antiretroviral treatment (O'Brien, et al., 2008; Rusch, et al., 2004a). In Rwanda, many PLWH have had access to antiretroviral treatment; however, there is no information about the extent of disability or functional limitations present among PLWH which might be caused by either the HIV infection or the antiretroviral treatment. In addition, the service delivery model may well be based on the

medical model, rather than the bio-psychosocial model. As a consequence, PLWH may be receiving medical treatment, but we do not know whether they need or are receiving rehabilitation within the hospital environment and support within the community. There is no literature that demonstrates the progress made in integrating rehabilitation care into HIV care or the role of rehabilitation in the management of functional limitations among PLWH in Rwanda.

1.4 Research questions

To explore the experience of living with HIV within a Rwandan context through the lens of a bio-psychosocial model, it is first necessary to examine the current management of the health condition, HIV. We should establish whether PLWH do indeed experience functional and contextual barriers despite receiving antiretroviral treatment and whether these problems are addressed by their medical care. We then need to explore whether supportive care is made available to them, both within the hospital and within the community setting. The specific questions are thus:

- 
- Who is receiving antiretroviral treatment? In other words what are the personal factors, e.g., gender, educational factors of PLWH who are receiving antiretroviral treatment?
 - How effective is the antiretroviral treatment received in terms of diminishing symptoms and improving the functioning of PLWH? Is there any need for further intervention and support? If it is effective, it is suggested that there will be few functional limitations present, the functional limitations will be less as the CD4 count increases and the longer that the PLWH receive antiretroviral treatment, the better their functioning will be.
 - What are the perceptions of PLWH with associated disabilities of the health services that address their functional limitations, in a hospital setting, in Rwanda? Are they satisfied that the care that they receive addresses all or a majority of their health related problems?
 - What are the profile and the prevalence of impairments, functional limitations and participation restrictions among PLWH in Rwanda? Is functional limitation common? If it is prevalent, then it is possible that the medical model of care does not result in complete recovery of functioning.

- What is the relationship between impairments, functional limitations, participation restrictions and family and community environmental factors? If support is to be offered, it should be targeted at the underlying cause of problems.
- Do PLWH receive the support that they need within the community?

In addition, it is necessary to validate the primary data collection tools to ensure that the data collected during the survey of impairments and functional limitations and participation restrictions were a true reflection of the functional abilities and health of PLWH within the context of the study.

1.5 Aims

The aim of the study was therefore to explore the need for and nature of care that PLWH living in Rwanda receive from their health care providers using a bio-psychosocial framework. A further aim was to determine if the Kinyawanda version of the World Health Organisation Disability Assessment Schedule 2.0 (WHODAS 2.0), which was used to gather the functional data, was valid within the Rwandan context. A mixed methods approach was used. Quantitative survey data were collected to document the medical care, impairments, functional limitations and participation restrictions, whereas qualitative data were collected to explore the functional implications of living with HIV and the impact of environmental factors on functioning. Both the quantitative and qualitative data were used to validate the survey instruments utilised.

1.6 Objectives

The specific objectives of the study were, in PLWH and receiving antiretroviral treatment:

With regard to personal factors:

- To establish the proportion of male/female; the age and income distribution; and the employment status of participants.
- To explore the impact of personal factors such as emotional and spiritual factors on functional limitations and participation restrictions.

With regard to the medical management and medical environment (quadrant 1 in the representation of the conceptual framework, Figure 3):

- To establish whether there is a relationship between antiretroviral treatment, CD4 count and functional limitations.

- To describe the reported satisfaction with the hospital service.
- To explore the experience of PLWH with associated disabilities with regard to how the hospital services assist them with their functional limitations.

With regard to the impairments of function, functional limitations and participation restrictions (quadrants 2 and 3 in Figure 3):

- To determine the prevalence of impairments, functional limitations and participation restrictions among PLWH attending health clinics.
- To determine the relationships between the body function impairments, functional limitations and participation restrictions through statistical analysis of survey results and analysis of the perceptions of PLWH with associated disabilities with regard to the relationship between the health condition , medication and functional limitations.

With regard to the community related environment (quadrant 4 in Figure 3):

- To describe the challenges PLWH with associated disabilities encounter in daily life.
- To validate the instruments used to establish the prevalence of impairments and functional limitations:
- To establish the linguistic and cultural appropriateness of the translation of the ICF core set of questions regarding the Impairment of body functions and the WHODAS 2.0 outcome instruments, through consensus group meetings conducted after forward and backward translation and a cognitive debriefing interview.
- To establish the face, construct and content validity and the reliability of the instrument.

1.7 Rationale for the study

There is no doubt that HIV continues to contribute greatly to the burden of disease in Rwanda, with many people affected by the virus. The shift from an acute and terminal health condition to a chronic health condition requires a parallel shift in health care delivery for PLWH. Health care facilities such as hospitals should be prepared and able to provide holistic and comprehensive care that would include preventive, curative, promotive and also rehabilitative care in order to respond holistically to the needs of PLWH. Rwanda has made substantial gains in the prevention of HIV infection and in scaling up antiretroviral treatment across the country, and the majority of health facilities, particularly hospitals, have HIV programmes (Ministry of Health (MoH) Rwanda, 2012b). However, it is possible that

rehabilitation services and community based support are not made available. Rehabilitation interventions for PLWH have the potential to prevent disability, reduce and prevent deterioration of the disability, restore and maximize functional independence and enhance and promote health and HRQoL of PLWH (Worthington, et al., 2005; Hanass-Hancock & Nixon, 2009a).

However, to date, there is a scarcity of literature about rehabilitation service delivery and HIV. Moreover the ICF is a framework that can be used in rehabilitation and that could assist in reconceptualising HIV beyond the focus on HIV as a disease (Hanass-Hancock & Nixon, 2009a). Unlike the medical approach, which focuses on the diagnosis of disease and examines symptoms only, the ICF, because it uses bio-psychosocial approach, emphasises the impact of these diagnoses and symptoms on PLWH and how people deal with their lives; it emphasises the influence of personal and environmental (contextual) factors (Nixon, Hanass-Hancock, Whiteside, & Barnett, 2011; Worthington, et al., 2005). This is important for rehabilitation.

Most of the hospitals in Rwanda have rehabilitation services such as physiotherapy and psychotherapy. At each hospital the health-care providers responsible for HIV care could work in a team with physiotherapists and other rehabilitation health-care providers to address any impairment, activity limitation, or participation restriction experienced by PLWH, thus preventing disability, deterioration and promoting health. Information regarding the perceptions of health services as well as the quantification of the impairments, functional limitations, participation restrictions will assist health care managers to plan appropriate and comprehensive management programmes for PLWH in Rwanda.

1.8 Structure of the thesis

This thesis is structured in the following chapters.

Chapter One: Introduction. This describes the context of the study, the conceptual framework, the statement of the problem that this study aims to address, the research questions and aims and objectives and the rationale for doing the study.

Chapter Two: Literature review. This reviews the literature on HIV and the antiretroviral treatment, and on models of disability, body impairments, activity limitations and social participation restrictions in PLWH. It examines the contextual factors related to HIV, the

hospital environment, health service delivery and rehabilitation care. Finally it looks at the measurement of disability/functional limitations among PLWH.

Chapter Three describes the methodology used to determine information related to the health condition and the prevalence and nature of the impairments and functional limitations. This chapter describes how a survey was carried out to gather quantitative information. The results are included in the chapter.

The next chapter, Chapter Four describes the methodology and results of the qualitative component of the study. In this chapter the participants' description of their impairments, functional limitations and environmental barriers and facilitators are presented. The chapter describes the running of two focus groups and includes the analysis of the results of the discussions.

Chapter Five integrates the results of the above studies to address the research questions. The results of the mixed methodologies are discussed and the research questions are addressed.

The process of the translation of the original English version of the ICF core set of questions regarding the impairment of body functions, and the translation of the WHODAS 2.0 questionnaire is described in Chapter Six. In addition, information gained from both the survey and the focus groups discussions is integrated to assist in validating the questionnaire.

Chapter Seven concludes the thesis. This includes a summary of the thesis. It reaches a conclusion drawn from the findings, discusses the limitations of the study and makes recommendations arising from this study.

2 CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter presents a review of the literature on PLWH and functionality. It includes sections on the following topics: HIV/AIDS; antiretroviral treatment; disability models; body impairments, activity limitations and social restrictions and contextual factors related to HIV; the hospital environment, service delivery and PLWH; and finally, disability measurements.

Electronic databases were used to search for literature and the following search engines were consulted; PUBMED, Science Direct, Scopus, Ebsco web (Academic search complete, Health source: Nursing/Academic Edition, Psyc ARTICLES, Medline, CINHAL), World cut, and Google scholar.

The following key search terms were used individually and in combination: HIV, HIV/AIDS, HIV and prevalence, HIV and incidence, HIV and disability, HIV or PLWH and impairment, HIV or PLWH and activity limitation, HIV or PLWH and participation restriction, HIV or PLWH and impairment, activity limitation and participation restrictions, PLWH and personal factors, PLWH and environmental factors, PLWH and functional needs, PLWH and functional limitations, HIV and health-related quality of life, PLWH and health-related quality of life, ICF, ICF and models of disability, health system, health system and Rwanda, health care delivery, health care delivery and Rwanda, primary health care, health care delivery and HIV or PLWH, health care delivery and HIV or PLWH and Rwanda, health service delivery, health service and HIV or PLWH, health service delivery and HIV or PLWH and Rwanda, hospital-based service delivery and HIV or PLWH; hospital-based service delivery and HIV or PLWH and disability or functional limitations, and rehabilitation, hospital-based service delivery and HIV or PLWH and functional limitations and rehabilitation and Rwanda; WHODAS 2.0 and validity and reliability, ICF and validity and reliability, Barthel and validity and reliability, and functional independence measure(FIM) and validity and reliability.

Books, printed journals and reports were also searched manually for additional information.

2.2 HIV and AIDS

2.2.1 Introduction

HIV is the virus that causes AIDS (Anderson, 2006; Holodniy & Miller, 2002; Sierra, Kupfer, & Kaiser, 2005; Strebel, Luban, & Jeang, 2009). AIDS is characterised by signs and symptoms of serious infections and cancers associated with a severe deficiency of the immune system. Infections associated with AIDS are known as opportunistic infections. The time between being infected with HIV and occurrence of AIDS symptoms and signs can be an average of 10 years (Sellmeyer & Grunfeld, 1996).

2.2.2 HIV types

There are two types of HIV: HIV1 and HIV2. They are both transmitted in the same way: by sexual contact, through blood (including transmission from mother to child); both types of HIV cause AIDS (De Cock et al., 1993; Mörner et al., 1999). HIV1 is the predominant virus; HIV2 is commonly found only in West Africa and it is very rare elsewhere in the world. It is, however, possible to find a combination of both types (De Cock, et al., 1993; Jaffar, Grant, Whitworth, Smith, & Whittle, 2004; Mörner, et al., 1999). In a study conducted in Nigeria; 83% of the PLWH had HIV1 infection; 16.7% had a combination of both HIV1 and HIV2 and no one had the HIV2 infection alone (Salawu et al., 2008).

Studies have indicated that HIV2 is less pathogenic than HIV1 and that the period between initial infection and illness is longer compared to that in the case of HIV1 (Jaffar, et al., 2004; Mörner, et al., 1999; Popper et al., 1999; Sousa, Carneiro, Meier-Schellersheim, Grossman, & Victorino, 2002). This could be because there are higher levels of HIV1 plasma viral RNA or viral load compared to that in the case of HIV2, with greater and higher rates of viral replication and a greater risk of progression to AIDS (De Cock, et al., 1993; Popper, et al., 1999; Sousa, et al., 2002).

HIV1 can be classified into three subtypes or genetic groups: HIV1 Major (HIV1M), outlier HIV (HIV O) and the HIV N group (non –M/non- O) (Hemelaar, Gouws, Ghys, & Osmanov, 2006; Osmanov, Pattou, Walker, Schwardländer, & Esparza, 2002). Globally, the majority of HIV1 cases belong to HIV1 group M; group O and group N cause only a small minority of infections in Central Africa. In addition HIV1M is divided into nine distinct genetic subtypes or sub-clades labelled by letter; A-D, F-H, J and K (Hemelaar, et al., 2006). Some studies have revealed the existence of inter-subtype recombination; this is found in individuals

infected with two or more subtypes of the virus simultaneously (Hemelaar, et al., 2006; Osmanov, et al., 2002). In Rwanda, 79% of infections are caused by subtype A (Hemelaar, et al., 2006).

2.2.3 HIV pathology

HIV is a ribonucleic acid (RNA) virus belonging to the lentivirus subfamily of the retrovirus family. During the life cycle of this family of viruses, it is necessary for replication and survival that there is integration of a copy of its genome with that of the human host cell genome. This type of virus contains an enzyme, reverse transcriptase, which the virus uses to convert the viral RNA into deoxyribonucleic acid (DNA) which can then be integrated into the genome of the host DNA cell it has infected (Holodniy & Miller, 2002).

HIV is a complex retrovirus that attacks and destroys the cells of the human immune system (Anderson, 2006; Palmer, 2008). This has a very negative impact on the role of the immune system, which is; to protect the body from foreign objects, such as microorganisms, by recognising, immobilising, neutralising or destroying them. The immune system contains different types of cells, and among these there are those called T-Cells (T-lymphocytes). Also, there are many different types of T-cells; one type has a molecule on its surface, a specific receptor site called CD4; this is the principal cell receptor for HIV and it is where the virus attaches itself before gaining entry (Palmer, 2008; Sierra, et al., 2005; Strebel, et al., 2009).

CD4 cells play a crucial role in the immune system, coordinating the actions of other immune system cells (Palmer, 2008). The destruction of the CD4 cell decreases the normal functioning of the immune system and inhibits its ability to produce an effective immune response to pathogens (Anderson, 2006); this leaves the body at risk and increases its susceptibility to opportunistic infections (Palmer, 2008; Sierra, et al., 2005).

2.2.4 Stages of HIV infection

The clinical stages of HIV infection progress from an initial acute phase, associated with primary infection, to an asymptomatic state and from that, to an advanced state of infection (Vajpayee, Kaushik, Sreenivas, Wig, & Seth, 2005). The asymptomatic stage is also called “clinical latency” and is accompanied by persistent viral replication in the lymph nodes. During this phase, the number of CD4+ T-lymphocytes decreases continuously, until the patient’s immune system is no longer capable of controlling opportunistic pathogens (Sierra, et al., 2005). Thus; the viral load can reflect progression, whereas a CD4 count is associated

with the risk of developing opportunistic infections. Ideally, a patient would possess a low viral load and a high CD4+ T cell level, and it is recommended that both the viral load and CD4 counts be examined when determining disease progression (Anderson, 2006; Holodniy & Miller, 2002).

2.2.5 2.2.4.1 Classification of HIV infection

Two main classifications of HIV infection have been described; one comes from the Centre for Disease Control and Prevention (CDC) and the other from the WHO.

CDC classification for HIV infection

In 1993 the CDC revised its 1981 classification. This was the first time the HIV infection had been classified, and where the CD4+ T- lymphocyte count was identified as a marker for HIV-related immune suppression. The current CDC classification categorises PLWH on the basis of CD4+T-lymphocyte counts and the clinical conditions associated with HIV infection. Three categories of CD4+ T-lymphocyte and also three categories of clinical condition associated with the disease have been identified (Buehler & Berkelman, 1992). The following are the categories for CD4+T-lymphocyte counts: (1) category1; CD4+ T- lymphocyte count is greater than or equal to 500 cells/ul; (2) category2; CD4+T- lymphocyte count ranges between 200-499 cells/ul; (3) category3; CD4+T-lymphocyte count is less than 200 cells/ul (Buehler & Berkelman, 1992).

With regard to the clinical conditions associated HIV disease; the following are the relevant categories: (1) category A (Asymptomatic HIV infection); this includes acute (primary) HIV infection and persistent generalised lymphadenopathy. (2) Category B (symptomatic HIV infection). It includes conditions such as bacillary angiomatosis, candidiasis vulvovaginal, (persistent, frequent, or unresponsive to therapy), cervical dysplasia (moderate or severe)/cervical carcinoma. It includes constitutional symptoms, such as fever (38.5 C) or diarrhoea lasting for longer than one month, and herpes zoster, involving at least two distinct episodes or more than one dermatome, as well as peripheral neuropathy (Buehler & Berkelman, 1992).

(3) Category C: it includes conditions that are indicators for AIDS: once a person has experienced one of the conditions; he or she will remain in the C category. This includes conditions such as candidiasis of bronchi, trachea, or lungs , oesophagus , cervical cancer, cryptococcosis (extrapulmonary) , diarrhoea (for longer than one month), encephalopathy,

herpes simplex(chronic ulcer(s) for longer than one month), bronchitis, pneumonitis, oesophagitis , Kaposi's sarcoma, Burkitt's Lymphoma, mycobacterium tuberculosis (pulmonary or extrapulmonary), pneumocystis carinii pneumonia, pneumonia (recurrent), progressive multifocal leukoencephalopathy, salmonella septicemia, recurrent , toxoplasmosis of brain and wasting syndrome due to HIV (Buehler & Berkelman, 1992).

WHO classification for HIV infection

The WHO classification has undergone several revisions (most recently in 2005). This classification was based on the stages of the clinical conditions associated with HIV, with or without access to CD4+ T-lymphocyte counts. However CD4+ testing is still considered useful to determine the degree of immunosuppression and to support clinical decision-making. For example, it helps to determine the need for antiretroviral treatment and other therapies. The system is intended to improve the management, treatment monitoring and surveillance of PLWH (World Health Organisation (WHO), 2005a).

Clinical staging of HIV/AIDS for adults and adolescents includes the following stages: primary HIV infection is asymptomatic and acute retroviral syndrome. Clinical stage 1 is asymptomatic with persistent generalized lymphadenopathy. Clinical stage 2 involves moderate unexplained weight loss (<10% of presumed or measured body weight), recurrent respiratory tract infections (sinusitis, bronchitis, otitis media, pharyngitis), herpes zoster, angular cheilitis, recurrent oral ulcerations, papular pruritic eruptions, seborrhoeic dermatitis and fungal nail infections of the fingers (World Health Organisation (WHO), 2005a).

Clinical stage 3 involves conditions where a presumptive diagnosis can be made on the basis of clinical signs or simple investigations. The indicators include severe weight loss (>10% of presumed or measured body weight), unexplained chronic diarrhoea for longer than one month, unexplained persistent fever (intermittent or constant for longer than one month), oral candidiasis, oral hairy leukoplakia, pulmonary tuberculosis (TB) diagnosed in the two previous years, severe presumed bacterial infections (e.g. pneumonia, pyomyositis, bone or joint infection, meningitis, bacteraemia), acute necrotizing ulcerative stomatitis, gingivitis or periodontitis. It also involves conditions where confirmatory diagnostic testing is necessary, including unexplained anaemia (< 8 g/dl), and/or neutropenia (<500/mm³) and or thrombocytopenia (<50 000/ mm³) for more than one month (World Health Organisation (WHO), 2005a).

Clinical stage 4 involves conditions where a presumptive diagnosis can be made on the basis of clinical signs or simple investigations. The indicators include HIV wasting syndrome, pneumocystis pneumonia, recurrent severe or radiological bacterial pneumonia, chronic herpes simplex infection (orolabial, genital or anorectal of more than one month's duration), oesophageal candidiasis, extrapulmonary TB, Kaposi's sarcoma, central nervous system (CNS) toxoplasmosis, etc. This also involves conditions where confirmatory diagnostic testing is necessary, such as extrapulmonary cryptococcosis (including meningitis), disseminated non-tuberculous mycobacteria infection, candida of the trachea, bronchi or lungs, visceral herpes simplex infection, cytomegalovirus (CMV) infection (retinitis or of an organ other than the liver, spleen or lymph nodes), recurrent non-typhoidal salmonella septicaemia lymphoma (cerebral or B cell non-Hodgkin), and invasive cervical carcinoma (World Health Organisation (WHO), 2005a) .

The World Health Organisation (WHO) (2005a) immunological staging of HIV infection includes the following stages: no significant immunosuppression: $>500/\text{mm}^3$; mild immunosuppression: $350\text{-}499/\text{mm}^3$; advanced immunosuppression: $200\text{-}349/\text{mm}^3$; and severe immunosuppression: $<200/\text{mm}^3$.

2.2.6 Antiretroviral treatment

HIV encodes at least three types of enzymes: protease, reverse transcriptase and endonuclease (Aymard, Legrand, Trichereau, & Diquet, 2000). In order to inhibit reproduction of the virus in the human body; pharmaceutical scientists have produced antiretroviral drugs, which are described as a treatment for people infected with HIV. Following advanced research on this treatment, scientists have introduced the highly active antiretroviral treatment. This consists of a triple combination of drugs, and significantly assists the suppression of HIV replication (Miranda et al., 2007); it results in reconstitution and augmentation of the CD4 count. Unfortunately, due to the persistence of viral reservoirs, highly active antiretroviral treatment does not eradicate HIV (Mahungu, et al., 2009).

There are three main types of antiretroviral drugs: the nucleoside reverse transcriptase inhibitors (NRTIs), the non-nucleoside reverse transcriptase inhibitors (NNRTIs) and the protease inhibitors (PIs) (Aymard, et al., 2000). NRTIs include Abacavir, Didanosine, Dideoxycytidine, Lamivudine, Stavudine and Zidovudine etc. The NNRTIs include Delavirdine, Efavirenz and Nevirapine etc. The PIs include Amprenavir, Indinavir,

Nelfinavir, Ritonavir and Saquinavir etc. Therapeutic strategy regimens are based on a combination of these antiretroviral drugs (Aymard, et al., 2000).

World Health Organisation (WHO) (2006b) recommends that the first-line treatment regimen for adults and adolescents should contain two NRTIs plus one NNRTI. It has been found that this combination is efficacious, less expensive and has generic formulations. The following NRTIs are considered preferable as a first-line regimen: Zidovudine (AZT) or Stavudine (D4T), Lamivudine (3TC) or Emtricitabine (FTC), Tenofovir (TDF) or Abacavir (ABC). If the choice is NNRTI, then Efavirenz (EFV) and Nevirapine (NVP) are preferable. The PIs are reserved for the second-line treatment regimen and are combined with an NRTI (Gilks et al., 2006; World Health Organisation (WHO), 2006b).

The antiretroviral treatment regimen in Rwanda follows the WHO recommendations, so the usual combinations comprise two NRTIs plus one NNRTI or two NRTIs plus one PI (MoH-Rwanda, 2011a). As it is shown in Table 1, in Rwanda, there are four combinations of drugs recommended for the first-line regimen (Ministry of Health (MoH) Rwanda, 2011a).

Table 1: Antiretroviral drugs combination recommended for the first line regimen, in Rwanda

| NRTI | NNRTI |
|---|------------------|
| Tenofovir (TDF) + Lamivudine (3TC) or FTC | Efavirenz (EFV) |
| Tenofovir (TDF) + Lamivudine (3TC) or FTC | Nevirapine (NVP) |
| Abacavir (ABC) + Lamivudine (3TC) or FTC | Efavirenz (EFV) |
| Abacavir (ABC) + Lamivudine (3TC) or FTC | Nevirapine (NVP) |

(Ministry of Health (MoH) Rwanda, 2011a)

2.2.5.1 Antiretroviral treatment side effects

Various side effects of antiretroviral treatment as a result of toxicity have been observed and these can vary in severity from mild to severe and may sometimes be life-threatening. Kumarasamy et al. (2008), in a prospective study, found that over half of PLWH developed at least one treatment-associated adverse event and this contributed to the need to change or discontinue the initial regimens. However, at times it might be difficult to distinguish between the complications of the HIV infection and the side-effects of antiretroviral

treatment toxicity. The common side effects are shown in Table 2 (World Health Organisation (WHO), 2006b).

Table 2: Antiretroviral drugs first line treatment regimen side effects

| Antiretroviral drug | Common associated side effects |
|---------------------|--|
| ABC | Hypersensitivity reaction |
| AZT | Severe anaemia or neutropenia Severe gastrointestinal intolerance (example of symptoms may be persistent nausea and vomiting) Lactic acidosis |
| D4T | Lactic acidosis Lipoatrophy/ metabolic syndrome Peripheral neuropathy |
| TDF | Renal toxicity (renal tubular dysfunction) |
| EFV | Persistent and severe central nervous system toxicity Potential teratogenicity (first trimester of pregnancy or women not using adequate contraception) |
| NVP | Hepatitis Hypersensitivity reaction Severe or life-threatening rash (Stevens-John syndrome). Severe rash with desquamation or sometimes with other health problems such as; fever, oral lesions, blistering, facial oedema or conjunctivitis |

(World Health Organisation (WHO), 2006b)

The World Health Organisation (WHO) (2006b) has suggested that countries select and keep a considerable stock of first-line treatment regimen drugs; they should also have a limited quantity of second-line regimen drugs available. Despite the side effects or toxicity of the

antiretroviral treatment; the majority of PLWH who are able to access and adhere to antiretroviral treatment can expect an improvement in their CD4 count and a decreased viral load (Heaton et al., 2011; Howard et al., 2002), a reduction in the occurrence of opportunistic infections and an overall reduction in disease-related morbidity and mortality (Heaton, et al., 2011; Russell et al., 2007).

2.2.7 Epidemiology of HIV

Towards the end of 2011, there were an estimated of 34 million PLWH globally, with one in every 20 adults living with HIV, or 4.9% of the global population (UNAIDS, 2012a). 68% of PLWH reside in Sub-Saharan Africa, which has only 12% of the total population of the world. Half of PLWH are women, and in sub-Saharan Africa this population is much higher than in other countries. In 2010 it was estimated that 59% of the women adults were HIV-positive (UNAIDS, 2011a; World Health Organisation (WHO), UNAIDS, & UNICEF, 2011). Of the 34 million PLWH, 2.7 million were newly infected (UNAIDS, 2012a; World Health Organisation (WHO), et al., 2011) and 70% of these new infections (which is the equivalent of 1.9 million people) were found in sub-Saharan Africa (UNAIDS, 2012a; World Health Organisation (WHO), et al., 2011).

Worldwide, the number of people dying from AIDS has decreased from 2.2 million in 2005 to 1.8 million in 2010 (World Health Organisation (WHO), et al., 2011). Sub-Saharan Africa reduced the rate of death by 32% between 2005 and 2011. The decrease was greater in some countries: Botswana, 71%, Rwanda, 68%, Namibia, 60% and Zambia 56% (UNAIDS, 2012b).

The reduced mortality rate has contributed to an increase in the number of PLWH. For example; globally, in 2001 the prevalence of PLWH was declared to be 28.6 million whereas, as is shown above, in 2010 it reached 34 million. This reflects a population increase of 17% in ten years. Sub-Saharan Africa had a total of 22.9 million PLWH in 2010, 12% more than in 2001. This can be explained by the improved availability of antiretroviral treatment, by the provision of quality care and by social/welfare support given to PLWH. Such support includes the creation of HIV associations, the initiation of HIV projects by local and international Non- Governmental Organisations (NGOs) and the design of HIV prevention policies and programmes. This has help to boost the life expectancy of PLWH (UNAIDS, 2011a).

In 2010, in low-and middle-income countries, around 6 650 000 PLWH had access to antiretroviral treatment. Sub-Saharan Africa has shown the greatest increase, with a total of 5 064 000 PLWH on antiretroviral treatment in 2010, up from 3 911 000 in December 2009. Ten Sub-Saharan Africa countries, including Rwanda, have achieved greater access to antiretroviral treatment: that is, drugs have been provided to at least 80% of the population in need (UNAIDS, 2011a). It has been observed that antiretroviral treatment coverage in these low- and middle-income countries is higher in women (68%) than in men (47%) (UNAIDS, 2012a).

In Rwanda, HIV prevalence statistics are available from the 2005 and 2010 Rwanda RDHS. Both surveys were population based surveys. The prevalence of HIV in the population aged 15-49 years was 3.0% in both surveys. This was higher in women (4%) than in men (2%) (National Institute of Statistics Rwanda, et al., 2012) . The prevalence increases with age in both sexes. It is highest among women aged 35-39 years (8%), and among men aged 40-44 years (8%). Between the ages of 45-49, the prevalence was reduced to 6% for both women and men. (National Institute of Statistics Rwanda, et al., 2012).

Among those aged between 15-49 years, the prevalence of HIV infection in the Rwandan population varies according to the socio-demographic and economic characteristics of the people surveyed. The prevalence of women and men living with HIV infection is 7% in urban areas, compared to 2% in rural areas. HIV prevalence is generally higher among those with no education (4%) than among those with primary education or higher (3%). Regarding employment status among men, HIV prevalence is higher among those who are employed (2%) than among those who are not employed (< 1%). Amongst women, the variation in HIV prevalence according to employment status is not significant. With regard to marital status, the prevalence of HIV is 17% amongst widows, 7% amongst divorced or separated women and 4% amongst married women. The rates are similar for men (National Institute of Statistics Rwanda, et al., 2012).

The social groups most affected include female sex workers, prisoners, men who have sex with men, and truck drivers. Among female sex workers, the prevalence of HIV infection is 50.8% and it is even higher in women aged 25 years and above (57%) (Ministry of Health (MoH) Rwanda, 2012a). In Rwanda, there has been a decline in incidence from 10.8% in 2004 to 1.7% in 2011, including 1.7% among women and 1.5% among men (MoH-

Rwanda, 2011b), 91.4% of PLWH who are eligible and need antiretroviral treatment are receiving the drugs (Ministry of Health (MoH) Rwanda, 2012a).

2.3 Models of Disability

There are a number of disability models that help to understand how people experience disability, how disability is understood and how people living with disability are treated. The most common models are the medical model, the social model, and the ICF (Vanleit, 2008).

According to Vanleit (2008), the medical model is a clinically oriented model. Disability is viewed as an attribute of the person, and can be directly caused by disease, trauma, or other health conditions and requires intervention provided by professionals to treat and fix the problem (Jette, 2006; World Health Organisation (WHO), 2001). The treatment deals with what the person cannot do, and the goal of the treatment is to try to correct or minimize impairments, with the aim of gaining or recovering function (Reed, et al., 2005; Vanleit, 2008). The Social model is a socially oriented model and considers disability as a problem resulting from exclusion from ordinary life rather than as a medical problem. With the social model, there is a shift from what is wrong with the person to what is wrong with society and the environment (Kearney & Pryor, 2004; Vanleit, 2008; World Health Organisation (WHO), 2001).

The ICF is a comprehensive classification system for health and functioning that integrates the medical and social models of disability. (Guscia, Ekberg, Harries, & Kirby, 2006; World Health Organisation (WHO), 2001). In the ICF, health and human functioning are considered to be more than the result of biological factors. It also includes psychological, social and contextual factors (Shaw & MacKinnon, 2004; World Health Organisation (WHO), 2001).

The ICF is based on a bio-psychosocial model of human functioning and disability that brings together the components of health with the aim of achieving a holistic understanding of disability (Geyh et al., 2011; World Health Organisation (WHO), 2001).

With the ICF, disability is considered to be a social construction; this is contrary to the traditional medical view that disability resides within the person. Disability is affected by the interaction between a person and the environment (Rosenbaum & Stewart, 2004). This allows for a more comprehensive conception and understanding of a person's experience with disability, an understanding that includes the environmental barriers and facilitators that impact on a person's functioning. The recognition of the central role played by the environmental factors has had a big impact on the design of intervention strategies; these seek

to overcome the disability and improve function, and the focus of the intervention might shift from the individual to the environment in which the person lives (Hwang & Nochajski, 2003; Rusch, et al., 2004a).

“The overall aim of the ICF classification is to provide a unified and standard language and framework for the description of health and health-related states”

(World Health Organisation (WHO), 2001, p. 3).

2.3.1 Principles of the ICF

Some of the ICF principles have been highlighted in certain articles. (i) The universal application: ICF has to be understood in a broader context: it is for all people and not only for people living with disability. (ii) It is a classification where all people can have their health, and experience of health condition described using the ICF (Chapireau, 2005; Schneidert, Hurst, Miller, & Üstün, 2003). (iii) It is an integrative approach: this principle recognises the impact of both the individual and the society in the understanding and treatment of disability (Schneidert, et al., 2003). (iv) It is an interactive approach: the ICF considers and acknowledges the complex and multi-dimensional aspect of disability (Schneidert, et al., 2003). (v) There is a shift from a classification of “disease consequences” to one that looks at “components of health”. This principle suggests that, to understand disability, ICF goes beyond the particular health condition and incorporates all aspects of human health, including some health components of well-being; it describes these in terms of “health domains” and “health-related domains” (Chapireau, 2005).

2.3.2 Components of the ICF

The ICF describes various components that combine or interact with any health condition that may be associated with the development of disability (Vanleit, 2008).

The ICF has two parts, and each part has two components. The first part deals with functioning and disability, while the second covers contextual factors. Components of functioning and disability are divided into (i) a body component (body structures and functions) and (ii) an activity and participation component. Contextual factors may be both environmental and personal (Cieza & Stucki, 2005; Kuijer et al., 2006; Perenboom & Chorus, 2003; Rentsch, Fluri, & Wenger, 2003; Steiner et al., 2002; World Health Organisation (WHO), 2001). Each ICF component can be expressed in both positive and negative terms (World Health Organisation (WHO), 2001).

2.3.2.1 Part one: Functioning and disability

Functioning is considered to be a positive term whereas disability is a negative term; therefore in the ICF positive or non-problematic aspects of health are summarised using the umbrella term “functioning,” while the negative or problematic aspects are described using the term “disability”. An individual’s functioning or disability in a specific domain represents an interaction between the individual and a health condition (e.g. one caused by injury, disease, or trauma) and the contextual factors (which include both environmental factors and personal factors) (Coenen et al., 2006; Steiner, et al., 2002). Schneidert et al. (2003) suggested that, if the interaction has an outcome resulting in less than the full range of functioning, then the person is said to experience disability or be disabled.

The components of functioning and disability include body function and structure, and activity and participation. Body structures include anatomical parts of the body, such as the organs and the structures of the nervous, sensory, and musculoskeletal systems. Body functions include physiological and psychological functions, and can be categorized as follows: mental; sensory and pain; voice and speech; cardiovascular; immunological; respiratory; digestive; metabolic and endocrine; genitourinary and reproductive; neuromuscular and movement-related; and functions related to the skin. Problems in body function or structure are referred to as “impairments” (Palisano, 2006; Vanleit, 2008; World Health Organisation (WHO), 2001). The ICF defines impairment as an anomaly, defect, loss, or other significant deviation or change in body function or structure (World Health Organisation (WHO), 2001) which is the manifestation of pathology (Hwang & Nochajski, 2003).

“Activity” is defined as the execution of a task or an action by an individual (Palisano, 2006; Vanleit, 2008; World Health Organisation (WHO), 2001). Difficulties are referred to as “activity limitations” (Palisano, 2006; Vanleit, 2008; World Health Organisation (WHO), 2001), and these limitations are experienced at the level of the individual (for instance an inability to walk) (Worthington, et al., 2005) An activity limitation occurs when an individual either has difficulty performing the activity in an expected manner, or is unable to perform it at all. It is assessed based on the individual’s ability to perform a task and does not take into account external influences, such as environmental factors (Gray & Hendershot, 2000).

“Participation” indicates involvement in life situations (World Health Organisation (WHO), 2001). It signifies also taking part, being included or engaged in an area of life, and being

accepted or having access to needed resources (Coster & Khetani, 2008). It represents the societal perspective of functioning (Stucki & Sigl, 2003; World Health Organisation (WHO), 2001). Participation restrictions are defined as limitations in an individual's ability to interact with society, for example an inability to work. This may be due to the external factors, such as the existence of barriers, and/or a lack of facilitators in the environment (Gray & Hendershot, 2000). The presence of a participation restriction is determined by comparing an individual's participation profile to that which would be expected of an individual without any disability in that particular society (Hwang & Nochajski, 2003).

Heerkens, Engels, Kuiper, Van Der Gulden, and Oostendorp (2004), Gibson and Strong (2003) and the World Health Organisation (WHO) (2001) all indicate that activity and participation components are also subject to the qualifiers, capacity and performance. While "performance" refers to what the person actually does in his or her environment, "capacity" denotes an individual's ability to accomplish a task. Ability and performance are influenced by the environment, which is considered to be an external factor. Transformation of the environment may be a way of improving participation (Chapireau, 2005).

2.3.2.2 Part two: Contextual factors

The ICF recognises aspects of social orientation that have reinforced the philosophy of social construction disablement. Contextual factors have two components, the environmental and the personal. (Rosenbaum & Stewart, 2004; Schneidert, et al., 2003; Stucki & Sigl, 2003; World Health Organisation (WHO), 2001). Environmental factors consist of all aspects of the world that are external or extrinsic to the individual and that have an impact on his or her functioning (Stucki & Sigl, 2003). These could involve the physical world and its features; the human-made physical world; other people in different relationships and roles; attitudes and values; social systems and services; and/or policies, rules and laws (Jette, 2006; Nieuwenhuijsen, Zemper, Miner, & Epstein, 2006; Schneidert, et al., 2003; Stucki & Sigl, 2003; Vanleit, 2008; World Health Organisation (WHO), 2001). Environmental factors can facilitate or hinder a person's level of functioning or participation in society (Hwang & Nochajski, 2003; Jette, 2006; World Health Organisation (WHO), 2001).

Personal factors are contextual factors that are intrinsic to the individual (Stucki & Sigl, 2003; Vanleit, 2008). There are individual characteristics which are unique and which are not part of the individual's health condition (Reinhardt, et al., 2006; Stucki & Sigl, 2003; World Health Organisation (WHO), 2001). These include individual characteristics, demographic

characteristics, a person's socio-economic background (age, gender, employment, education etc.), lifestyle, coping styles, psychological factors, and past and current experiences. These can have a positive or negative influence on functioning (Reinhardt, et al., 2006) and disability, and they can play the role of moderators or modifiers with regard to functioning, disability and health. Additionally, in the context of clinical intervention, a consideration of personal factors encourages a patient-centred care approach (Geyh, et al., 2011).

2.4 PLWH and body impairments, activity limitations, social participation restrictions and contextual factors

Studies have shown that PLWH encounter health-related challenges which manifest as various types of condition and impairment; these may be classified as belonging to both the physical and the mental or psychological and the social domains. These can affect the general functional status of PLWH and may restrict them from participating fully in society or like any other person without HIV infection (Crystal, Fleishman, Hays, Shapiro, & Bozzette, 2000; Heidari & Kippax, 2009; Lorenz, Shapiro, Asch, Bozzette, & Hays, 2001; Myezwa, et al., 2009; O'Brien, et al., 2008; Rusch, et al., 2004a; Van As, et al., 2009).

Participants in a study conducted by Rusch et al. (2004a) in Canada demonstrated that even PLWH with high CD4 counts experienced impairments, activity limitations and participation restriction as a consequence of HIV infection: there was little difference in the functional limitations of people with different levels of CD4 count. Functional limitations can affect the HRQOL of PLWH (Lorenz, et al., 2006).

O'Brien et al. (2008) found the disability or the functional limitations from HIV infection, were multidimensional and episodic by nature, characterised by unpredictable periods of wellness and illness. Participants in their study believed this was due to HIV infection itself and to the side effects of antiretroviral treatments. They reported that they experienced numerous impairments, limitations in daily activity performance, and restrictions on social life. They also recognised the influence on functioning (either positively or negatively) of external factors such as support from friends, access to health services, and internal factors (factors within themselves), such as age, and coping strategies that assist in dealing with HIV infection. In addition, they were uncertain prognosis and progression of the disease (O'Brien, et al., 2008). The most frustrating experience for PLWH is the situation of uncertainty and the inability to predict disease complications or progression and obtain a clear prognosis.

PLWH live with the worry and fear that some complication or functional problem may occur in the future – the next day or the next year (McReynolds & Garske, 2001).

2.4.1 PLWH and body impairment

Impairments identified in PLWH may be caused by the HIV infection and its associated pathologies or by antiretroviral treatment (Alexander, 2011).

Vogl et al. (1999) indicated that PLWH rarely present with a single impairment. This was confirmed by the findings of their study, conducted in USA, that aimed at assessing physical and psychological functioning among PLWH. They identified several impairments, ranging in prevalence from 19% to 85.5%. Twelve impairments had a prevalence of more than or 60%: these were worrying (85,5%), lack of energy (85,1%), feeling sad (81.5%), pain (75,6%), feeling irritable (75,1%), difficulty sleeping (73,8%), feeling nervous (68%), dry mouth (67,6%), difficult concentrating (64,5%), shortness of breath (62,4%), feeling drowsy(61,9%) and a persistent cough (60.3%) (Vogl, et al., 1999).

Similarly, Newshan, Bennett, and Holman (2002), found in their study that two-thirds (68%) of their sample reported at least one impairment. Of these 96% reported more than one impairment and almost half of the sample reported more frequent problems. These varied from moderate to severe: fatigue scored 43%, insomnia 35%, anxiety 34% and pain 31%. However; multiple problems were often present.

A more recent study by Lee et al. (2009) of another selected population in the USA demonstrated almost similar findings: it found that the mean number of present impairments was nine. Remarkably, those who were on antiretroviral treatment had more impairments than the naive patients. The most prevalent impairments were: lack of energy (65%), drowsiness (57%), difficulty sleeping (56%), and pain (55%) (Lee, et al., 2009). Furthermore, in Canada, the results from a cross-sectional population-based survey, carried out among PLWH, have shown a higher proportion (90%) of the study population experiencing one or more impairments, with approximately one-third reporting more than ten impairments. Both physical and psychological symptoms were present (Rusch, et al., 2004a).

Alexander (2011) reported on reviewed studies from some of the developed countries; including France, Italy and USA. Participants in all the reviewed studies were receiving a combination of antiretroviral treatments. Findings from those studies often revealed repeated impairments in PLWH. The most common were fatigue (55%-85%), anorexia (34%-55%),

worry or feelings of sadness/depression (47%-82%) , pain from multiple parts of the body (29%-76%), dyspnea/shortness of breath (19%-62.4%), a persistent cough (30.4%-60.3%), problems with sleep (48%-73.8%), weight loss (37.1%-60%), and fever (14%-59%). In Africa, only a few studies have looked at the functional status of PLWH. For example; a cross-sectional descriptive study utilising the ICF checklist conducted in South Africa by Van As et al. (2009) reported many impairments affecting different body functions among PLWH. The most common problems were haematological problems (96%), followed by problems with sensory functioning, particularly sight and pain (71%), and mental health problems (69%). A similar South African study by Myezwa et al. (2009) demonstrated that 100% of the participants experienced one or more impairments, with a mean of eleven impairments per person. There was a high rate of impairment of physical and mental/psychological functions . The most common problems were digestive, metabolic and endocrine system problems (83.9%), sensory problems (83.5%), and mental problems (72.6%) etc.

In Rwanda, a study by Uwimana and Struthers (2008) found that most PLWH in Rwanda also experienced impairments related to HIV infection. Their study has shown that 69% of PLWH experience impairments most of the time. Physical problems were complained of by 92%; among these; neuromuscular conditions were reported by 70% of PLWH. Mental/psychological problems were complained of by 65% of PLWH.

2.4.1.1 PLWH and impairments in mental function

In the ICF, mental function is broadly described as referring to the functions of the brain and the central nervous system (CNS), including both global mental functions and specific mental functions (World Health Organisation (WHO), 2001). There is increasing evidence that HIV infection affects the mental functionality of PLWH and that the prevalence of mental health conditions is very high (Ciesla & Roberts, 2001; Collins, Holman, Freeman, & Patel, 2006).

In a study by Rusch et al. (2004a), mental impairments are the most commonly reported problems among PLWH, with a prevalence of 62.9%. These were also found to have a strong association with participation restrictions in society. The results of a study in South Africa by Freeman, Nkomo, Kafaar, and Kelly (2007) demonstrated a prevalence rate of various mental disorders among PLWH of 43.7%. Another South African study by Van As et al. (2009) reported that mental health impairment was among the most frequently complained about body function problems: it was the third most commonly reported problem (69%). Energy and drive, and sleeping and emotional problems were commonly reported.

It is likely that among the reasons for the high prevalence of mental health problems in PLWH are the effects of the virus on the central nervous system, the psychological and emotional impact of the disease, the side-effects of the antiretroviral treatment and the consequences of stigmatization and discrimination against PLWH (Freeman, Patel, Collins, & Bertolote, 2005).

HIV and psychological/emotional disorders

Collins et al. (2006) evaluated a number of studies on the impact of HIV infection on mental health ; these have shown that there is a high rate of psychological distress and depression among PLWH, and this might be associated with the severity of their physical impairments. Likewise, as was demonstrated above, emotional impairment was among the three most frequently cited mental health problems, as expressed by a group of PLWH in a selected area in South Africa (Van As, et al., 2009). Coleman et al. (2006) have shown that more than half of the participants in their study suffered from depression. Hudson, Kirksey, and Holzemer (2004) reported that there was a very high prevalence rate for depression (83%) among PLWH in their study. Similarly Rusch et al. (2004a) found that depression was the most commonly complained about mental impairment, with a prevalence of 58.1%.

It has been observed that in the era of antiretroviral treatment, psychological distress has shifted from fears, worries and sadness about the death of relatives, children, partners and others to problems and anxieties with regard to forming relationships and the disclosure of a person's serostatus to others (Catalan, Meadows, & Douzenis, 2000). There is also discouragement and anxiety regarding the multiple complications of antiretroviral treatment (Catalan, et al., 2000; Ciesla & Roberts, 2001).

In addition, the uncertainty of the disease prognosis affected patients' psychological adjustment to a lifelong and life-threatening disease. This limited the individual patient's ability to plan for the future, created barriers in family and social relationships, and led to difficulties with regard to social, work and recreational activities; these factors could severely affect the psychological well-being of PLWH (McReynolds & Garske, 2001).

Several other studies have shown that there is evidence that PLWH experience a multitude of emotions, including psychological distress; this occurs from the onset of the disease and throughout its progression (Vogl, et al., 1999). However, such cases are more likely to be found during the period following the diagnosis than other times. The occurrence of

psychological distress /depression disorders in PLWH may be approximately twice that found in HIV-negative people (Ciesla & Roberts, 2001; Valente, 2003). In addition, this is supported by findings from a study carried out by Miles, Holditch-Davis, Pedersen, Eron Jr, and Schwartz (2007); this aimed to determine the relationship of personal factors such as demographic characteristics and perceptions of health with emotional distress and depression among PLWH. Their study revealed that there was a highly significant association between youth and depression. A significant association was also found between depression and adverse perceptions of a person's health status.

Chan et al. (2006) and Vosvick et al. (2002) discovered that individual patient's positive thinking about his or her health correlates positively with lower levels of psychological distress, whereas avoidance was associated with higher levels of distress; moreover, it also impacts negatively on quality of life (Vosvick, et al., 2002). Furthermore, studies by Kowal et al. (2008) and Vosvick et al. (2002) demonstrated that PLWH who dealt with psychological stressors and faced their problems in an active manner and used adaptive coping strategies were found to have fewer depressive emotional symptoms and a higher quality of life, compared to those who used avoidance, or emotionally oriented and maladaptive strategies.

Social support particularly emotional social support, was found to be associated with less psychological distress and improved psychological quality of life (QoL) (Friedland, Renwick, & McColl, 1996). Notably, Jia et al. (2004) and Ashton et al. (2005) reported that in their studies social support was found to be a very strong predictor of patients' general health status and of their physical and psychological and social functioning; it also improved overall quality of life.

Signs and symptoms of psychological distress could take the form of feelings of shock, feelings of guilt, decreased self-esteem, feelings of anxiety, loss of identity, fear, anxiety, sadness, and a depressed mood (Vogl, et al., 1999). Temporary emotional distress such as that expressed by mood (for instance, anger, sadness, fear etc.) could be a reaction to immediate psychological distress, whereas depressive symptoms could manifest after a prolonged state of psychological distress (Miles, et al., 2007). Assessments of health should focus on such things as the persistent experience of sadness, discouragement, lack of motivation and activity (Richardson et al., 2009).

Failure to detect depression due to the health care provider's mistaken diagnosis or to patients not reporting their symptoms (perhaps for of being judged or because of shame for their mental health dysfunction) can result in severe depression on the part of PLWH, with possible consequences such as lower life expectancy and poor treatment adherence. The immune function could be adversely affected and there could be an increased risk of suicide (Valente, 2003).

There is accumulated evidence that emotional distress and depression could be caused by HIV stigma and discrimination, and positive associations have been found between depression and both perceived and internalised stigma (Emlet, 2007; Freeman, et al., 2007; Kalichman et al., 2009; Simbayi et al., 2007; Vyavaharkar et al., 2010) and between emotional distress and depression and discrimination (Freeman, et al., 2007). Furthermore, a multi-country study conducted by Holzemer et al. (2009) among PLWH reported high HIV stigma scores that were significantly and negatively correlated with the quality of life of the participants.

HIV Stigma and discrimination

Several studies have highlighted the effects of stigma on PLWH (Emlet, 2006; Holzemer, et al., 2009; Kalichman, et al., 2009; Lee, Kochman, & Sikkema, 2002; Simbayi, et al., 2007), as well as the effects of discrimination (Duffy, 2005; Freeman, et al., 2007; Simbayi, et al., 2007).

For example, the findings of a qualitative study carried out by Zukoski and Thorburn (2009) in one selected rural area in USA indicated that, of sixteen PLWH who participated in the study, fourteen had experienced stigma and discrimination from people in their community, including in their health-care community. Participants complained mostly about feeling socially isolated and rejected by friends and family. They were sometimes asked to follow rules and were treated differently because of their HIV status. With regard to the health-care setting, participants complained that health care providers were sometimes afraid of them, thinking that they would be contaminated; they also refused to treat them or they treated them differently from other people; they sometimes referred them to other health care providers when they were in fact able to treat them.

In various surveys Simbayi et al. (2007) have also looked at the issue of discrimination among PLWH in one selected area in South Africa. These results have shown an increased

presence of discrimination and HIV stigma. The following are examples of discrimination: almost one person in three said there were treated differently after they had disclosed their HIV status to friends and family. Nearly 40% experienced discriminated from others because they were living with the HIV infection. One in five individuals indicated that they had lost their job or a place to stay because of their HIV status. Many participants said also that there were friends and family members who had stopped visiting them after learning that they were HIV positive.

The HIV stigma is a very complex and multidimensional problem (Emlet, 2007). Herek and Capitanio (1999) identified four characteristics that explain why HIV is a much stigmatized disease. (1) It is a disease which is seen as the bearer's responsibility; this is because the mode of infection transmission often involves behaviour that is considered voluntary and therefore avoidable. (2) Despite the tremendous impact of antiretroviral treatment on the general health status of PLWH, the HIV disease is still considered to be a life threatening disease. (3) The HIV disease is perceived to be contagious. (4) HIV disease is also apparent to others; symptoms are often obvious, particularly when the disease is far advanced.

HIV stigma can be expressed in different ways. It can be related to the individual's inner feelings and thoughts; for example, the individual may feel ashamed, and may be aware that other people are not comfortable living with an HIV infected person. Types of internal/internalised stigma include personalized stigma and having a negative self-image (Emlet, 2007).

Simbayi et al. (2007) have also looked at the issue of internalised stigma among PLWH. Many participants complained about internalised stigma, such as the emotions they experienced since being diagnosed. The most commonly experienced feelings connected to the HIV stigma were: feeling dirty and ashamed, feeling guilty and worthless, blaming oneself, and lack of disclosure of their HIV serostatus to others. Makoae et al. (2008) carried out a multisite study involving five African countries; using qualitative methods; they showed that internalised stigma can include the following: negative perceptions of the self, social withdrawal, self-exclusion, and fear of disclosure.

Lee et al. (2002) found that PLWH who demonstrated higher levels of HIV-related impairments also had significant levels of internalised stigma. Moreover, the same group with increased levels of internalised stigma and greater HIV impairments was reluctant to look for social support, perhaps because of feelings of shame and embarrassment. They complained of

receiving less support from their families, because their families did not accept their disease. The stigma was also more prevalent among those recently diagnosed with the HIV infection.

HIV stigma can also find its source outside the individual patient: it can come from the patient's family and from the society in general in this case it is social stigma. For example HIV-infected individuals can experience rejection from their parents or from their employer (Emlet, 2007). Social stigma can be reflected by negative treatment or negative attitudes from other people in the society towards PLWH; this can take the form of avoidance, disdain, denial of recognition, and job loss (Li, Ji, Ding, Tian, & Lee, 2012). Makoae et al. (2008) conducted a study in five African countries; they reported that external stigma or social stigma could include the following: neglecting, negating, avoiding, rejecting, labelling, gossiping, pestering, and abusing.

Emlet (2007) suggested that generally stigma can result in the following: (1) rejection: this is when PLWH are rejected by their society and do not receive any support from other people. However lack of social support is a factor in social stigmatization and can also lead to internalized stigma (Kalichman, et al., 2009). This can cause someone to isolate himself or herself (Li, et al., 2012). Rejection can be observed in the relationship between PLWH and family members, for instance, parents, siblings and partners, and also in the relationship with other people in the society; such as friends, employers, church members and health care providers.

Emlet's (2007) other suggestions were (2) fear of contagion: sometimes PLWH are stigmatized because non-infected people in their society fear contamination; as a result; PLWH feel isolated and lonely. Isolation and loneliness could also be a consequence of rejection and lack of trust from other people. (3) Negative self-image: it often happens that PLWH feel ashamed, embarrassed, humiliated and guilty about their HIV status. (4) Self-depreciation is also an issue to consider in relation to HIV and stigma: it is expressed in low self-esteem. To the extent that the individual is affected by self-depreciation and is not able to value himself or herself, the person might see himself or herself as different from others, thus limiting his or her participation in the society.

Findings from the study conducted by Makoae et al. (2008) identified the different coping strategies PLWH have adopted to deal with issues such stigma, described above. Two kinds of strategy were identified: (1) emotional coping strategies in which the individual patient looked for solutions from within: this involved emotional behaviour to be able to cope with

stigma. This included rationalization: that is, trying to make stigma less painful, seeing oneself as normal, avoidance of confrontation and accepting or ignoring stigmatization from others. It could include turning to God; which would involve activities such as praying, joining religious groups, and depending on and building up hope in God in response to the illness. Hope and having sense of humour about the illness were also identified as important factors. (2) The second category included problem-oriented coping strategies. These included being more active and involving other people or taking part in certain activities, such as joining a group (for example an HIV group), disclosure, going for counselling, interacting or socializing with others, helping others, acquiring more knowledge about HIV illness, educating others, changing one's lifestyle, keeping oneself busy, and learning from others.

A household survey carried out by Genberg et al. (2009) involved four countries (Northern Thailand, South Africa, Zimbabwe and Tanzania) and showed that in general knowledge about HIV and related issues had a big impact on people's attitudes towards PLWH. For example; never being involved in HIV talks, and never having taken an HIV test, as well as a lack of knowledge about antiretroviral treatment, were all significantly associated with negative attitudes towards PLWH. In addition, never having been involved in HIV discussions and lack of knowledge about antiretroviral treatments were associated with increased perceived discrimination against PLWH. It was also observed that high levels of discrimination were predominant in the sites where there was insufficient support and unsatisfactory care for PLWH.

PLWH and disclosure

The literature suggests that the majority of PLWH do not easily disclose their HIV serostatus. Emlet (2007) stressed that many PLWH refuse to disclose because they do not understand why they should tell others that they are infected. Others (because of internalised stigmatization), are embarrassed by being infected and are very reluctant to inform other people (Kalichman, et al., 2009; Lee, et al., 2002). Sometimes they decide to keep their status a secret because they fear discrimination (Tarakeshwar, Pearce, & Sikkema, 2005). It has also been observed that there are PLWH who express anxiety and fear of disclosure while at the same time feeling a need to share their serostatus with others; this creates a dilemma and leaves them uncertain of what to do (Emlet, 2007). Li et al. (2012); found that PLWH who refused to disclose their HIV status were able to live normal physical and social lives but

were not psychologically healthy. These participants revealed that secrecy and pretending to be normal was not only for their own protection but also for the protection of their families.

Gaskins, Foster, Sowell, Lewis, Gardner, and Parton (2012) describe disclosure as an ongoing process, and that can take years. Soon after being diagnosed, people tend to experience denial and fail to communicate what they themselves have not accepted. For many there is a need for time to try to understand the mysterious world of HIV and how to change their lives and adapt to a new way of living, before making disclosure. Moreover, participants revealed also that there were other factors which could influence how decisions were made. This included social, cultural, and environmental factors and, most importantly, the anticipated response from the recipients of disclosure.

Some of the advantages of disclosure include: (1) being provided with social and emotional support (Emler, 2006, 2007; Gaskins, et al., 2012; Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003); (2) a reduction of the stress caused by the disease (Gaskins, et al., 2012; Kalichman, et al., 2003); and (3) the ability to make others aware of the disease and to observe preventative measures (Gaskins, et al., 2012).

Studies have also demonstrated that the disadvantages and risks of disclosure can also discourage someone from disclosing. Some of the disadvantages and risks include the negative attitudes and reactions of others – this can be expressed through rejection, discrimination and stigma (Emler, 2007; Gaskins, et al., 2012; Sowell, Seals, Phillips, & Julious, 2003). There is also a fear that this information might be spread more widely (Gaskins, 2006; Gaskins, et al., 2012). Fear of the consequences of disclosure also affects people's involvement in relationships (Emler, 2007).

PLWH who are willing to disclose have preferences when it comes to the choice of recipient to be told. Several studies have identified the following possibilities, in rough order of preference: family members, partners, friends, neighbours, church leaders or members and health care providers (Emler, 2006; Gaskins, 2006; Gaskins, et al., 2012; Maman, Cathcart, Burkhardt, Omba, & Behets, 2009). Gaskins et al. (2012) found that family members were likely to be trusted by most PLWH, with mothers the most likely to be told first, followed by the siblings. However Emler (2006) found the majority of older PLWH preferred to disclose their status to their children. Maman et al. (2009); in a study conducted in Kinshasa, DRC; found that participants had chosen to divulge their HIV status first to their partners and also to their church leaders or pastors because they believed pastors were gifted by the power of

God and were able to keep secrets. Furthermore, participants in Gaskins (2006) suggested it was best to avoid informing the employers of one's HIV serostatus as this could affect their work status. They believed employers were not supportive.

PLWH and Spirituality

Studies have shown that PLWH use their spiritual beliefs as one of the most effective strategies to cope with challenges linked to HIV (Makoae, et al., 2008; Siegel & Schrimshaw, 2002), including stigma (Makoae, et al., 2008).

It has been found that PLWH's spiritual beliefs can interfere with their understanding about HIV to the extent that it affects their adherence to antiretroviral treatments. For example, a prospective observational study conducted in Uganda by Wanyama et al. (2007) found that some PLWH decided to interrupt their therapy because they believed they had been cured by the power of God and no longer needed antiretroviral treatments. This behaviour could lead to drug resistance and affect the viral load and the general clinical status of these patients (Oyugi et al., 2007).

Siegel and Schrimshaw (2002), and Ironson, Stuetzle, and Fletcher (2006) found an increase in the practice of spirituality after HIV diagnosis. Furthermore Siegel and Schrimshaw (2002) revealed that some PLWH who had stopped practicing their faith or who did not have strong spiritual beliefs before the diagnosis found themselves seeking spiritual involvement and support and developing very strong spiritual beliefs. However, the majority of the participants in their study had not opted for formal religious practices, such as attending church; instead they preferred prayer and meditation in the home setting. Other spiritual practices included watching religious television programs and listening to services and religious music on the radio.

Scarinci, Quinn Griffin, Grogoriu, and Fitzpatrick (2009) found that PLWH in the USA had also exhibited stronger spiritual beliefs. Many prayed alone and or listened to gospel music. A preference for private spiritual practices was also described by Dalmida, Holstad, Diiorio, and Laderman (2009).

A growing body of research indicates the benefits PLWH gain from religious/spiritual beliefs and practices. Spirituality beliefs encourage positive emotions, such as tranquillity, contentment and feelings of peace (Maman, et al., 2009; Siegel & Schrimshaw, 2002; Tarakeshwar, et al., 2005). They reduce the reaction to the diagnosis and reduce feelings of

self-blame and guilt and shame, thus enhancing self-acceptance (Siegel & Schrimshaw, 2002).

PLWH indicate that faith and belief in God's power increased their resilience and ability to deal with HIV and take control of their lives (Maman, et al., 2009; Siegel & Schrimshaw, 2002; Tarakeshwar, et al., 2005). Most importantly, some PLWH believed that their illness could be cured by God (Maman, et al., 2009; Siegel & Schrimshaw, 2002). Participants in a study by Siegel and Schrimshaw (2002) reported that spiritual beliefs reduced the fear and uncertainty of death. Coleman et al. (2006) found PLWH used prayer as a self-care management strategy to overcome some of the symptoms associated with HIV, such as fatigue, nausea, anxiety and depression.

Maman et al. (2009) reported that participants in their study said that their religious leaders (pastors) and even their health care providers, particularly their counsellors, also had a conviction in the power of God. They believed that prayer could heal the HIV disease and encouraged them to continue praying and have faith in God.

Spiritual practices, such as prayer, are described as assisting PLWH to be able to surrender their destiny and the burden of HIV disease into God's hands. This helps them to feel better and alleviates their emotional and psychological distress (Maman, et al., 2009; Siegel & Schrimshaw, 2002).

Through spiritual practices such as prayer and meditation, whether in private or public, participants said that they managed to develop a relationship with God and talk to him; this provided them with support and comfort (Maman, et al., 2009; Siegel & Schrimshaw, 2002). This enabled them to accept and give meaning to their illness (Siegel & Schrimshaw, 2002), and to find meaning and purpose in their lives (Litwinczuk & Groh, 2007). Studies have demonstrated that PLWH's stronger spiritual beliefs and practices have been positively associated with improved physical and mental health (Frame & Reid, 2005). Spiritual well-being can predict lower depressive symptoms (Braxton, Lang, Sales, Wingood, & DiClemente, 2007; Dalmida, et al., 2009; Tarakeshwar, et al., 2005). Spiritual practices can also positively influence social functioning (Frame, et al., 2005). For those who are able to attend church services, this improves their social interaction and fosters the sense of social acceptance and of belonging to a religious community (Siegel & Schrimshaw, 2002).

There is evidence that spiritual beliefs and practices not only improve health but also assist PLWH to maintain their health by slowing the progression of HIV illness (Ironson, et al., 2006; Siegel & Schrimshaw, 2002). A longitudinal study by Ironson et al. (2006) found that PLWH who indicated increased spiritual beliefs and practices; maintained their CD4 cell counts and had good control of their viral load throughout the four-year period of observation. This was also demonstrated by Dalmida et al. (2009), who found a positive relationship between higher scores in the spiritual well-being of PLWH and higher CD4 cell counts.

PLWH and sleep disorders

There is a large body of research indicating that PLWH often suffer from problems with sleep quality (Cruess et al., 2003; Hudson, et al., 2004; Lee, et al., 2009; Lee et al., 2012; Reid & Dwyer, 2005; Rubinstein & Selwyn, 1998; Taibi, 2013; Vosvick et al., 2004). Sleep disturbance has been reported in the early stages of HIV illness (White et al., 1995). A review of the literature by Reid and Dwyer (2005) indicated that sleep disturbance continues to manifest and is often present across all stages of the disease, accompanied by changes in an individual patient's sleep profile. Furthermore, there is evidence that sleep disturbance is associated with other HIV impairments (Robbins, Phillips, Dudgeon, & Hand, 2004). Rubinstein and Selwyn (1998) found that 73% of the PLWH complained about sleep disturbance, and among them 41% experienced depression, whereas in the group of those without sleep disturbance only 10% were detected with depression (P value < .005). A correlation between depression and sleep disturbance was also shown in studies conducted by Lee et al. (2012); Robbins et al. (2004), Rubinstein and Selwyn (1998) and also in a review of literature by Reid and Dwyer (2005).

Other mental and psychological problems found to be associated with sleep disturbance among PLWH were psychological/emotional distress and anxiety, and cognitive impairment. Cruess et al. (2003) and Robbins et al. (2004) found a significant relationship between sleep disturbance and psychological distress. Sleep disturbance was also shown to be correlated with anxiety by Robbins et al. (2004), by Reid and Dwyer (2005) and by Newshan, Bennett and Holman (2002). A relationship between cognitive impairment and sleep disturbance was found by Rubinstein and Selwyn (1998).

A relationship has been demonstrated between sleep disturbance and impairments such as fatigue and pain. Robbins et al. (2004) and Vosvick et al. (2004) found that increased levels

of sleep disturbance were significantly correlated with increased pain. Significant correlations were also demonstrated between sleep disturbance and fatigue by Salahuddin, Barroso, Leserman, Harmon, and Pence (2009), Robbins et al. (2004), and Lee et al. (2009).

An environmental factor was also found to have an impact on quality sleep. It was found that the greater the number of adults living in a house, the poorer the quality of sleep (Robbins, et al., 2004). One type of antiretroviral treatment in the group of NNRTIs; EFV, is related to poor quality of sleep (Raines, Radcliffe, & Treisman, 2005; Reid & Dwyer, 2005).

2.4.1.2 PLWH and neurological disorders

HIV can affect every part of the nervous system and it is possible that more than one pathology can simultaneously affect the same part (Verma, 2001). Neurological impairments that manifest in PLWH may be primary complications that are directly associated with HIV infection, but they can also be secondary complications (Clifford & Mitike, 2008; Koppel & Akfirat, 2003). The primary complications result from infection in the nervous system. The HI virus could enter the brain and the cerebrospinal fluid immediately after exposure or early in the course of infection. Primary complications include HIV-associated dementia, cognitive motor disorders, HIV-associated myelopathy and HIV-associated peripheral neuropathy (Clifford & Mitike, 2008). Secondary complications are consequences of the dysfunction or changes that occur to the immune status of the person who has been infected. These changes may be due to immunodeficiency and may include cryptococcal meningitis, toxoplasma encephalitis, cytomegalovirus encephalitis and radiculomyelitis, progressive multifocal leukoencephalopathy, and varicella zoster (Clifford & Mitike, 2008). These changes may also be due to dysregulation of the immune system. The most commonly affected site is the peripheral nervous system, leading to chronic inflammatory demyelinating polyneuropathy or Guillain-Barre syndrome, and mononeuritis multiplex (Koppel & Akfirat, 2003).

The use of antiretroviral treatment had decreased the incidence of primary and secondary neurological complications (Clifford & Mitike, 2008; Portegies et al., 2004). Where drugs are available the majority of the neurological conditions may only manifest in advanced stages of the disease, especially when the immune system has been severely impaired and the CD4 count has gone below 200 cells/ul (Clifford & Mitike, 2008). The prevalence of HIV dementia with its marked neurocognitive and motor impairments, once a common

neurological complication (Nath & Berger, 2004), has dropped below 5% (Clifford & Mitike, 2008; Heaton et al., 2010).

Cognitive impairments

However, despite the substantial benefits of antiretroviral treatment there are still mild to moderate neurocognitive impairments among PLWH who are on antiretroviral treatment (Clifford & Mitike, 2008; Heaton, et al., 2011; Robertson et al., 2007; Vance, Fazeli, Moneyham, Keltner, & Raper, 2013). Even among those with undetectable plasma viral loads, neurocognitive impairments are present (Cysique, Maruff, & Brew, 2004). Memory loss, slowing of mental functions (McArthur, Brew, & Nath, 2005; Simioni et al., 2010), and difficulty in performing tasks that require reasoning are common (McArthur, et al., 2005).

Ciccarelli et al. (2011) found a prevalence of 47%, particularly for minor cognitive disorders. Salawu et al. (2008) found a prevalence of 30% for attention impairment, 30% for calculation impairment, 27% for memory recall impairment, and 27% for orientation to place impairment. Similarly, in another group of PLWH from Switzerland, Simioni et al. (2010) found that PLWH with suppressed HIV viremia had no history of major opportunistic infections of the central nervous system; 27% complained of cognitive impairments, the most frequent being memory loss (18%), slowing of mental functions (16), and attention deficit (9%).

Heaton et al. (2011) listed factors that could lead to persistent neurocognitive impairments; these could include irreversible brain damage prior to the initiation of antiretroviral treatment, incomplete viral suppression in the CNS (this might be due to poor penetration of antiretroviral treatment into the CNS and/or medication-resistant viral strains or also possibly the neurotoxicity of antiretroviral treatment). Ciccarelli et al. (2011) found evidence that efavirenz is a risk factor for cognitive impairments.

Poor cognitive functions can have also an impact on adherence to antiretroviral treatment (Becker, Thames, Woo, Castellon, & Hinkin, 2011; Vance, et al., 2013). There is evidence that the presence of cognitive impairments in PLWH could lead to a decline in adherence to antiretroviral treatment (Becker, et al., 2011; Harzke et al., 2004). On the other hand studies have shown that an interruption to antiretroviral treatment can adversely affect cognitive impairments (Becker, et al., 2011; Parsons, Braaten, Hall, & Robertson, 2006).

Cognitive impairments can also have a negative influence on daily functioning, increase patient dependence and reduce the quality of life (Vance, et al., 2013). In addition, it has been observed also that PLWH who are affected by neurocognitive impairments might show behavioural abnormalities, such as apathy and emotional distress (Simioni, et al., 2010).

Corless et al. (2000) found that the general functional status of individual patients could influence cognitive functioning, and depression could predict impairment of the cognitive function. This was also described by Vance, Larsen, Eagerton, and Wright (2011), Thames et al. (2011), Atkins et al. (2010), and Fazeli, Marceaux, Vance, Slater, and Long (2011). PLWH who receive greater social support show higher levels of cognitive function (Atkins, et al., 2010).

Peripheral neuropathy

Peripheral neuropathy is a common neurological condition among PLWH (Clifford & Mitike, 2008; Moylett & Shearer, 2002; Nicholas et al., 2007a; Wulff, Wang, & Simpson, 2000), and can occur at every stage of HIV infection (Verma, 2001). The most common types of peripheral neuropathy in HIV infection disease are the following: distal symmetrical polyneuropathy, inflammatory demyelinating polyneuropathy, mononeuritis multiplex, progressive polyradiculopathy and autonomic neuropathy (Wulff, et al., 2000). In the early stages of the infection, sometimes even when the patient is unaware that he or she has been infected, inflammatory demyelinating polyneuropathy may already be present (Koppel & Akfirat, 2003; Wulff, et al., 2000). However the manifestation of peripheral neuropathy is usually associated with the severe or advanced stage of the disease (Lopez, Becker, Dew, & Caldararo, 2004; McArthur, et al., 2005; Nicholas et al., 2007; Wulff, et al., 2000), along with a low CD4 count (Luma et al., 2012).

The most common peripheral neuropathy is the distal symmetrical polyneuropathy (Koppel & Akfirat, 2003; Moylett & Shearer, 2002; Ownby & Dune, 2007; Wulff, et al., 2000), also known as distal sensory polyneuropathy (Clifford & Mitike, 2008; Mullin, Temu, Kalluvya, Grant, & Manji, 2011; Nicholas, et al., 2007b; Verma, 2001; Wiebe, Phillips, Li, Allen, & Shetty, 2011). This is usually chronic (Moylett & Shearer, 2002; Ownby & Dune, 2007), very painful and may lead to disability (Nicholas, et al., 2007a; Verma, 2001); and it can have a negative impact on quality of life (Luma, et al., 2012). Its symptoms are reported by almost 50% of PLWH (Moylett & Shearer, 2002), and usually involve numbness, burning sensations, tingling, intense pain, paraesthesias, dysesthesias and allodynia (Ownby & Dune,

2007). Nicholas et al. (2002) suggest that pain is the most common descriptor of peripheral neuropathy, followed by numbness.

Distal symmetrical polyneuropathy can also occur as a side effect of antiretroviral treatment (Anwikar et al., 2011; Kumarasamy, et al., 2008; Lopez, et al., 2004; Moylett & Shearer, 2002; Nicholas, et al., 2007a; Nicholas et al., 2007b; Ownby & Dune, 2007; Peltier & Russell, 2006; Verma, Estanislao, & Simpson, 2005). In particular the group of NRTIs, such as Zalcitabine, Didanosine, Stavudine, and Lamivudine (Clifford & Mitike, 2008; Huang et al., 2013; Peltier & Russell, 2006), and occasionally in the group of Protease Inhibitors (PIs) (Centner, Bateman, & Heckmann, 2013), and it is branded; “antiretroviral toxic neuropathy” (Clifford & Mitike, 2008; McArthur, et al., 2005; Wiebe, et al., 2011).

There is accumulative evidence concerning the prevalence of peripheral neuropathy in PLWH, especially with regard to distal symmetrical polyneuropathy, which is the most common (as described above) and is frequently related to the side effects of antiretroviral treatment. Kumarasamy et al. (2008) found a prevalence of 9% in PLWH on a combination of one or two drugs in the group of NRTI. Furthermore, there is evidence that peripheral neuropathy is frequently found in PLWH living in sub-Saharan Africa (Mullin, et al., 2011). Among a group of PLWH in Malawi, Van Oosterhout et al. (2005) found more than half (56%) complained of peripheral neuropathy, which they described as causing pain and numbness in the lower extremities. In Cameroun, Luma et al. (2012) found a prevalence of neuropathic symptoms of 28.5%, the most common of which was pins and needles in the legs or feet. The prevalence of symptomatic distal symmetrical polyneuropathy was 21%. In Kenya, Cettomai et al. (2010) found that 20% of PLWH demonstrated moderate to severe peripheral neuropathy. In India, Lopez et al. (2004) found a percentage of 22% of PLWH with peripheral neuropathy.

A comparative study in Tanzania by Mullin, Temu, Kalluvya, Grant, and Manji (2011) involving PLWH who were taking antiretroviral treatment and those who were not; found that the prevalence of distal symmetrical polyneuropathy was much higher (43.2%) in the group who were on antiretroviral treatment, particularly with a combination of one NRTI, mostly Stavudine; the prevalence for those who were not on antiretroviral treatment was 22.1%. The most common symptom was numbness.

A large randomised controlled trial study which involved twelve selected sites from USA, Puerto Rico and Kenya and South Africa by Nicholas et al. (2010) found that 44% of the

overall study population reported neuropathy symptoms, and antiretroviral treatment was found to increase the frequency of neuropathy symptoms by 28%. Their findings indicated that the intensity of neuropathy and its impact on the quality of life were higher in the African populations. In both South-Africa and Kenya it was reported that the antiretroviral treatment regimens included NRTIs with Didanosine and Stavudine, which could contribute to the peripheral neuropathy. In addition, this study also revealed that antiretroviral treatment regimens in the group of PIs could also contribute to an increased prevalence of peripheral neuropathy.

2.4.1.3 PLWH and musculoskeletal disorders

Musculoskeletal impairments are common in PLWH (Cuellar & Espinoza, 2000; Mody, Parke, & Reveille, 2003). Bony conditions associated with HIV infection include; osteomyelitis (Cuellar & Espinoza, 2000; Walker, Tyndall, & Daikeler, 2008), osteoporosis and bone necrosis (Walker, et al., 2008). However, bone necrosis has at times been reported to be linked to antiretroviral treatment and its metabolic complications, such as hyperlipidaemia (Mody, et al., 2003).

Articular conditions associated with HIV include arthralgia, psoriatic arthritis, Reiter's syndrome, acute syndrome polyarthritis and undifferentiated spondyloarthropathy (Biviji, Paiement, & Steinbach, 2002; Cuellar & Espinoza, 2000). These conditions are more prevalent in PLWH than in those who are HIV-negative (Biviji, et al., 2002). Articular conditions are usually caused by the HIV infection itself, triggered by changes in the immune system and also at times by microbial infections (Walker, et al., 2008).

Articular pain is the most frequent impairment among the conditions affecting the joints in PLWH (Cuellar & Espinoza, 2000; Mody, et al., 2003); its prevalence can reach 40% to 45% (Buskila et al., 1990; Cuellar & Espinoza, 2000). Both small and large joints are involved (Cuellar & Espinoza, 2000). Arthralgia does not show signs of inflammation and the affected joint are not expected to become damaged (Reveille & Williams, 2006).

Reiter's syndrome occasionally manifests in PLWH. It is in the arthritis family, and it is also termed "reactive arthritis" (Cuellar & Espinoza, 2000; Moylett & Shearer, 2002). It involves large joints of the lower extremities and sacroilitis (Moylett & Shearer, 2002). Articular manifestations are accompanied by other non-articular symptoms, for example, keratoderma, blenorrhagica, conjunctivitis and circinate balanitis (Cuellar & Espinoza, 2000; Moylett & Shearer, 2002).

Psoriatic arthritis, which is arthritis with epidermal disorders, is also sometimes present in PLWH, and at times it is noticeable in the early course of HIV infection. Generally, however, it occurs in late stages of the disease, and its prevalence among PLWH varies from 1 % to 32%. Joint involvement pattern is frequently poly-articular and asymmetric; however in rare cases the mono-articular pattern may occur (Cuellar & Espinoza, 2000).

Other articular conditions have been identified as associated with HIV infection. These include HIV-associated arthritis, septic arthritis, undifferentiated spondyloarthropathy, and infiltrative lymphocytosis syndrome (Mody, et al., 2003; Reveille & Williams, 2006). Gout can also occur, mostly due to the side effects of metabolic changes related to antiretroviral treatment (Walker, et al., 2008). In rare cases; rheumatoid arthritis, systemic lupus erythematosus, and sarcoidosis may be present (Reveille & Williams, 2006).

Muscular impairment in PLWH can be manifested in both inflammatory and non-inflammatory conditions (Cuellar & Espinoza, 2000). Myopathies such as pyomyositis and polymyositis are common (Biviji, et al., 2002; Buskila, et al., 1990; Owczarek, Jasinska, & Orszulak-Michalak, 2005; Scruggs & Naylor, 2008; Walker, et al., 2008).

Polymyositis is an autoimmune disease (Koppel & Akfirat, 2003); it is common among PLWH and is likely to occur at any stage during the course of the disease. It is usually sub-acute, and presents the following symptoms: progressive proximal muscle weakness associated with elevated creatine phospho-kinase levels (Koppel & Akfirat, 2003; Moylett & Shearer, 2002; Sangle, Dasgupta, Ratnalikar, & Kulkarni, 2010). Weakness of proximal muscle could lead to limitations in the performance of certain daily activities, such as combing hair, climbing stairs, rising out of a chair etc. (Koppel & Akfirat, 2003; Sangle, et al., 2010). Infectious pyomyositis is usually caused by staphylococcus aureus (Moylett & Shearer, 2002).

Myopathy is also related to antiretroviral treatment, especially zidovudine in the group of NRTIs (Owczarek, et al., 2005; Sangle, et al., 2010; Scruggs & Naylor, 2008). There is evidence that Zidovudine, like other NRTIs, has an affinity for the mitochondrial gamma DNA polymerase, and this results in mitochondrial DNA depletion and dysfunction and oxidative stress (Scruggs & Naylor, 2008). Zidovudine myopathy presents with the following clinical symptoms: myalgia, muscle tenderness, proximal muscle weakness (Cuellar & Espinoza, 2000; Moylett & Shearer, 2002; Sagar, Mohanty, & Bahal, 2010), muscle wasting, elevated serum concentrations of creatine phospho-kinase and intense

fatigue (Owczarek, et al., 2005; Sagar, et al., 2010). Other HIV-associated myopathies include nemaline myopathy, diffuse infiltrative lymphocytosis syndrome, HIV wasting syndrome, myasthenia gravis and reversible mitochondrial myopathy (Authier, Chariot, & Gherardi, 2005; Gherardi, Chariot, & Authier, 1995).

2.4.1.4 PLWH and skin disorders

Skin and mucous membrane diseases are very often present in PLWH (Tschachler, Bergstresser, & Stingl, 1996). The skin has often been found to be the first organ affected and the complications can be seen in almost 90% of PLWH (Osborne, Taylor, & Fuller, 2003; Tschachler, et al., 1996; Uthayakumar, Nandwani, Drinkwater, Nayagam, & Darley, 1997).

Skin diseases associated with HIV include viral infectious diseases such as Herpes simplex, characterised by chronic and painful ulcers frequently located at the junction between skin and mucous membranes (Tschachler, et al., 1996). Common clinical manifestations are orolabial, genital and anorectal mucocutaneous diseases (Osborne, et al., 2003). Varicella zoster is also in the family of herpes viruses and may be the first sign of HIV infection (Osborne, et al., 2003). Its clinical symptoms involve vesicular eruptions that occur in a dermatome pattern and sometimes progress to haemorrhagic and then necrotic lesions, and this can extend to several dermatomes (Osborne, et al., 2003; Tschachler, et al., 1996). It is accompanied by symptoms of localised itching, tenderness or burning pain. If it attacks the ophthalmic division of the trigeminal nerve, the eyeball may become infected, resulting in conjunctivitis, uveitis and even keratitis, and, if not well treated; this can lead to serious disabling complications (Osborne, et al., 2003). Human papillomavirus is a very common condition (Osborne, et al., 2003; Tschachler, et al., 1996) and can most frequently affect the women's genital organ; the severity of the symptoms is associated with the progression of the disease (Tschachler, et al., 1996).

Bacterial skin infections also exist in PLWH, such as a skin infection related to staphylococcus aureus, which is the most frequent bacterial skin infection (Osborne, et al., 2003; Tschachler, et al., 1996). Mycobacteria, syphilis, and bacillary angiomatosis are also sometimes present. Bacillary angiomatosis is most common in patients with low CD4 counts and might also involve the internal organs (Osborne, et al., 2003; Tschachler, et al., 1996).

Fungal and dermatophytes infections may manifest in PLWH. Common fungal infections involve mucous disorders, and the most common are oral and vulvo-vaginal candidosis. Dermatophyte infections affect the skin and the nails (Tschachler, et al., 1996).

Other common skin disorders include seborrhoeic dermatitis, which is the most common dermatosis associated with HIV infection. Psoriasis vulgaris is also present at times and pruritus is a common complaint among PLWH and correlates with some of the disorders mentioned above, such as staphylococcus aureus infection. Cases of adverse cutaneous drug reaction are also common, associated with the antiretroviral treatment Zidovudine (Tschachler, et al., 1996). Skin tumours have been seen also in PLWH, and the most frequently reported is Kaposi's sarcoma, especially in people with AIDS. It is strongly associated with immunosuppression (Ledergerber, Telenti, & Egger, 1999; Tschachler, et al., 1996).

2.4.1.5 PLWH and pain

Pain has been recognised as an impairment among PLWH (Alexander, 2011; Koeppe, Armon, Lyda, Nielsen, & Johnson, 2010), and affects different parts of the body (Alexander, 2011). The most frequent painful conditions include headache, peripheral neuropathy (Nair, Mary, Prarthana, & Harrison, 2009), oral cavity pain, throat and oesophagus pain (Alexander, 2011; Gray & Berger, 2007; Larue, Fontaine, & Colleau, 1997; Singer et al., 1993), genital and rectal pain (Alexander, 2011), back pain (Nair, et al., 2009; Newshan, et al., 2002), herpes zoster (Singer, et al., 1993), arthralgia (Hewitt et al., 1997; Larue, et al., 1997; Singer, et al., 1993), myalgia (Hewitt, et al., 1997; Larue, et al., 1997), chest and abdominal pain (Del Borgo et al., 2001; Gray & Berger, 2007), and dermatological conditions and pain that are caused by extensive Kaposi's Sarcoma (Gray & Berger, 2007). However, according to Singer et al. (1993) headache, throat pain and arthralgia were identified as having been induced by Zidovudine.

It is reported that painful conditions are present at all stages of HIV infection, but most predominantly in the later stages of the disease (Del Borgo, et al., 2001; Larue, et al., 1997; Singer, et al., 1993). There is evidence that pain is correlated with a low CD4 count and a higher viral load (Aouizerat et al., 2010; Richardson, et al., 2009; Tsao & Soto, 2009), and also with increased age (Tsao & Soto, 2009; Tsao, Dobalian, & Stein, 2005). HIV-related pain is more frequent in women than in men (Breitbart et al., 1996; Dobalian, Tsao, & Duncan, 2004; Gray & Berger, 2007; Mathews et al., 2000; Miaskowski et al., 2011; Tsao, et al., 2005). Gray and Berger (2007) argue that this is because of women's biological nature, and the psychological factors and social factors that affect women.

The aetiology of pain in HIV could involve the HIV infection itself and its complications, antiretroviral treatment and related side effects and pre-existing unrelated conditions, but sometimes the cause of the pain is unknown (Hewitt, et al., 1997; Larue, et al., 1997). Many authors have reported the association between pain and depression (Richardson, et al., 2009; Rosenfeld et al., 1996; Singer, et al., 1993), and between pain and anxiety and mood disorders (Tsao & Soto, 2009), and sleep disturbance (Aouizerat, et al., 2010). Richardson et al. (2009) commented that depression and pain influence one another in a such a way that those who are depressed could also experience pain; on the other hand those who experience pain could become depressed. Both problems could affect a patient's functioning.

Like depression, pain has been also identified in many studies as a predictor of increased disability in PLWH (Singer, et al., 1993), and it affects their quality of life (Hughes, 2004; Larue, et al., 1997; McCormack, Li, Zarowny, & Singer, 1993; Nair, et al., 2009; Newshan, et al., 2002). Pain affects both physical and psychological functions (Gray & Berger, 2007; Nair, et al., 2009).

The prevalence of pain among PLWH is estimated at 25% to 80%, depending on the methodology used in the study and the characteristics of the sample (Dobalian, et al., 2004; Singer, et al., 1993). Dobalian et al. (2004) found a prevalence of 67% among PLWH; Del Borgo et al. (2001) found 61% of the sample experienced pain: for the majority, the intensity of the pain was very high; ranging from moderate to unbearable. Richardson (2009) found a prevalence of 56% among PLWH. The pain was persistent and its intensity was very high, with almost 50% of the sample reporting levels of grade four or five, where five indicates extreme pain. Aouizerat (2010) found a prevalence of 55%. Of those who felt pain, 67% reported that it occurred frequently, while 82% indicated that it was severe or very severe (Aouizerat, et al., 2010).

2.4.1.6 PLWH and pulmonary disorders

The lungs are frequently involved throughout the course of HIV disease (Murray, 1996). Diaz et al. (2003) found respiratory symptoms occurred more often in PLWH; this included dyspnea or shortness of breath (41.6% vs 7.7% in those without HIV); a persistent cough (40% vs 25%) and mucus production (41.9% vs 23.1%). Cigarette smoking is an important predictor of respiratory symptoms among PLWH. George, Kannass, Huang, Scirba, and Morris (2009) found that the prevalence of all respiratory symptoms was 31.5% among

PLWH; a cough was the most often reported complaint (23%), followed by dyspnea (16%). Malignant respiratory pathologies are also often present in PLWH (Moylett & Shearer, 2002).

Before the era of antiretroviral treatment, pneumocystis carinii pneumonia (PCP) was very common in PLWH; it was among the most prevalent opportunistic infections, and was found to correlate with the decline of the CD4 count (Murray, 1996; Wagner & Chaisson, 2003).

However, with the introduction of antiretroviral treatment; the incidence of PCP has significantly decreased (Hull, Phillips, & Montaner, 2008; Wagner & Chaisson, 2003). PCP, also named pneumocystis Jirovecii pneumonia, belongs to the family of fungal infections.

The most commonly observed clinical manifestations involve fever, dyspnea, non-productive cough, night sweats, anorexia and weight loss, fatigue and chest tightness (Wagner & Chaisson, 2003).

Aderaye et al. (2007) indicate there has been a rising prevalence of PCP in sub-Saharan Africa. In Ethiopia bacterial pneumonia was most commonly found (33.6%), and the prevalence of PCP was 29.8%, followed by pulmonary tuberculosis (23.7%).

Another study in Uganda found a prevalence of PCP of 38.6%, followed also by pulmonary tuberculosis (24%) and by a small prevalence of pulmonary Kaposi's sarcoma (11%) (Worodria, Okot-Nwang, Yoo, & Aisu, 2003). In Malawi, the prevalence of PCP was 9% (Hargreaves et al., 2001). Other fungal infections in PLWH that are associated with advanced immunodeficiency include pulmonary histoplasmosis, coccidioido mycosis and aspergillosis (Wagner & Chaisson, 2003).

Bacterial pneumonia was very common in PLWH before the introduction of antiretroviral treatment (Hull, et al., 2008); it can occur with all CD4 cell count levels, but there is a higher incidence in people with very low CD4 levels (Wagner & Chaisson, 2003). Common signs and symptoms include fever, dyspnea, productive cough with purulent sputum, and pleuritic chest pain (Wagner & Chaisson, 2003). Another common bacterial infection in PLWH is tuberculosis. Evidence has shown that in sub-Saharan Africa, there is an increased incidence of tuberculosis associated with HIV, particularly in those countries where it is difficult to access antiretroviral treatment (Corbett, Marston, Churchyard, & De Cock, 2006; Murray, 1996). This has caused rate of death among PLWH to increase (Corbett, et al., 2006). The clinical symptoms include fever, weight loss and cough (Wagner & Chaisson, 2003). Extra-pulmonary tuberculosis may also occur and the pathogen frequently attacks the lymphatic system. Other common bacterial infections in HIV patients include cryptococcosis

pneumonia, non-tuberculous mycobacteria, rhodococcus equi, and nocardiosis (Wagner & Chaisson, 2003).

Influenza, which is a viral infection, is present in upper respiratory tract infections and bronchitis, often with the following clinical manifestations: fever, myalgia, and a non-productive cough. Another common viral infection that affects the lungs is cytomegalovirus pneumonitis, which has the following symptoms: shortness of breath, dyspnea, a non-productive cough, and hypoxemia (Wagner & Chaisson, 2003). However, with the advent of antiretroviral treatment, there has been a change in the manifestation of HIV-related pulmonary complications, especially in settings where there is wide antiretroviral coverage, HIV-related infectious pulmonary complications have declined considerably, but there has been an increase in non-infectious pulmonary disorders, such as chronic obstructive pulmonary diseases, malignancies and immune reconstitution inflammatory syndrome (IRIS) (Hull, et al., 2008).

Various studies have reported a significant prevalence of airway obstruction disorders or of varieties of obstructive pulmonary diseases in PLWH. George et al. (2009) found airway obstruction symptoms present in 6.8% of a sample of PLWH. A study conducted by Hirani et al. (2011) found that the prevalence of obstructive pulmonary disease among a sample of PLWH was significantly higher (16.3%) than in the general population (6.8%). Obstructive pulmonary diseases, including asthma, bronchitis, and chronic obstructive pulmonary disease, are non-infectious respiratory diseases, and are characterised by airway obstruction (Hirani, et al., 2011).

Crothers et al. (2006) found that 10% of the sample of PLWH suffered from chronic obstructive pulmonary disease, compared to 9% in the group of HIV-negative people (using the ICD 9 codes). When using a self-report method, the prevalence increased to 15% among PLWH and 12% among HIV-negative people. The risk of developing chronic obstructive pulmonary disease increased with age, with smoking behaviour and with a medical history of bacterial pneumonia. The discrepancy in prevalence was more exaggerated in a study conducted by Diaz and King (2000); where the prevalence of emphysema was 15% in the group of PLWH, compared with 2% in the HIV-negative group. Gingo et al. (2012) found asthma to be the most commonly diagnosed chronic pulmonary condition among PLWH, with a prevalence of 20.6% more than double the estimated prevalence in the general population (8.2%).

There is no clear evidence of the side effect of antiretroviral treatment on the respiratory system. However, there is a problem with drug interaction, particularly between inhaled corticosteroids (used in the management of certain obstructive lung diseases such as asthma and chronic obstructive pulmonary disease), and the antiretroviral treatment Ritonavir, a protease inhibitor (Foisy, Yakiwchuk, Chiu, & Singh, 2008; Gillett, Cameron, Nguyen, Hurley, & Mallal, 2005; Hirani, et al., 2011; Kedem, Shahar, Hassoun, & Pollack, 2010). This is also known as Cushing's syndrome (Gillett, et al., 2005; Kedem, et al., 2010). The corticosteroids are metabolised by cytochrome P4503A4 (CYP3A4), while Ritonavir, a potent CYP3A4 inhibitor, may inhibit the corticosteroid degradation and increase its accumulation (Kedem, et al., 2010). Fluticasone is the most affected inhaled corticosteroid (Foisy, et al., 2008; Gillett, et al., 2005; Kedem, et al., 2010). The most common symptoms include increased appetite with significant weight gain, abdominal striae, buffalo hump (Foisy, et al., 2008; Gillett, et al., 2005), facial acne, and (in rare cases) hypertension, osteoporosis, irritability and depression (Foisy, et al., 2008).

IRIS is the development of an autoimmune response (Lipman & Breen, 2006; Twigg Iii & Knox, 2007). This usually manifests within six to eight weeks after starting antiretroviral treatment (Hull, et al., 2008). The PLWH who are more predisposed to IRIS are those with lower CD4 cell counts and higher levels of viral load at the initial stage of antiretroviral treatment (Grubb, Moorman, Baker, & Masur, 2006; Hull, et al., 2008). IRIS is also found among those who start the antiretroviral treatment when they have already experienced opportunistic infections (Gilks & Vitoria, 2006; Grubb, et al., 2006); and it is found among those who have experienced a rapid decline in their HIV viral loads in response to antiretroviral treatment (Shelburne et al., 2005).

IRIS has been associated with HIV related infection and inflammatory pathologies, in particular tuberculosis or mycobacterium avium complex infection and cryptococcal disease (Gilks & Vitoria, 2006). In addition, PLWH who have been affected with mycobacterium tuberculosis but who have had only a short period of tuberculosis therapy before starting antiretroviral treatment have been found to be more at risk of IRIS (Hull, et al., 2008). Common symptoms may involve fever and lymphadenopathy (Crothers & Huang, 2009; Grubb, et al., 2006).

Kaposi's sarcoma and non-Hodgkin's lymphoma are the most common HIV-related malignancies and that may affect the lungs. Pulmonary involvement with Kaposi's sarcoma

follows the manifestation of mucocutaneous lesions (Murray, 1996; Wagner & Chaisson, 2003), and occurs in almost 20 to 40% of patients with mucocutaneous Kaposi's sarcoma (Wagner & Chaisson, 2003). Pulmonary symptoms include shortness of breath or dyspnea, dry cough (Grubb, et al., 2006; Wagner & Chaisson, 2003), and chest pain (Grubb, et al., 2006). Other symptoms include night sweats, fevers and weight loss. Non-Hodgkin's lymphoma usually manifests at an advanced stage of the disease (Wagner & Chaisson, 2003), and occurs primarily in a lymph node; it may be disseminated to various extranodal sites involving the lungs (Wagner & Chaisson, 2003; Zar & Bye, 2009) and can also involve the gastrointestinal track, the bone marrow, the central nervous system and mucocutaneous sites (Wagner & Chaisson, 2003).

2.4.1.7 PLWH and cardio-vascular disorders

Various studies have reported on cardiovascular diseases in PLWH. The incidence and the prevalence may continue to increase with the improvement in life expectancy of PLWH (Monsuez et al., 2009). Conditions such as dilated cardiomyopathy, pulmonary hypertension and right ventricular dysfunction, endothelial dysfunction, coronary heart disease, hypertension and coagulative disorders, endocardial and pericardial dysfunction and cardiac HIV-related tumours may be present (Barbaro, Fisher, & Lipshultz, 2001).

The risk of cardiovascular diseases in PLWH occurs with advanced HIV infection. Possible causes include myocardial infection, opportunistic infections, viral infections, autoimmune response to viral infection, toxicity of antiretroviral treatment or other drugs with regard to opportunistic infections, neoplasms management (Barbaro, Fisher, Giancaspro, & Lipshultz, 2001; Lewis, 2000), and prolonged immunosuppression (Lewis, 2000). There are also factors that are unrelated to HIV infection or to its treatment, which might be intrinsic or extrinsic. PLWH might have a family history of cardiovascular diseases or a higher prevalence of smoking behaviour, and this could contribute to higher risk of cardiovascular disease (Currier et al., 2008). Nutritional deficiencies have been reported to be among the risk factors (Lewis, 2000).

Evidence suggests that PLWH are at a higher risk of cardiovascular events (Currier, et al., 2008; McDonald & Kaltman, 2009). In a longitudinal study by Triant, Lee, Hadigan, and Grinspoon (2007) increased incidence of myocardial infarction and cardiovascular risk factors were found in PLWH, particularly women (11.13/1000 persons/year) compared to the HIV-negative group (6.98/1000 persons/year). Moreover, PLWH had significantly higher

proportions of hypertension (21.2%), compared to non- infected people (12.9%). The same was found for diabetes (11.5%), in comparison to non-infected people (6.6%).

There is a substantial relationship between risk of cardiovascular disorders and antiretroviral treatment among adults, especially when using a combination of drugs (Friis-Møller et al., 2003; McDonald & Kaltman, 2009; Worm et al., 2010). Friis-Møller et al. (2003) found that among PLWH starting antiretroviral treatment the most important risk factor for cardiovascular disease was a high prevalence of dyslipidaemia.

Friis-Møller et al. (2007) found that increased exposure to a combination of antiretroviral treatments was associated with an increased risk of myocardial infarction. The incidence increased significantly when PLWH were exposed to protease inhibitors (6.01 vs 1.53 per 1000 persons per year). In this study 60.8% of the sample were smokers or had smoked before. Crane, Van Rompaey, & Kitahate (2006) found that patients on Ritonavir or Lopinavir demonstrated a significant risk of developing hypertension.

2.4.1.8 PLWH and metabolic disorders

Metabolic disorders, such as dyslipidaemia, body fat redistribution or lipodystrophy syndrome, insulin resistance (Calza, Manfredi, & Chiodo, 2003; Grinspoon & Carr, 2005; Moylett & Shearer, 2002), hyperglycaemia and lactic acidosis (Gilks & Vitoria, 2006; Moylett & Shearer, 2002) and reduced bone mineral density (Gilks & Vitoria, 2006) are common among PLWH; and may be caused by HIV infection (Sellmeyer & Grunfeld, 1996) or they may be a side effect of the antiretroviral treatment (Calza, et al., 2003; Grinspoon & Carr, 2005; Tsiodras, Mantzoros, Hammer, & Samore, 2000), particularly where a combination of antiretroviral treatment is used (Calza, et al., 2003). Tsiodras et al. (2000) found that PIs was the most effective antiretroviral treatment for metabolic disorders. In a five-year study after the initiation of PI treatment, the prevalence of hyperglycaemia increased by 5%, of hypercholesterolemia by 24%, of hypertriglyceridemia by 19%, and of lipodystrophy by 13%

Dyslipidaemia or disorders in lipid metabolism manifest frequently among PLWH and may be secondary to the HIV infection itself. The reduction in higher density lipoprotein (HDL) and lower density lipoprotein (LDL) cholesterol may occur at any stage of HIV infection; this may manifest in early stage asymptomatic patients, and could contribute to elevated triglycerides levels (Grinspoon & Carr, 2005; Penzak & Chuck, 2000; Sellmeyer & Grunfeld,

1996). However, there is accumulative evidence about the influence of antiretroviral treatment on disorders in lipid metabolism among PLWH; particularly those receiving a combination regimen that contains PIs (Calza, et al., 2003; Gilks & Vitoria, 2006), with Ritonavir having the most significant influence on hyperlipidaemia (Calza, et al., 2003; Penzak & Chuck, 2000; Tsiodras, et al., 2000), or Ritonavir in combination with Saquinavir (Calza, et al., 2003; Penzak & Chuck, 2000) or Ritonavir with Lopinavir (Calza, et al., 2003). Disturbance in lipid metabolism predisposes people to cardiovascular complications (Grinspoon & Carr, 2005). Dyslipidaemia may mediate the effect of antiretroviral treatment on the risk of developing cardiovascular complications, particularly for the therapy regimen with PIs combination.

Disorders in insulin metabolism that might lead to hyperglycaemia and cause diabetes are also not uncommon among PLWH, and may be related to the HIV infection itself (Florescu & Kotler, 2007). The incidence can increase as a result of the use of combination antiretroviral treatment (Brown et al., 2005; Florescu & Kotler, 2007; Ledergerber et al., 2007), particularly those in the group of PIs (Brown, et al., 2005; Justman et al., 2003). Evidence from a study conducted by Brown et al. (2005) showed that the prevalence of diabetes among PLWH who were on antiretroviral treatment (especially with PIs combination) was almost triple (14%) that of non-infected people (5%), and was positively associated with a low CD4 count.

Deficiencies in bone density and bone disease have been reported to occur in PLWH due to a disturbance in bone metabolism which can be caused by antiretroviral medication (Gilks & Vitoria, 2006; Valencia et al., 2003). Tebas et al. (2000) found that PLWH receiving antiretroviral treatment with PIs combination were more likely to lose bone minerals. They highlighted a significant association between antiretroviral treatment and the increased prevalence of osteopenia and osteoporosis among PLWH; this might lead to more frequent pathological fractures.

Lipodystrophy syndrome which consists of lipoatrophy or peripheral fat loss and central fat accumulation is common in PLWH and it is characterised by morphological changes in the body (Carr, 2003; Jacobson et al., 2005). Peripheral fat loss includes the loss of subcutaneous fat in the face, arms, legs and buttocks (Gilks & Vitoria, 2006; Grinspoon & Carr, 2005), and can also manifest in the trunk (Grinspoon & Carr, 2005). Central or localized fat accumulation involves the abdomen and visceral fat accumulation, the neck (buffalo hump),

and the breasts (Gilks & Vitoria, 2006; Grinspoon & Carr, 2005). These morphological changes can affect the psychosocial well-being of the patient and lead to low self-esteem, poor body image, anxiety and/or depression; they can also have an effect on intimate relationships. There may be problems with low libido, and these might result in poor social functioning, in social isolation (Power, Tate, McGill, & Taylor, 2003) and in stigmatisation (Gilks & Vitoria, 2006).

In addition, the lipodystrophy syndrome often manifests in association with metabolic changes, including hyperlipidaemia, fat redistribution, and insulin resistance (Caron-Debarle, Lagathu, Boccara, Vigouroux, & Capeau, 2010; Gilks & Vitoria, 2006; Hadigan et al., 2001; Norris & Dreher, 2004), and hypercholesterolemia (Hadigan, et al., 2001; Mutimura, Stewart, Rheeder, & Crowther, 2007). Mutimura et al. (2007) found that in Rwanda, 34% of the participants showed a combination of lipodystrophy and peripheral lipomatosis; abdominal lipohypertrophy was observed in about 72% of lipodystrophic patients. The total cholesterol concentrations were significantly higher in PLWH with lipodystrophy than in those who were found to be non-lipodystrophic and who were in the control group. There is evidence that the metabolic disorders that occur in PLWH with lipodystrophy could predispose them to cardiovascular diseases such as hypertension, coronary artery disease, myocardial infarction and diabetes (Caron-Debarle, et al., 2010) and sometimes also hepatic complications; which may even be fatal (Caron-Debarle, et al., 2010).

Studies have reported also that lipodystrophy is caused by antiretroviral treatment and mainly manifests after the initiation of antiretroviral treatment (Gilks & Vitoria, 2006; Haubrich et al., 2009). Carr and Cooper (2000) found that the prevalence of lipodystrophy among PLWH ranged from 18% to 83% and seemed to occur after 12 to 18 months of therapy. This was also confirmed by Miller et al. (2003) who found the prevalence of lipodystrophy was 53%; the presence of lipodystrophy correlated significantly with prolonged exposure to both NRTIs and PIs. Lipodystrophy was associated also with increased age, the presence of HIV-infection-related impairments and HIV viral suppression.

Duran et al. (2001) found that four months after initiating antiretroviral treatment with PIs in its combination drugs; 76.4% of the sample reported at least one symptom of lipodystrophy. Consequently 30% had discontinued the treatment due to the appearance of these symptoms. However Mutimura et al. (2007) found that majority of participants with lipodystrophy

(81.6%) were receiving a combination of antiretroviral treatment including Stavudine, Lamivudine, and Nevirapine, but none were receiving PIs

2.4.1.9 PLWH and digestive disorders

Problems related to the digestive system are common among PLWH, and the gastrointestinal tract is among the major target organ for HIV infection and related conditions (Lew, Poles, & Dieterich, 1997). Several studies have identified numerous digestive impairments. In a multisite comparative study in South Africa and Brazil, digestive problems, such as nausea, difficulty with weight maintenance, and problems with defecation, were reported by 57% to 75% of PLWH (Myezwa, Buchalla, Jelsma, & Stewart, 2011). Similarly Alexander's (2011) review found that PLWH and who were on antiretroviral treatment experienced nausea, diarrhoea, anorexia and weight loss. Mathews et al. (2000) found that diarrhoea, nausea, anorexia and weight loss were present; Lee et al. (2009) reported nausea, diarrhoea, weight loss, constipation as well as lack of appetite, vomiting and difficulty swallowing.

2.4.1.10 PLWH and reproductive disorders

The most significant reported reproductive impairment among PLWH is sexual dysfunction (Bell, Richardson, Wall, & Goldmeier, 2006; Rusch, et al., 2004a; Scanavino & Abdo, 2010). Bell et al. (2006) found that women experienced significant sexual problems, including lack of desire (33%) and lack of orgasm (7%). In Scanavino and Abdo (2010) 36% of the females reported sexual inactivity; they found sex unsatisfactory and were not able to maintain sexual arousal until the end of the sex intercourse. As much as 50% of males reported problems with ejaculation and 33% experienced erectile dysfunction. Van As et al. (2009) and Rusch et al. (2004a) found that reduced libido was major problem.

A qualitative study in Tanzania found that the majority of the participants revealed that they had "forgotten" about sexual intercourse and viewed it as a leading cause of transmittable diseases and the cause of many deaths. Schrooten et al. (2001) found that a decrease in sexual interest was more frequently reported by those who were receiving antiretroviral treatment that contained PIs (40%) than by those on non-PIs in their antiretroviral treatment (16%). In addition, 34% of the males on PIs complained about decreased sexual potency, compared to 12% in the non-PIs group.

2.4.1.11 PLWH and haematological disorders

Haematological disorders are very common among PLWH. Van As et al. (2009) found that almost 96% of their sample demonstrated haematological deficiencies. Anaemia is frequently

reported (Barroso, 1999; Sullivan, Hanson, Chu, Jones, & Ward, 1998; Volberding, 2000), and its prevalence seems to be higher in African countries than in industrialized countries (Ssali et al., 2006). Its diagnosis is confirmed when haemoglobin falls below 14g/dl in men and below 12g/dl in women (Adinolfi, 2001). Fatigue is one of the most important symptoms of anaemia in PLWH (Barroso, 1999; Breitbart, McDonald, Rosenfeld, Monkman, & Passik, 1998).

Risk factors for anaemia include the HIV infection itself and its associated conditions, including opportunistic infections, particularly those which attack the bone marrow. Other risk factors are HIV infection treatment, anti-neoplastic and anti-microbial drugs (Adinolfi, 2001; Volberding, 2000; Volberding et al., 2004), nutritional problems/deficiencies; (such as malnutrition, malabsorption and or difficulty with the digestion of certain important nutrients) (Adinolfi, 2001; Volberding, 2000).

The antiretroviral treatment zidovudine has been found to cause anaemia. Anwikar et al. (2011) found that anaemia occurred in patients receiving antiretroviral treatment in combination with zidovudine, within the first month after the initiation of therapy. Similarly Kumarasamy et al. (2008) found more than half of those who developed anaemia within one year of initiation of antiretroviral treatment were receiving a combination therapy containing zidovudine. Anaemia can increase the progression of the disease and can have a negative impact on patient survival; it can also affect a patient's physical functioning and quality of life (Volberding, 2000; Volberding, et al., 2004).

2.4.1.12 PLWH and fatigue

Fatigue has been identified as a very common symptom among PLWH (Aouizerat, Gay, Lerdal, Portillo, & Lee, 2012; Jong et al., 2010; Newshan, et al., 2002; Rusch, et al., 2004a; Sullivan & Dworkin, 2003). Its prevalence ranges from 50% and up (Alexander, 2011; Anandan, Braveman, Kielhofner, & Forsyth, 2006; Aouizerat, et al., 2012; Breitbart, et al., 1998; Henderson, Safa, Easterbrook, & Hotopf, 2005). In some studies, fatigue is described as a lack of energy or tiredness (Aouizerat, et al., 2012; Corless et al., 2002; Rose, Pugh, Lears, & Gordon, 1998; Siegel, Bradley, & Lekas, 2004), or weakness or sometimes even as malaise (Sullivan & Dworkin, 2003). Aouizerat (2012) states that although the term "lack of energy" has been used interchangeably with fatigue, many studies emphasise measuring fatigue in an attempt to determine a measure of energy.

Siegel et al. (2004) found that fatigue was the most difficult symptom for PLWH to live with, and 88% of participants thought that it was caused by the HI virus. However, according to some researchers their findings have demonstrated a lack of association between the presence of fatigue and decreased CD4 cell counts and increased HIV viral loads (Breitbart, et al., 1998; Henderson, et al., 2005; Sullivan & Dworkin, 2003). Few participants recognised the influence of antiretroviral treatment as a contributing factor to fatigue (Adinolfi, 2001; Siegel, et al., 2004). Surprisingly Pence et al. (2009) in a longitudinal study found that patients who had diagnosed with HIV for long time and who used antiretroviral treatment, demonstrated low fatigue scores.

Factors contributing to fatigue have been reported in various studies. These include pathologies and physiological abnormalities associated with HIV infection, such as anaemia, diabetes (Adinolfi, 2001; Barroso, 1999; Breitbart, et al., 1998; Siegel, et al., 2004; Sullivan & Dworkin, 2003), and abnormality of thyroid gland (Adinolfi, 2001; Barroso, 1999). Medicines used for HIV-infection-associated conditions, such as chemotherapy for cancer, or interferon for hepatitis (Adinolfi, 2001; Breitbart, et al., 1998; Siegel, et al., 2004) also contributed to fatigue. Many studies report and emphasise the contribution of psychological factors, including stress, depression, anxiety and sleep problems, as significant causal factors of fatigue (Adinolfi, 2001; Barroso, 1999; Henderson, et al., 2005; Jong, et al., 2010; Pence, et al., 2009; Siegel, et al., 2004; Sullivan & Dworkin, 2003). Others highlight the influence of socio-economic and demographic factors such as age (Siegel, et al., 2004), income and employment status (Jong, et al., 2010; Pence, et al., 2009) and lifestyle habits, such as poor diet, lack of exercise and lack of rest (Adinolfi, 2001; Siegel, et al., 2004). There is evidence that fatigue can lead to a limitation in physical functioning (Ferrando et al., 1998), and this can interfere with activities that are part of daily functioning (Aouizerat, et al., 2012) and contribute to a poor quality of life (Breitbart, et al., 1998).

2.4.2 PLWH and activity limitations and participation restrictions

Various studies have found the presence of impairments in PLWH, whether due to the HI virus itself or to the antiretroviral treatment. These can affect their activity performance levels and their participation in society (Crystal, et al., 2000; Ferrando, et al., 1998; Gaidhane et al., 2008; Myezwa, et al., 2009; Rusch, et al., 2004a; Van As, et al., 2009).

Rusch et al. (2004b) indicated that even those with CD4 counts higher than 500 cells/mm³, still experience significant limitations in activity, compared to the general population, and to

people who experience other chronic diseases, such as arthritis and cancer. HIV infection and related physical and psycho-social complications as well as the side effects of the antiretroviral treatment might be contributing factors to the activity limitations among PLWH. Socio-economic factors could also influence the situation (Rusch, et al., 2004b).

The key findings of the studies reviewed are summarised in Table 3



Table 3: PLWH, activity limitations and participation restrictions

| Author and date of publication | Methods | Major findings |
|--------------------------------|--|---|
| Myezwa et al., 2009 | <p>Study design: cross-sectional descriptive study conducted at the hospital</p> <p>Tool used: ICF checklist</p> <p>Sample size: 80 PLWH ; 23 males and 57 females</p> | <p>Higher rate of activity limitations in mobility function (56.4%), in major life areas (55.1%) and in community, social and civic life (50%).</p> <p>Patients with sensory impairments were four times more likely to experience self-care problems, and five times more likely to experience problems with domestic life activities compared to people without sensory problems.</p> <p>Patients with digestive impairments were 20 times more likely to have problems with general tasks, compared to those without digestive problems.</p> <p>Patients with cardiovascular, haematological, immunological and respiratory impairments were 14 times more likely to experience problems with the execution of general tasks than those without these impairments.</p> <p>Patients with voice and speech function limitations were six times more likely to experience problems with communication than those without this problem.</p> <p>Participants reported that they had limited access to the community because of stigma and</p> |

| | | |
|-----------------------|--|---|
| | | sometimes the inability to find a toilet quickly. |
| Van As et al., 2009 | <p>Study design: cross-sectional descriptive study conducted at an HIV clinic in a hospital.</p> <p>Tool used: ICF checklist.</p> <p>Sample; 45 PLWH; 29 females and 16 males.</p> | <p>The functions most affected involved major life areas (58%), interpersonal interactions and relationships (56%), and mobility functions (40%).</p> <p>Participants reported having problems with participation in society. The domains of learning and applying knowledge and that of major life areas, such as participation in paid employment were problematic.</p> <p>Various impairments predicted activity limitations and participation restrictions. Sensory and pain impairments predicted problems with the mobility function ($p=0.04$), as well as difficulties with interpersonal interactions and with relationships ($p=0.002$).</p> <p>Digestive, metabolic, and endocrine system impairments predicted limitations in mobility function ($p=0.02$).</p> <p>Impairments in neuro-musculoskeletal and movement-related functions predicted problems in learning and applying knowledge ($p=0.04$), mobility ($p=0.007$), interpersonal interactions and relationships ($p=0.04$).</p> |
| Gaidhane et al., 2008 | <p>Study design: cross-sectional descriptive study conducted at the hospital.</p> | <p>64% of the participants had problems with self-care activities, as measured by performance qualifier (patient current environment).</p> <p>Around 30% of the participants had problems with bathing a body part or bathing the whole body or with drying themselves, measured by capacity qualifier (in a standard environment), and 15%</p> |

| | | |
|--|--|--|
| | <p>Tool used: ICF checklist (only the self-care (d5) component of activities and participation domain (d) of the ICF was used).</p> <p>Sample; 194 PLWH; 82% male.</p> | <p>by performance qualifier.</p> <p>28% of the participants had problems with eating, measured by capacity qualifier and by performance qualifier; it was 16%.</p> <p>45% of the participants had problems with urinating, measured by capacity qualifier and 25% by performance qualifier.</p> <p>64% of the participants had problems with defecating measured by capacity qualifier, but 45% by performance qualifier.</p> <p>57% of the participants had problems with dressing.</p> |
|--|--|--|



| | | |
|-----------------------------|---|---|
| <p>Rusch et al., 2004a</p> | <p>Study design: cross-sectional descriptive population-based survey.</p> <p>Tool used: developed a self-administered questionnaire based on ICF checklist</p> <p>Sample; 762 PLWH completed and returned the questionnaires; however only 614 were considered for analysis as the rest did not provide information about their CD4 counts.</p> | <p>Activity limitations were reported by 80.6% of the participants, and participation restrictions were reported by 93.2%.</p> <p>Logistic regression models were used to test for associations between impairments, activity limitations and participation restrictions. All impairments and activity limitations were significantly associated with social role restriction.</p> <p>It was demonstrated that social role restrictions were more often associated with mental function impairments than with other impairments.</p> <div data-bbox="994 643 1243 882" style="text-align: center;">  <p>UNIVERSITY of the WESTERN CAPE</p> </div> |
| <p>Crystal et al., 2000</p> | <p>Study design: cross-sectional population-based survey using questionnaire.</p> <p>Tool used: Designed 9-item physical limitation</p> | <p>51% of the participants experienced functional limitations in performing role functioning activities such as work, school and household activities.</p> <p>64% of the participants experienced functional limitations in energy-demanding or vigorous activities, such as climbing stairs, walking long distances.</p> <p>Significant associations were found between physical and role functioning limitations and</p> |

| | | |
|--|--|---|
| | scale and 2-item ACTG SF21 role functioning scale Sample; 2836: 77.5% males and 22.5% females | increasing age, lower education, low CD4 cell counts, advanced disease and higher levels of pain and fatigue impairments. |
|--|--|---|



| | | |
|-----------------------------|---|--|
| <p>Ferrando et al.,1998</p> | <p>Study design: Longitudinal comparative study</p> <p>Tool used: Designed self-reported questionnaires (for fatigue, physical limitations and depression)</p> <p>Sample: 187 PLWH (Men)</p> <p>46 HIV negative (Men)</p> | <p>Fatigue and physical functional limitations were very common; both were significantly associated with advanced disease progression.</p> <p>The prevalence of fatigue in PLWH with CD4 counts <500 was 14%, and it was significantly higher than in the HIV-negative group, and in the group of PLWH with CD4 counts>500.</p> <p>Fatigue appeared to be a chronic symptom over a one-year period of follow up, and it contributed independently to physical functional limitations and disability. It was found to be a strong predictor for physical activity limitations at both the baseline and after one year. In the linear regression, fatigue accounted for 12% of the variance in physical limitations.</p> <p>The presence of physical functional limitations in PLWH after one year was highly predicted by physical functional limitations at intake, and which accounted for one third of the variance. This proves that, like fatigue, physical functional limitations tended to be chronic.</p> |
|-----------------------------|---|--|

2.4.3 PLWH and contextual factors

There is a dearth of information in the literature regarding contextual factors that influence functioning among PLWH, and that could be categorised as either personal or environmental contextual factors. O'Brien et al. (2009) highlighted four contextual factors that can influence functioning among PLWH. These were social support, stigma, living strategies and personal attributes. They considered two categories, intrinsic and extrinsic factors, and further described extrinsic factors as factors that come from the external environment to the person, while intrinsic factors are the personal attributes of the individual.

According to O'Brien et al. (2009), intrinsic factors that influenced functioning involved living strategies and personal attributes. Living strategies were considered to be behaviours, attitudes and beliefs PLWH could adopt to help them face the challenges of living with HIV, and its consequences for their daily functioning. An example of a living strategy was being able to create and seek social relationships or interaction with others; self-acceptance could be expressed through the ability to remove HIV from the mind and fight internalised stigma. Another reported strategy was the person's ability to maintain a sense of control over his or her own life and over the HIV infection. This included being able to rebuild oneself and re-establish a sense of purpose in life, being able to control one's own nutrition, avoiding stress and improving adherence to antiretroviral treatment. Personal attributes were regarded as an individual's particular characteristics, such as age and inherent or genetic diseases. Increasing age was reported by the participants in Crystal et al. (2000) to be a strong barrier to effective functioning.

According to O'Brien et al. (2009) extrinsic factors that influenced function included social support and stigma. Social support was found to be a facilitator for functioning, whereas lack of support was considered to be a barrier. Possible sources for social support were identified. These included support from friends and family, support from the health care services and personnel, and programme and policy support, including the medical insurance cover. Stigma was experienced from family members, from the workplace (employers and colleagues) and from health care providers. Similarly, Myezwa et al. (2009) reported that most participants experienced barriers to functioning from community services, from systems and policies and also from relationships and interactions with friends and other people in their community.

Van As et al. (2009) also found that a lack of support from services, systems and policies and other people's negative attitudes constituted barriers to effective functioning. Health care

providers' positive attitudes and support and good relationships with other people were found to be strong facilitators of effective functioning. Myezwa et al. (2009) found PLWH were satisfied with the attitude and support provided by health care providers.

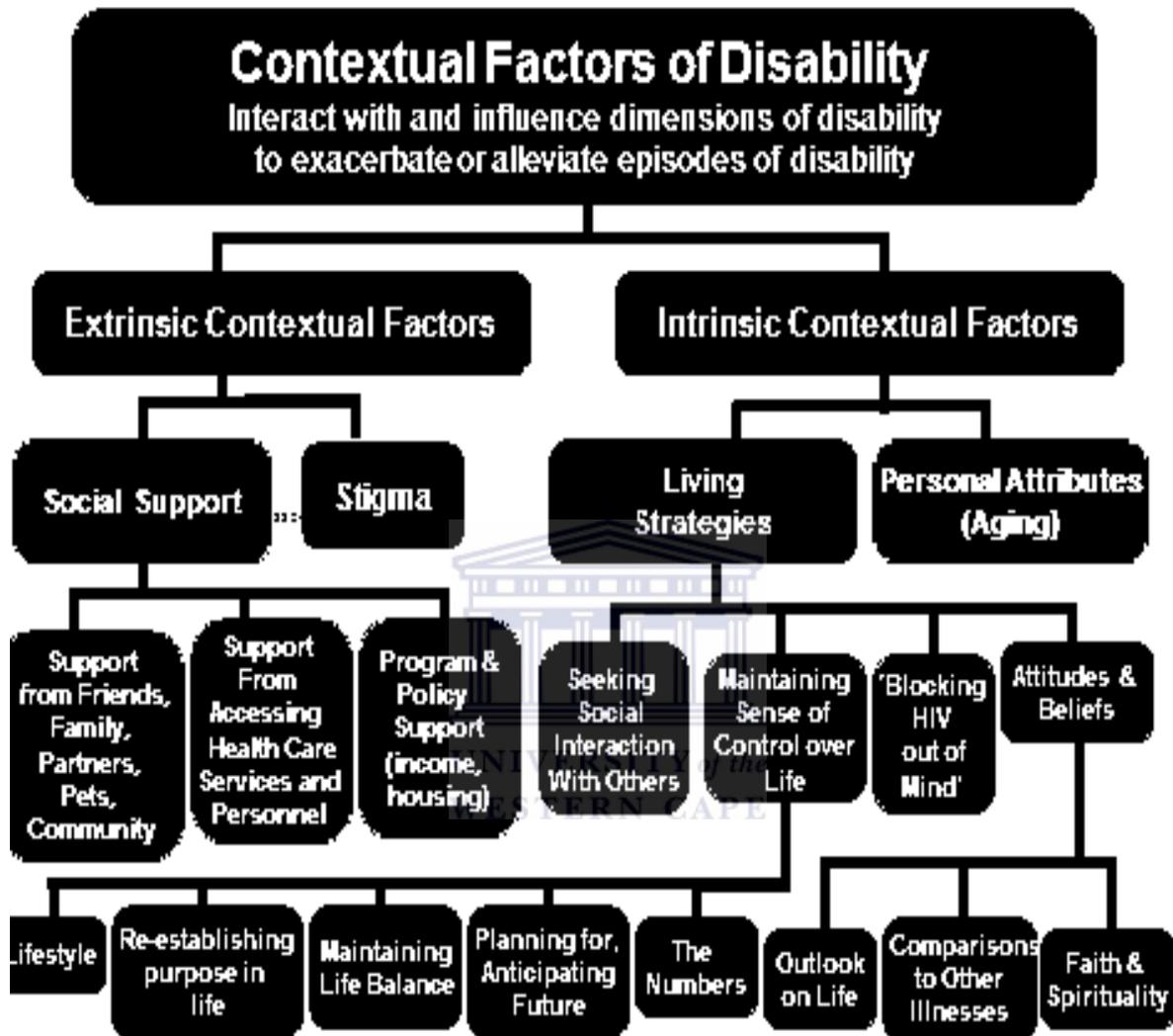


Figure 4 Contextual factors of disability in PLWH

(O'Brien, et al., 2009) Permission granted for reproduction 11th November 2013.

2.5 PLWH and the Hospital environment

2.5.1 Health for all and the primary health care approach

In the WHO constitution, health is defined as a state of complete physical, mental and social well-being, and not merely as the absence of disease or infirmity (World Health Organisation (WHO), 2006a). It should be noted that the WHO international primary health care conference at Alma Ata in 1978 reinforced the consideration of health as a holistic

conception and declared that health was for all people: the whole of humanity without distinction of race, religion, economic or social status needs to enjoy health of a satisfactory standard (Cueto, 2004; Lawn et al., 2008; Magnussen, Ehiri, & Jolly, 2004; World Health Organisation (WHO), 2006a).

To achieve the goal of health for all people, the Alma Ata conference launched and decided on a philosophy of comprehensive primary health care that consists of strategies which promote health and assist people to respond more equitably, appropriately and effectively to their health needs (Magnussen, et al., 2004); this requires health systems which empower people and which base health interventions on what people value as relevant for their own health needs (World Health Organisation (WHO), 2008).

There is evidence that health systems that adopt the approach of providing comprehensive primary health care deliver better health outcomes (Gillam, 2008). Comprehensive primary health care provides prevention services, such as immunisation against some infectious diseases; it also promotes health, for example by the promotion of the food supply and by providing proper nutrition, curative services (such as treatment of common diseases and provision of essential medications), and rehabilitative services (De Sa, 1993; Lawn, et al., 2008; World Health Organisation (WHO), 1979). Primary health care interventions recognise and consider the impact of environmental, social and economic and political factors such as education, a lack of resources on health management and improvement (Lawn, et al., 2008; Magnussen, et al., 2004). This means that, in order to successfully and holistically respond to the health needs of people, health systems based on the primary health care approach, look beyond the health sector, and adopt multisectoral and intersectoral approaches: this involves other sectors such as education, social welfare, agriculture, public labour, etc (Lawn, et al., 2008).

However, it should be noted that, most countries; both developed and under-developed, face the challenge of an increased prevalence of non-communicable diseases, such as cardiovascular diseases, and the presence of persistent infectious diseases, such as HIV infection; these challenges lead to increased health demands and might require policy makers to revisit and if necessary rethink strategies and priorities with regard to primary health care in order to achieve the ultimate goal of health for all (Gillam, 2008; Lawn, et al., 2008). Noticeably, for the middle- and low-income countries, in addition to the increased prevalence of the above-mentioned diseases, persistent infectious disease such as HIV and its associated

pathologies such as tuberculosis place a strain on limited resources and weak health care. This means that access to health services is sometimes limited (Goudge, et al., 2009).

2.5.2 Barriers and facilitators to hospital care

A study conducted in a selected rural area with poor resources in South Africa by Goudge et al. (2009) found the following barriers to accessing chronic care, including care related to complications arising from HIV infection: the inability to pay for the treatment cost because of low income; an inadequate availability of the inputs and services required for chronic care. The following problems were identified: clinical weaknesses in management, diagnosis and prescribing medication at clinics; a shortage of drugs leading to interrupted drug supplies; weaknesses in the referral system; and poor transport facilities. Another important barrier was poor communication between patients and health care providers, which could lead to poor treatment. The health care providers were unable to engage effectively with the patients, and were unable to give patients adequate explanation regarding their illnesses.

Gilson, Palmer, and Schneider (2005) reported similarly that, in another sector of the South African population, respectful treatment was identified as a very important factor influencing patients' levels of satisfaction and demand for care. Respectful treatment was defined as respectful attitudes and behaviour on the part of health care providers; this included good communication with patients; health care providers should possess the necessary technical competence, and should give due consideration and attention to patients.

2.5.3 Comprehensive care and collaboration

One of the key strategies of primary health care is quality training of competent and comprehensive health care providers able to deliver preventive, promotive, curative and rehabilitative health care at all levels, that is, at community, district, regional and national levels (Lawn, et al., 2008; Magnussen, et al., 2004). It has been demonstrated that appropriate training for a comprehensive health care provision should also emphasise interdisciplinary collaboration and team spirit among health care providers at all levels (Gillam, 2008; Lawn, et al., 2008). Interdisciplinary collaboration is regarded as one of the characteristics of the primary health care approach. It is a process by which individuals from different professions structure a collective action in order to coordinate the services they render to individual clients or groups (Sicotte, et al., 2002).

Sicotte et al. (2002) describe interdisciplinary collaboration in clinical practice as requiring health care providers from different professional backgrounds to share their expertise, for

example, in assessment-diagnostic activities, and in planning treatment, reassessment and intervention adjustment. Interdisciplinary collaboration requires sharing information and joint decision-making. This process of collaboration is found to strengthen inter-professional relationships, for example with respect to the mode and frequency of communication; it also assists with patient referrals. A two-way referral system has been identified as an outcome and benefit of using a collaborative approach, with the patients being the beneficiaries (Gaboury, Bujold, Boon, & Moher, 2009). A systematic review by Van Manen et al. (2005) found that due to the multiple problems caused by HIV infection, an interdisciplinary approach involving collaboration between and within health care disciplines is essential in the provision of care for PLWH.

There is evidence that low-income countries, particularly African countries, experience a shortage of health care providers, particularly in public (government) institutions. There are a number of factors that could contribute to a shortage of health care providers in African countries: these include inadequate funds allocated to the training of health care providers, a lack of strong retention strategies, internal and international immigration, and the loss of health care providers due to HIV infection. HIV has become an area of interest for many NGOs and that mobilise funds and establish projects and they are able to pay better salaries than government institutions, thus attracting health care workers from the public sector (Schneider, et al., 2006). It has been argued that retention strategies are crucial: it is important that these are put in place, particularly for those working in rural areas (Magnussen, et al., 2004).

2.5.4 Health service delivery in Rwanda

The Rwandan health system employs a primary health care approach (Ministry of Health (MoH) of Rwanda, 2009; USAID, 2007). Health services offer preventive, promotive, curative and rehabilitative services (Ministry of Health (MoH) Rwanda, 2012b).

Health services in Rwanda comprise five referral hospitals, 40 district hospitals, 450 health centres, and various health posts within the community which operate under the supervision of the health centres; there also community-based associations that offer community outreach activities. The Ministry of Health coordinates, oversees and supports the provision of the different services. It has an organ, the “Rwanda Biomedical Centre”, that consists of specialised programs and technical working groups that provide policies and technical

guidance to assist with improving health service delivery (Ministry of Health (MoH) Rwanda, 2012b).

As it was mentioned in Chapter One, in 2000 the government of Rwanda committed itself to Vision 2020 (Logie, et al., 2008). In 2004, the Ministry of Health revised its health policy, based on vision 2020 and a strategy to reduce poverty; this led to the Good Governance and Decentralization policy (Ministry of Health (MoH) Rwanda, 2012b). The following points were emphasised: the need to improve the availability of quality drugs, vaccines and consumables; the need to make the health services more accessible; the need to make the health services more affordable; the need to improve the quality and demand for services that control the disease; the need to strengthen national referral hospitals and research and treatment; and the need to reinforce institutional capacity (Ministry of Health (MoH) Rwanda, 2012b).

The recent health sector strategic plan, elaborated in 2012, sets up priorities based on key elements of the policies described above. Firstly, in relation to the Millennium Development Goals, by 2015 it aims to improve nutrition, maternal and child health and disease control. Secondly, it aims to improve the accessibility of health services in terms of financial, geographical and community health. It also aims to improve the quality of health provision through quality assurance, improved training, ensuring the availability of medical equipment and proper supervision; it will strengthen institutions; and, finally, it will improve the quantity and quality of human resources for health (Ministry of Health (MoH) Rwanda, 2012b).

Disease prevention and control in the recent health sector strategic plan emphasized various health conditions, among them; HIV infection and related disability conditions. Some of the strategies to prevent and control disability include establishing preventive, promotive and rehabilitative interventions to reduce mortality and morbidity. Studies will be conducted to determine the burden of disability in Rwanda and to develop guidelines for managing disability and for rehabilitation. The aim is to improve access to health services for people with disabilities; this could involve developing and disseminating protocols for the provision of services to people with disabilities and training health care providers in the control, prevention and treatment of disability (Ministry of Health (MoH) Rwanda, 2012b).

An improvement in the quantity and quality of health care providers has been identified as a priority of the Rwandan ministry of Health. The ratio for medical doctors to population,

changed from 1:33 000 in 2008 to 1:20 000 in 2010; the ratio for nurses in 2010 was 1:1 500. The number of physiotherapists in Rwanda increased from 58 in 2009 to 70 in 2011, and that of mental health workers from 50 in 2009 to 67 in 2011 (Ministry of Health (MoH) Rwanda, 2012b). According to the Ministry of Health this was still not sufficient to respond to the health needs of the Rwandan population (Logie, et al., 2008; Ministry of Health (MoH) Rwanda, 2012b). There has been internal migration from the public government health institutions to NGOs and from rural to urban areas (Logie, et al., 2008). In an attempt to prevent this, the Ministry of Health has established a performance-based pay strategy, aimed at staff retention (Logie, et al., 2008; Ministry of Health (MoH) Rwanda, 2012b).

With regards to quality, the norms and standards that guide practice have been established, and the Ministry of Health has also developed human resources for strategic health planning (2011-2016); this aims to coordinate all activities specifically related to human resources for health. For example, the strategic plan could involve developing and implementing a curriculum for Continuing Professional Education training for various medical professionals. Additionally, there is a plan to strengthen the capacity of teaching institutions that are mandated to train health care providers, and which provide both pre-service and in-service training (Ministry of Health (MoH) Rwanda, 2012b).

Access to health services has been improved; this is due in part to increased health insurance coverage (Logie, et al., 2008; Ministry of Health (MoH) Rwanda, 2012b; National Institute of Statistics Rwanda, et al., 2012). Many people in Rwanda have health insurance. The types of insurances include: RAMA (*Rwandaise d'Assurance Maladie*) which is usually for civil servants and private people; MMI (Military Medical Insurance); and a few other private health insurance schemes (Ministry of Health (MoH) Rwanda, 2010; National Institute of Statistics Rwanda, et al., 2012).

However, most people have the Rwandan community-based health insurance, *Mutuelle de santé* (Ministry of Health (MoH) Rwanda, 2010; National Institute of Statistics Rwanda, et al., 2012). This enables even the most vulnerable and poorest people in the community to be included in the health insurance system and to access quality health care (Ministry of Health (MoH) Rwanda, 2010). Its management is decentralised and involves community participation. In each health centre there is a department for *Mutuelle de Sante* with a coordinator. At the community level, that is, at the village, cell, and sector levels, there is a

mobilisation committee for the insurance system which is composed of people elected by the community (Ministry of Health (MoH) Rwanda, 2010).

Each member is required to pay 1000 Rwandan Francs per year, (approximately US\$2), and for every consultation a member pays 10% of the overall cost, including the cost of medication. The poorest people in the community and PLWH are exempt from this payment. However, despite its significant impact on access to health services; the *Mutuelle de Sante* covers only limited services, such as basic laboratory examinations, generic drugs and some tertiary care (Logie, et al., 2008).

2.5.5 Rehabilitation care and PLWH

Through its various disciplines, such as physiotherapy, occupational therapy, speech therapy and psychology, rehabilitation can transform the concept of HIV infection from a disease perspective to one where it is seen as a health condition that impacts on people's physical, psychological and social functioning (Hanass-Hancock & Nixon, 2009b; S. Nixon, et al., 2011).

Worthington et al. (2005) suggest that the goal of rehabilitation for PLWH should be to improve their overall health and quality of life, including the maintenance or restoration of physical, psychological and social functioning and vocational safety. However, because of the unpredictable and complex nature of HIV and its associated pathologies, monitoring is imperative to ensure the individual's needs are addressed adequately. There might be a need for some adjustment of the goals to be met.

In western countries such as Canada, as well as in sub-Saharan countries such as Kenya, Ethiopia and Mozambique, there is evidence that an increasing number of PLWH are seeking rehabilitation services, including physiotherapy, psychotherapy, nutrition care and occupational therapy. These practices may contribute to individual well-being and improve quality of life (Nixon, et al., 2011).

2.5.5.1 Physiotherapy and PLWH

There is evidence that physiotherapy techniques such as exercise can combat or alleviate the severity of some impairments such as fatigue that manifest in PLWH (Barroso & Voss, 2013).

A Cochrane systematic review by O'Brien, Nixon, Tynan, and Glazier (2010) indicates that aerobic exercise contributes to improvement in certain health conditions associated with HIV.

These include cardiopulmonary function, improvement in body composition (such as reducing fat mass, strengthening of leg muscles) and also improvement in psychological functions, particularly with regard to depression. A systematic literature review by Fillipas, Cherry, Cicuttini, Smirneos, and Holland (2010) demonstrated that aerobic exercise such as walking, jogging, swimming, etc. had a significant effect in the decreasing body-mass index among PLWH who presented with central adiposity. Progressive resistive exercise (weight training, isotonic and isometric exercises) had a significant effect in increasing body weight and muscle mass, particularly in relation to peripheral muscular atrophy. Mutimura, Crowther, Cade, Yarasheki, and Stewart (2008) reported that among a group of PLWH on ART in Rwanda, cardiorespiratory exercise training significantly improved cardiorespiratory functioning, reduced central adiposity, improved metabolic function (by reducing total cholesterol and insulin levels), and improved cardiovascular functions.

Ownby (2006) found that pain scores and pain intensity in PLWH reduced overtime with the use of both the ice massage and dry towel massage on peripheral pain. There was no significant difference between the two treatments. A systematic search by Hillier, Louw, Morris, Uwimana, and Statham (2010) found that massage therapy can improve the quality of life of PLWH, and its effects and benefits increased when used with other treatment modalities such as stress management modalities.

2.5.5.2 Psychotherapy/psychosocial therapy and PLWH

Using a systematic review and meta-analysis of double-blinded randomized controlled trials to test the effect of group psychotherapy treatment on depressive symptoms that manifest in PLWH, Himelhoch, Medoff, and Oyeniyi (2007) found that group psychotherapy, particularly group cognitive behavioural therapy, could be effective in the management of depressive symptoms.

Post and Wade (2009) and Belcher (2002) found that spiritual/religious interventions could be effective in the management of psychological or mental distress and could be integrated into psychotherapy. It has been demonstrated that spiritual practices can combat the side effects of stress resulting from HIV; they can also reduce the symptoms of depression and can improve the psychological well-being of PLWH (Braxton, et al., 2007).

2.5.5.3 PLWH and nutrition care

Reid and Courtney (2007), using an experimental design, found that an individualised diet programme for healthy eating, supervised by a dietician, has a positive effect on the quality

of life of PLWH and on the treatment of lipodystrophy; it was strongly recommended for weight loss.

Evidence from a randomized clinical trial by Anastasi, Capili, Kim, McMahon, and Heitkemper (2006) showed that nutritional intervention can be efficacious in decreasing stool frequency and can improve stool consistency in PLWH who experience chronic diarrhoea. A diet low in fat, lactose, insoluble fibre and caffeine and high in soluble fibre was found very beneficial.

2.5.5.4 PLWH and occupational therapy

Occupational therapy interventions have been found to assist PLWH to identify goals and to improve their perceptions of their ability to work (Bedell, 2008). The use of self-management strategies can assist those who are not ready to work to identify their potential to work (Bedell, 2008).

Martin, Arns, Batterham, Afifi, and Steckart (2006) found that in a comparative intervention among PLWH that consisted of vocational case management and encouragement, together with basic education and job training, individuals in the intervention group took less time and were more motivated and more likely to return to work than those in the comparison group.

2.6 Disability/functional limitations and outcome instruments

There are a number of outcome instruments that measure people's disability or functional limitations. They can be grouped into those that are generic, and which are designed to assess the functional status of an individual with or without the presence of impairment or disability, and those which are designed to assess functional status in specific health conditions (Cohen & Marino, 2000). As is described in Chapters Three and Four, WHODAS 2.0 outcome instrument was used in this study. It was based on the ICF model, and designed to be used within surveys or population-based studies (Chisolm, Abrams, McArdle, Wilson, & Doyle, 2005; Üstün, Kostanjsek, & Chatterji, 2010a). WHODAS 2.0 has been mostly validated in developed countries (Üstün, et al., 2010b). Other disability outcome instruments such as the Barthel index and the functional independence measure (FIM) are designed for more clinical settings (Gosman-Hedström & Svensson, 2000).

2.6.1 Validity and reliability and disability/functional limitations outcome instrumentations

Validity and reliability are two important concepts to consider when determining the value of any assessment tool. The validity of a measure is the extent to which it measures what it was intended to measure, while reliability is concerned with the degree to which a measure is consistent and can be replicated.

2.6.1.1 Validity and reliability of WHODAS 2.0

The WHODAS 2.0 is applicable across diverse populations and cultures (Cohen & Marino, 2000; Kucukdeveci et al., 2012). When used in health services research, WHODAS 2.0 can assist in identifying the changes that follow treatment under specific conditions (Üstün, et al., 2010b).

WHODAS 2.0 has been through numerous field-tests in the course of its development. It was found to have good validity and reliability across cultures and populations and among people with both physical and mental health problems. Its internal consistency was found to be very high: for example for the 36 items; it was 0.96. Factor analysis showed a stable factor structure; the test-retest reliability was very good, and the overall intra-class correlation coefficient was 0.98. It had a good concurrent validity in patient disability classification when compared with other disability instruments, such as FIM and the Short Form Health Survey (SF) (Üstün, et al., 2010b).

Garin et al. (2010) conducted a study that aimed at assessing the validity and reliability of WHODAS 2.0 in relation to chronic diseases. It involved a large number of patients presenting one of 13 identified chronic health conditions. Patients were selected from various health centres in seven countries in Europe. The findings confirm the ability of WHODAS 2.0 to measure disability in both physical and mental chronic health conditions. It showed a very high reliability and validity.

Schlote et al. (2009) reported in their article that WHODAS 2.0 was also found to be a valid, reliable and useful instrument in the assessment of stroke patients. Its internal consistency as assessed by Cronbach's alpha was rated good to excellent. Validity was generally satisfactory for its applicability to stroke patients, using their relatives as proxies.

A literature review by Noonan, Kopec, Noreau, Singer, and Dvorak (2009) identified instruments that assess participation as defined by ICF, and found that the WHODAS 2.0 was

among the ten selected outcome instruments. Most of the instruments showed a higher validity and reliability (with WHODAS 2.0, construct validity was the most tested feature) with sufficient evidence for all instruments of good internal consistency among the domains, supporting their use for the different health conditions being assessed. WHODAS 2.0 was found to be the most broadly tested instrument. The instruments also varied, especially with regard to whether the self-care domain should be included in participation functions; in WHODAS 2.0, it was recommended that this be considered under activity functions instead of under participation (Noonan, et al., 2009).

2.6.1.2 Validity and reliability of ICF

ICF is a multidimensional and multipurpose classification, which is not restricted to a single health condition (Stucki, et al., 2003).

Soberg, Sandvik, and Ostensjo (2008) examined the applicability and reliability of the ICF codes in the rehabilitation service at one university hospital in Norway, in order to improve functional status of patients. The emphasis was on determining the level of agreement among physiotherapists in assigning ICF codes to clinical problems, and on setting goals for rehabilitation, particularly, the rehabilitation of persons with multiple injuries. The findings demonstrated at least moderate inter-rater and excellent intra-rater reliability. Kappas for the inter-rater reliability ranged from 0.41 to 0.73 while most of the Kappas for the intra-rater were above 0.80. The findings have reinforced the importance of the use of the ICF by physiotherapists when documenting a patients' problems and resources and setting goals for rehabilitation.

Devoogdt, Van Kampen, Geraerts, Coremans, and Christiaens (2011) assessed the reliability and validity of the ICF by measuring the functioning (impairment, activity limitations and participation restrictions) of people experiencing lymphedema after axillary dissection for breast cancer in a selected hospital in Belgium. The findings have demonstrated that the overall reliability of the ICF-lymphedema was good. The intra-class correlation coefficients for test-retest reliability ranged from 0.65 to 0.93. The Cronbach alpha coefficients for internal consistency were higher than 0.70, and measurement variability was acceptable with standard errors of measurement equal to 4.8 – 12.5. Content validity and construct validity were good. Furthermore, there was also good convergent validity as five expected domains of the lymphedema-ICF had a strong correlation with the five expected domains of the 36-item short-form health survey questionnaire (SF-36).

Ewert, Allen, Wilson, Üstün, and Stucki (2010) described how a retrospective international multicentre study (of 32 countries); involving different rehabilitations centres, with 3227 rehabilitation patients presenting different chronic conditions (such as low back pain osteoarthritis) supported the construct validity of the functioning part of the ICF. Additionally, findings have shown a strong correlation between the functioning components of the ICF, and thus support the use of the multidimensional ICF core set of questions on functioning. These involve all functioning components: body structures and functions, and activities and participation, instead of dealing with functioning components separately. Also, the findings encouraged researchers and clinicians to construct functioning instruments while integrating the ICF categories related to functioning components.

2.6.1.3 Validity and reliability of FIM

Küçükdeveci et al. (2001) discussed the adaptation of the FIM in Turkey and the assessment of its validity and reliability. The instrument was first translated, and thereafter its reliability and validity were tested among stroke and spinal cord injury patients admitted for rehabilitation care. The overall internal consistency of the instrument for both health conditions was tested by Cronbach's alpha, and was very high (>0.92), which justified a strong association of items in the FIM scale. The intra-class correlation coefficients were good and were all above 0.9 for both the spinal cord injury and stroke scales. Construct validity was assessed by Rasch analysis and revealed that items in both scales were not in the same hierarchical order. Convergent validity was tested and showed expected levels of agreement with other disability instruments. For example, for the spinal cord injury scale, convergent validity showed a significant relationship between the FIM and the ASIA impairment scale; an exception, however, were the cognitive motor/sensory scores.

Gosman-Hedström & Svensson (2000) carried out a study in Sweden among stroke patients admitted at one of the University Hospitals; this aimed to assess the concordance between FIM and the Barthel index, while assessing the activities of daily living. The results showed that items of the FIM and Barthel index had high levels of construct validity and face validity, and that the concordance between the two scales was high.

2.6.1.4 Validity and reliability of Barthel ADL index

Leung, Chan, and Surya (2007) developed a Chinese version of the Barthel index and assessed its validity and reliability. The subjects involved in the testing were old people (mean age 76.0; SD 7.6) who had suffered a stroke. The instrument was first translated into

Chinese language. The findings demonstrated that the test-retest reliability of the items in the Chinese version was comparable with that of the original version, with Kappa statistics ranging from 0.63 to 1.000 ($P < 0.001$). Additionally, the items in the Chinese version showed higher internal consistency, and this was comparable to that of the original instrument. Its items showed satisfactory inter-rater reliability and they seemed to have higher inter-rater consistency than those in the original version. Furthermore, there was the influence of cultural issues, especially for items in the self-care activities. For example for the item “toileting” and “bathing”; it was indicated that older Chinese people tended to use various methods, compared to their counterparts from Western countries. For instance while bathing; some would prefer a towel (or a sponge) bath while sitting on a low stool and using a basin of water rather than immersion in a bathtub or a shower.

2.7 Conclusion

This chapter has demonstrated that the HIV infection can have a significant influence on the functioning of the whole human body and can affect both physical and psychological/mental functions as well as the social functions. The literature related to HIV was reviewed to provide a general overview of the types of HIV, the pathology of HIV, the stages of HIV infection, the effect of antiretroviral treatment, and the epidemiology of HIV worldwide and in Rwanda. The literature review also highlighted models of disability with an emphasis on the ICF as the model used to guide and achieve the objectives of the present study. This was followed by a description of several body impairments that manifest in PLWH, and by a summary of reviewed studies on activity limitations and social restrictions and contextual factors related to HIV. The literature review gave also a general overview of the approach to health service delivery in a hospital environment, with a focus on health service delivery in Rwanda and the impact of rehabilitation services on the functioning of PLWH. Finally, the literature review discussed the WHODAS 2.0, the outcome instrument used in this study, as well as other outcome instruments that measure disability/functional limitations, with particular reference to their validity and reliability.

3 CHAPTER THREE: THE PROFILE OF PLWH ATTENDING ARV CLINICS – METHODOLOGY AND RESULTS

3.1 Introduction

Chapter Three describes the profile of PLWH and discusses the prevalence of impairment, activity limitation and participation restriction amongst PLWH. The chapter provides a brief background, describes the aims and objectives and the methodology of the study and the findings obtained.

3.2 Background

A while back, HIV disease was a progressive, deteriorating terminal illness with no effective treatment; it caused an often rapid decline in health, leading to death (Gaidhane, et al., 2008). However, in the past two decades, HIV management has undergone some important changes. Today, people are living longer with the disease and its numerous complications. These include musculoskeletal, neurological, and cardio-respiratory complications due to the HIV infection and the antiretroviral treatment (O'Brien & Brooks, 2006; Tehranzadeh, Ter-Oganessian, & Steinbach, 2004; Vidrine, Amick, Gritz, & Arduino, 2005).

The disease is increasingly viewed as a chronic, long-term condition and as a disabling condition (Ferrier & Lavis, 2003; Mkanta & Uphold, 2006; Paul-Ward, Braveman, Kielhofner, & Levin, 2005). The disability associated with HIV and antiretroviral treatment is multi-dimensional, characterized by unpredictable periods of wellness or illness, and it includes several impairments, as well as limitations to physical and mental functions. These might lead to difficulties in carrying out day-to-day activities, difficulties with community participation/social inclusion; these difficulties might lead to feelings of uncertainty, and these serve as a source of emotional distress, fear and anxiety (O'Brien, et al., 2008). One of the methods of understanding the impairments, functional limitations and participation restrictions associated with HIV, is to classify the condition according to the ICF, which is a systematic framework for describing the full range of human functions that might be affected by a health condition. It is based on a bio-psychosocial approach that allows users to document the impact of health conditions on human functioning from biological, individual, and social perspectives (Reed, et al., 2005).

3.3 Aims and Objectives

3.3.1 Aim

The aim of this section is to determine the profile and the prevalence of disability among PLWH, by measuring impairment, activity limitation and participation restriction amongst PLWH who are also on antiretroviral treatment. In addition the relationship between functioning and medication is explored.

3.3.2 Objectives

- To determine the proportion of PLWH who have impairments;
- To determine the proportion of PLWH who have activity limitations and participation restrictions;
- To determine the prevalence of disability among PLWH attending ARV clinics;
- To establish whether there is a relationship between the body function impairments, the functional limitations and participation restrictions.
- To document the relationship between length of time on antiretroviral treatment, CD4 count and functioning.

3.4 Methodology

3.4.1 Research design

A quantitative, exploratory, cross-sectional analytical and descriptive design was used.

3.4.2 Research setting

The study was carried out in hospitals in Rwanda. Rwanda consists of five provinces, namely Eastern, Western, Southern, Northern and Central. There are 30 Districts extending throughout the five provinces, and there are 45 public hospitals, most of which contain an ARV clinic. The study was carried out in selected public hospitals among the 30 Districts.

3.4.3 Study population, sampling technique and sample size, selection of districts and hospitals

Each province (big cluster) contains a number of districts (small clusters). Three districts per province were purposively chosen to ensure both urban and rural areas were represented.

Fifteen hospitals were selected, one hospital from each district. A simple random sampling of hospitals was done from the lists of all hospitals in the selected districts that had an ARV clinic and a physiotherapy department. The selected hospitals were considered study areas.

Table 4: Hospitals selected for the study

| Province | District | Hospital |
|-------------------|------------|---------------------------|
| Western province | Rusizi | Gihundwe Hospital |
| | Rubavu | Gisenyi Hospital |
| | Karongi | Mugonero Hospital |
| Northern province | Gicumbi | Byumba Hospital |
| | Musanze | Ruhengeri Hospital |
| | Rulindo | Rutongo Hospital |
| Eastern province | Bugesera | Nyamata Hospital |
| | Rwamagana | Rwamagana Hospital |
| | Kayonza | Gahini District Hospital |
| Southern province | Kamonyi | Remera Rukoma Hospital |
| | Muhanga | Kabgayi Hospital |
| | Huye | CHUB Hospital |
| Kigali city | Gasabo | Kibagabaga Hospital |
| | Kicukiro | Kanombe Military Hospital |
| | Nyarugenge | Muhima Hospital |

3.4.3.1 Selection of participants: Study population, sampling technique and sample size

Study population: This consisted of adult PLWH (females and males).

Inclusion criteria:

Participants had to be HIV positive, on antiretroviral treatment and attending an ARV clinic at one of the selected hospitals.

Participants had to be aged 18 years and above.

Participants could be either employed or unemployed.

Sampling technique and sample size: All PLWH on antiretroviral treatment who attended the ARV clinic at the selected hospitals during the period of data collection, and who voluntarily agreed to participate in the study, were recruited. Patients were identified by the clinical team, the majority of whom were nurses. Five hundred and twenty (520) people were approached to participate in the study.

3.4.4 Instrumentation

In this study, the WHODAS 2.0 questionnaire (36-item version) was used as the research instrument, with a recall period of 30 days and response options on the following scale: 1=no difficulty, 2=mild difficulty, 3=moderate difficulty, 4=severe difficulty and 5=extreme difficulty (or cannot do). Impairment items are lacking in WHODAS 2.0 (Üstün, et al., 2010).

An ICF core set of questions on impairments identified among people living with HIV by Myezwa et al. (Myezwa, et al., 2011) was therefore added. It was necessary to include impairment questions which assess body problems, as one of the objectives of the study was to examine the interaction of impairments and functional limitations. The validation of these instruments was done post-hoc and is presented in Chapter Six.

3.4.5 Procedure

Step1: Prior to data collection, permission was first given by the University of the Western Cape (UWC) (Appendix I) and the WHO to use the questionnaire. In order to obtain ethical clearance and permission in Rwanda, the proposal was sent for assessment by two research bodies in the country: these were the National Aids Control Commission; “Commission Nationale de Lutte contre le Sida⁴” (CNLS), which is the institution that supervises and coordinates all activities related to HIV in Rwanda, the KHI Institutional Review Board (KHI IRB), which represents the National Research Ethical Committee in Rwanda at the institutional level.

After one month, the researcher was called to present the proposal at CNLS; the panel consisted of five medical doctors, two psychologists, and one person living with physical

⁴ Commission Nationale de Lutte contre le Sida (CNLS) is a French word, it means National Aids Control Commission, and it is what is commonly used.

disability with a qualification in Public Health, working at the National Disability Organisation, but under the umbrella of disability and HIV organisation; this person was the principal reviewer of the research proposal. Thereafter, the researcher presented the proposal at KHI IRB; this panel included two physiotherapists, one medical doctor with a qualification in Public Health, and one nurse with a qualification in Medical Education. One of the physiotherapists and the nurse with the Medical Education qualification were the reviewers of the proposal.

Step 2: After getting authorisation from CNLS (Appendix I) and KHI IRB, the next step was to ask permission for data collection from the hospitals. Letters requesting permission were sent to all fifteen selected hospitals via the post office (Appendix II). Thereafter, the researcher visited each site. This enabled face-to-face contact with the directors of each hospital after they had received the letters. The researcher reiterated the purpose of the study, and this resulted in some of the directors granting permission on the day of the visit. Preparation for the fieldwork was done, and the appointments and days for data collection were confirmed.

After a month and a half, permission was obtained from fourteen (14) hospitals. One hospital, *Centre Hospitalier Universitaire de Kigali (CHUK)*, did not wish to participate as most of its patients were in-patients, and out patients were usually referred to the Treatment and Research AIDS Centre Plus (TRAC Plus), a Centre for treatment and research in HIV/AIDS in Rwanda. The researcher then decided to include Muhima Hospital, which was selected for the debriefing interview/pre-test, and which is in the same province and same district as CHUK. The Director of Muhima granted permission. However, all patients who participated in the debriefing interview/pre-test were excluded.

Step 3: The researcher's visits to the sites were followed by the training of two research assistants. The training took place at Kigali Health Institute (KHI), and only took two days as the research assistants were already familiar with the research instrument. They had participated in the consensus meetings and the debriefing interview/pre-test, and had contributed to the development of the Kinyarwanda version. The training covered the assistants' roles in the study and their understanding of the research topic, as well as their understanding of the aims and ethical considerations of the study.

Step 4: Face-to-face interviews were conducted in 15 hospitals scattered all over the country, from June 2010 to August the same year. Interviews were conducted by the researcher and

the research assistants. An average of two to three days was spent at each site; the time spent depended on the location of the hospital and the frequency of patients' attendance. At each site, patients preferred morning hours (7h30-12h30) which allowed them to return home early, as in certain areas the hospital was located some distance from their homes. At each daily session, the nurse responsible for the clinic had to first give a general introduction, welcoming the patients and the interviewers, and explaining the reason for the visit. Then the researcher or the research assistant had to explain the purpose of the study by using the Participant Information sheet (Appendix III); participants were informed of their right to participate in, or indeed to withdraw from the study at any time should they feel uncomfortable.

Participants were further assured that their participation in the study would remain anonymous and confidential. Comfortable rooms were prepared for interviews. Participants who volunteered were then invited to join the interviewers where they were seated, one interviewer per room for privacy. An interview session took at least 20-25 minutes, and began with some small talk, for example, regarding the environment; this helped the participants to relax. Participants were requested to sign a consent form agreeing to their participation in the study (Appendix IV). In addition, they were requested to give permission to access their medical records/files. Ethical issues were considered throughout the process of data collection, and at the end of every interview, the participant was thanked.

3.4.6 Ethical considerations

Following approval of the research proposal by the Senate Higher Degrees Committee of UWC and ethical approval by the Senate Research, Ethics and Study Leave Committee, permission was granted by the WHO to use and translate the WHODAS 2.0 instrument. Ethical clearance was sought from KHI IRB, and from CNLS and permission was sought from different hospitals where the study was to be conducted. The participants' information letter explaining the nature of the study and inviting participants to participate in the study was read out to them prior to their recruitment for the study. Participants were requested to sign a consent form agreeing to their participation in the study. In addition, they were requested to give their permission to access their medical records/files. Participation was voluntary, and confidentiality and the anonymity of the participants were maintained. Participants were assured of their right to withdraw from the study at any time without any repercussions.

3.4.7 Data management analysis

Data was entered into Excel, and then analysed using SPSS packages. Descriptive statistics were produced for all demographic variables. For categorical variables, cross tables and bar charts were used to present the data; while for continuous variables, measures of central tendency (mean and standard deviations) were used. The T test was used to test equality of the means for the age of females and of males. The Pearson correlation was also used to determine the relationship between years spent at school and the age of participants. The Chi-Square and Spearman tests were used to determine the association and the relationship between certain categorical variables under impairments, activity limitations and participation restriction domains. The WHODAS 2.0 Manual provides an algorithm for calculating the percentage scores for each domain, with 0 representing the least activity limitation which was used to calculate domain scores. This included the ANOVA to determine which domains were the most affected, and a *post-hoc* Tukey to determine where the differences lay.

Multiple regression analysis was used to identify which impairments were predictive of WHODAS 2.0 scores in the different domains that demonstrated internal consistency. Dummy tables were created for all impairments with variables =0 for no and mild problems, and =1 for moderate, severe and extreme problems. All impairments were then entered in a stepwise regression to identify which contributed significantly to the variation. Those that were significant were then subjected to further analysis using the enter method (i.e. all variables entered simultaneously). Outliers whose residual scores were greater than two standard deviations from the mean were excluded and the regression was rerun with these scores excluded. Statistical significance was set at the .05 level.

3.5 Results

3.5.1 Demographic data

Fifteen health centres throughout the country were visited between June and August 2010. Five hundred and twenty people met the inclusion criteria and volunteered to take part in the study (see Table 5). In all, 502 questionnaires were completed and were included in analysis. Eighteen questionnaires were excluded due to missing information.

The subjects represented 35.7% (136/381%) of the males and 56.6% (384/678%) of the females who attended the clinics on the days of data collection. Of all those who attended, both male and female, 48.3% were interviewed. There was an association between gender

and being interviewed (Pearson Chi Square = 8.2398, df=1, p=0.004), with more females being interviewed.

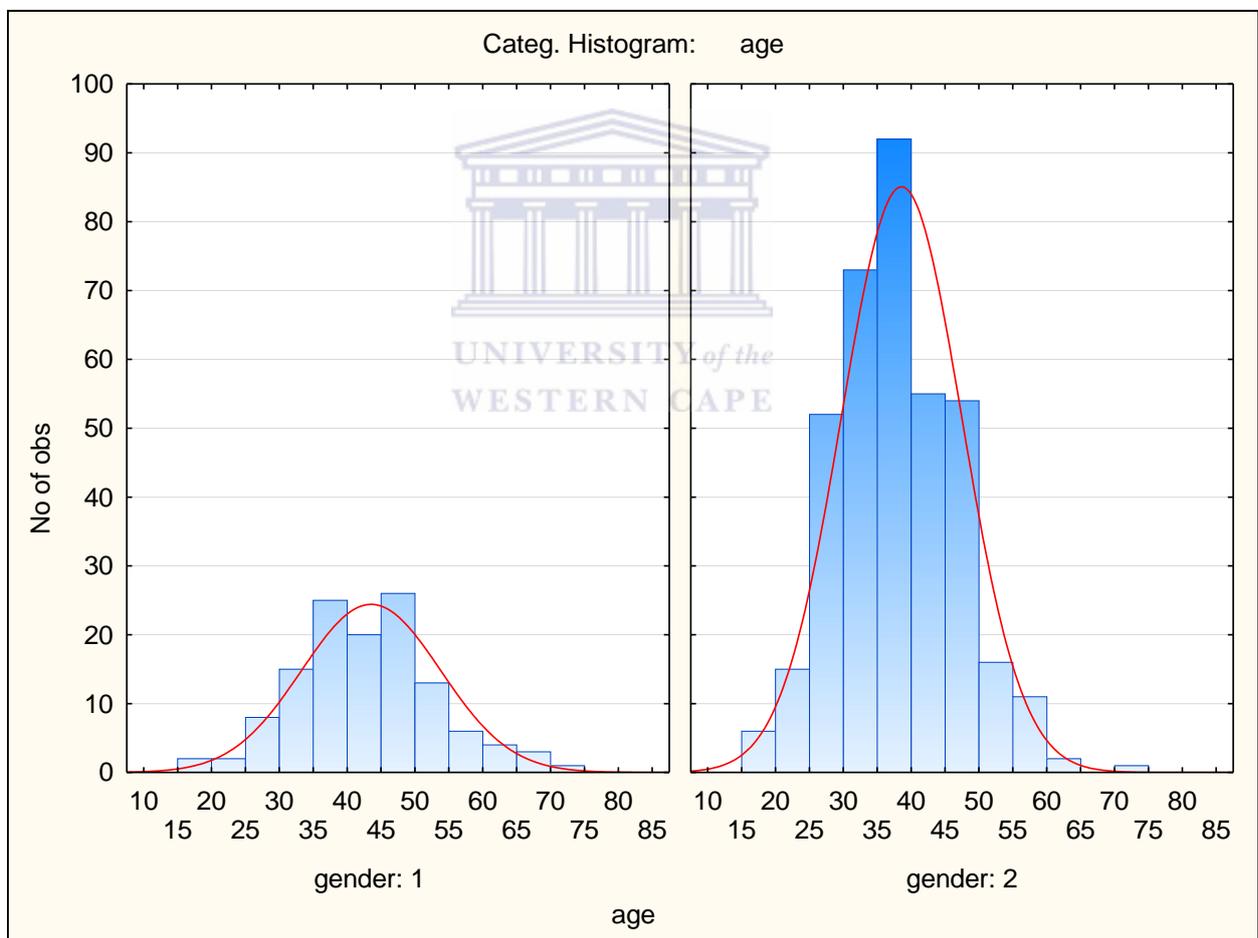
Table 5: Health Centres visited (n=15)

| District Hospital | Urban/Rural | Target | Male Patients attended | Number of males recruited | Female Patients attended | Number of female recruited | Total number attended | Total number recruited |
|--------------------------|-------------|--------|------------------------|---------------------------|--------------------------|----------------------------|-----------------------|------------------------|
| Gihundwe | Semi-Rural | 25 | 36 | 3 | 71 | 22 | 107 | 25 |
| Gisenyi | Semi-Rural | 25 | 22 | 7 | 50 | 13 | 72 | 20 |
| Mugonero | Rural | 25 | 21 | 7 | 44 | 19 | 65 | 26 |
| Byumba | Semi-Rural | 45 | 28 | 16 | 45 | 36 | 73 | 52 |
| Ruhengei D | Semi-Rural | 25 | 10 | 4 | 34 | 10 | 44 | 14 |
| Rutongo | Rural | 25 | 8 | 1 | 18 | 18 | 26 | 19 |
| Nyamata | Semi-Rural | 45 | 33 | 12 | 57 | 20 | 90 | 32 |
| Rwamagana | Semi-Rural | 45 | 30 | 6 | 57 | 52 | 87 | 58 |
| Gahini | Rural | 25 | 17 | 10 | 29 | 11 | 46 | 21 |
| Remera Rukoma | Semi-Rural | 45 | 15 | 7 | 32 | 31 | 47 | 38 |
| Kabyayi | Semi-Rural | 45 | 27 | 9 | 57 | 37 | 84 | 46 |
| CHUB | Urban | 40 | 27 | 9 | 46 | 24 | 73 | 33 |
| Kibagabaga | Urban | 45 | 22 | 17 | 40 | 36 | 62 | 53 |
| Rwanda Military Hospital | Urban | 45 | 36 | 16 | 30 | 25 | 66 | 41 |
| Muhima | Urban | 45 | 49 | 12 | 68 | 30 | 117 | 42 |
| Total | 15 | 550 | 381 | 136 | 678 | 384 | 1059 | 520 |

The final sample consisted of 502 respondents, of whom 125 (25%) were male. Of these, 436 (87%) declared themselves to be living independently in community, whereas 66 (13%) were assisted. 411 (82%) reported earning less than US\$82, and 11 (2%) reported earning between US\$85 and US\$167 per month.

3.5.1.1 Gender and age

The mean age of the sample was 39.7 (SD=9.43, range 18-79 years): the mean age of the males was 43.4 years (SD=10.2, range 18-75 years) and that of the females was 38.4 (SD=8.8, range 18-74 years). Males were approximately five years older than the females and this was significantly different ($t=4.82$, using separate variances, $df=189$, $p<.001$).



(gender 1=male, gender 2=female, n=502)

Figure 5: Age distribution

As can be seen in the figure above, there were relatively few men or women below the age of 25 years.

3.5.1.2 Gender and marital status

Approximately one third of the sample was married or cohabitating and a similar percentage was widowed. Marital status was associated with gender (Chi-Square =65.193; df= 3 .p<.001). The most common marital status was ‘married’ in males (65%) and ‘widowed’ in females (41%). Both groups had a similar number of ‘never married’ respondents (14%) (Table 6).

Table 6: Gender and marital status (N=502)

| Gender | | Marital Status | | | | Total |
|--------|-----|----------------|------------------------|------------------------|---------|--------|
| | | Never married | Married/ Cohabiting | Separated/ Divorced | Widowed | |
| Male | N | 17 | 81 | 12 | 15 | 125 |
| | % n | 13.6% | 64.8% | 9.6% | 12.0% | 100.0% |
| Female | N | 53 | 101 | 67 | 156 | 377 |
| | % | 14.1% | 26.8% | 17.8% | 41.4% | 100.0% |
| Total | N | 70 | 182 | 79 | 171 | 502 |
| | % | 13.9% | 36.3% | 15.7% | 34.1% | 100.0% |

3.5.1.3 Gender and employment

A large majority of the respondents were self-employed (77%). Employment was associated with gender, (Chi-Square = 28.683, df= 7, p<.001) with more males in paid work (12% compared to 4%) and fewer males unemployed (7% compared to 15%) (Table 7).

Table 7: Gender and employment (N=502)

| | | Occupation | | | | | | Total |
|--------|-----|------------|---------------|------------------------|---------------|---------|---------------------------------|--------|
| | | Paid work | Self-employed | Non paid work /student | Keeping house | Retired | Unemployed-health/other reasons | |
| Male | N | 15 | 97 | 0 | 1 | 3 | 9 | 125 |
| | % | 12.0% | 77.6% | .0% | .8% | 2.4% | 7.2% | 100.0% |
| Female | N | 14 | 291 | 7 | 7 | 0 | 58 | 377 |
| | % n | 3.7% | 77.2% | 1.9% | 1.9% | .0% | 15.4% | 100.0% |
| Total | N | 29 | 388 | 7 | 8 | 3 | 67 | 502 |
| | % n | 5.8% | 77.3% | 1.4% | 1.6% | .6% | 13.3% | 100.0% |

3.5.1.4 Gender, age and education

Sixty percent (60%) of the respondents had achieved a primary school level of education. Gender was associated with education, (Chi-square=14.263, df: 4, p=.006) with more males attaining above secondary school level education (A level) (13% compared to 5 %). There was a weak negative correlation between age and years spent at school (correlation coefficient (r) = -.149, p=.006).

Table 8: Gender and education (N=502)

| Gender | | Level of education | | | | | Total |
|--------|---|--------------------|-------------------------|-------------------------|-------------------------|--------------------|--------|
| | | None | Primary education (1-6) | Secondary school (S1-3) | Secondary school (S4-6) | Tertiary education | |
| Male | N | 15 | 68 | 26 | 16 | 0 | 125 |
| | % | 12.0% | 54.4% | 20.8% | 12.8% | .0% | 100.0% |
| Female | N | 65 | 233 | 60 | 17 | 2 | 377 |
| | % | 17.2% | 61.8% | 15.9% | 4.5% | 0.5% | 100.0% |
| Total | N | 80 | 301 | 86 | 33 | 2 | 502 |
| | % | 15.9% | 60.0% | 17.1% | 6.6% | 0.4% | 100.0% |

3.5.2 Health status

3.5.2.1 HIV symptoms and time from diagnosis with HIV

As can be seen in Table 4.6, most of the participants had been diagnosed with HIV four to six years previously (36%), with about 80% having been diagnosed between one and nine years previously. There were few very recent diagnoses.

Table 9: Length of time with HIV diagnosis and HIV status (N=502)

| Time since diagnosis | HIV status | | Total | % of Total | |
|----------------------|--------------|-------------|-------|------------|------|
| | Asymptomatic | Symptomatic | | | |
| | n | 2 | 4 | 6 | 1.2 |
| 1-6 months | % | 33.3 | 66.7 | 100.0 | |
| | n | 6 | 12 | 18 | 3.6 |
| 6-12 months | % | 33.3 | 66.7 | 100.0 | |
| | n | 53 | 68 | 121 | 24.1 |
| 1-3years | % | 43.8 | 56.2 | 100.0 | |
| | n | 71 | 110 | 181 | 36.1 |
| 4-6years | % | 39.2 | 60.8 | 100.0 | |
| | n | 25 | 70 | 95 | 18.9 |
| 7-9years | % | 26.3 | 73.7 | 100.0 | |
| | n | 14 | 48 | 62 | 12.4 |
| 10-15years | % | 22.6 | 77.4 | 100.0 | |
| More than 15years | n | 6 | 13 | 19 | 3.8 |



| | | | | | |
|-------|---|------|------|-------|-----|
| | % | 31.6 | 68.4 | 100.0 | |
| Total | n | 177 | 335 | 502 | 100 |
| | % | 35.3 | 64.7 | 100 | |

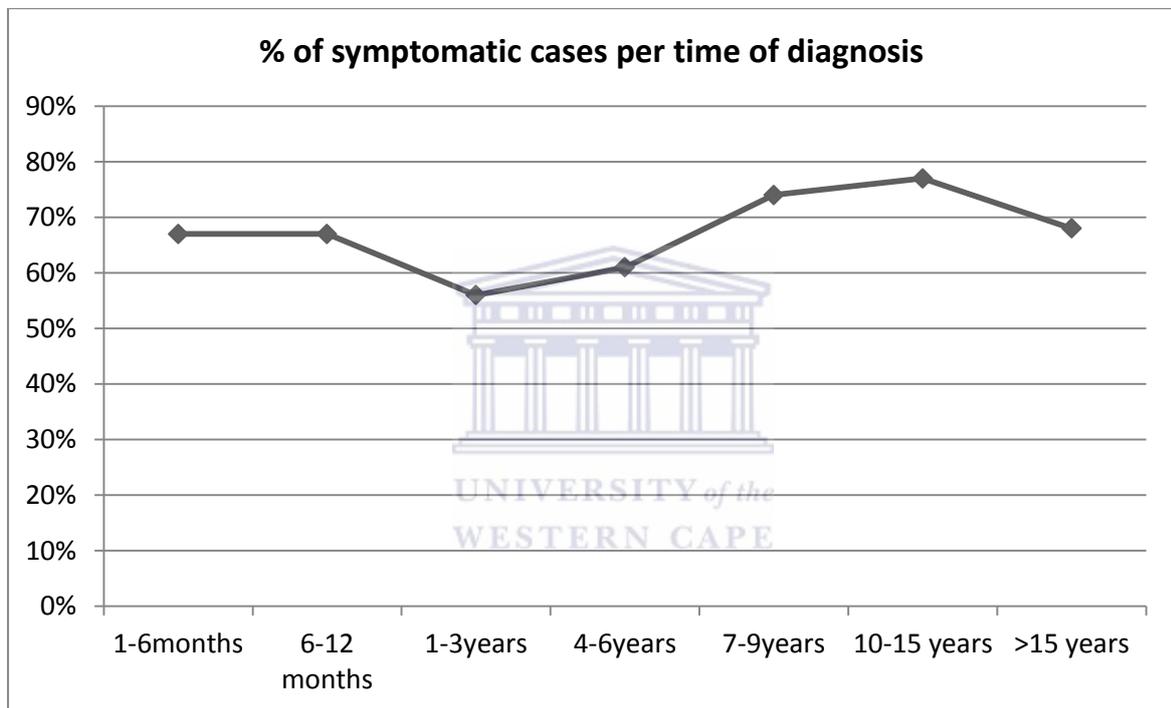


Figure 6: Percentage of participants who were symptomatic from time of diagnosis (N=502)

The percentage of cases with symptoms was between 55 and 77%, while the percentage of participants who had had HIV for a longer period was higher.

3.5.2.2 HIV status and time started antiretroviral treatment

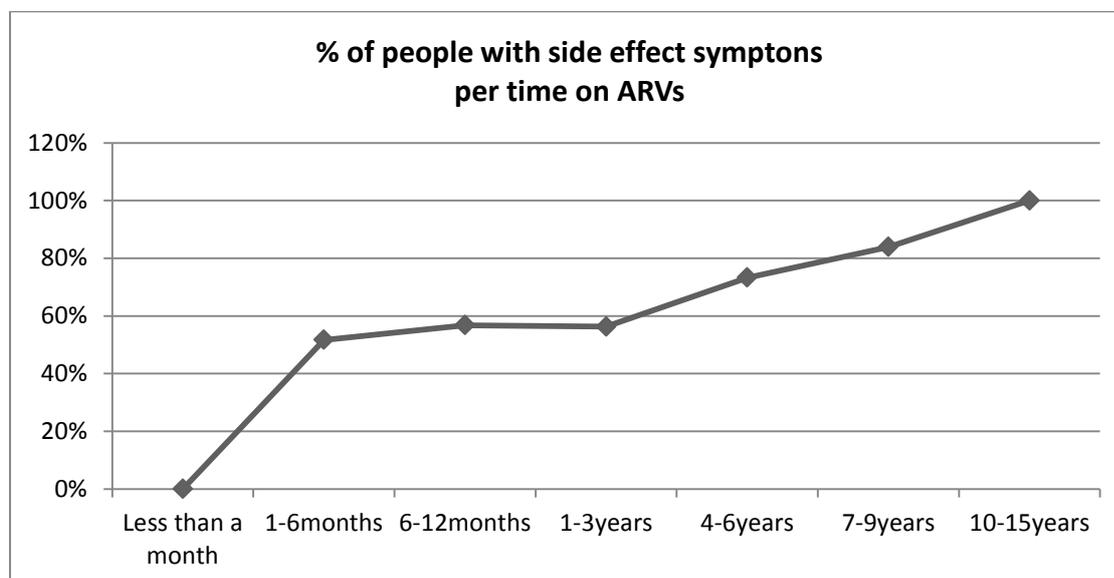


Figure 7: Percentage of participants who had side effect symptoms per time on antiretroviral treatment (N=502)

A higher percentage of those who had been on antiretroviral treatment for longer, reported having more symptoms; it can be seen that the longer the participants were on antiretroviral treatment, the more likely they were to be symptomatic.

3.5.2.3 HIV status and CD4 count

Almost two thirds (62.4%) of the participants had a CD4 count greater than 500. There was no difference in the CD4 count category (above and below 500) for participants who were symptomatic or asymptomatic (Table 10) (Chi-square =1.182, df=1, p=.277).

Table 10: HIV status and CD4 count (N=502)

| | | CD4 Count | | | | Total (n) % | |
|------------|--------------|---------------|------|---------------|------|-------------|------|
| | | Less than 500 | | More than 501 | | | |
| | | n | % | n | % | | |
| HIV status | Asymptomatic | 61 | 34.5 | 116 | 65.5 | 177 | 35.3 |
| | Symptomatic | 128 | 39.4 | 197 | 60.6 | 325 | 64.7 |

| | | | | | | |
|-------|-----|-----|-----|-----|-----|-------|
| Total | 189 | 100 | 313 | 100 | 502 | 100.0 |
| | | | | | | 0 |

3.5.2.4 CD4 count and time since starting antiretroviral treatment

The table below shows that, in general, the longer the participants had been on antiretroviral treatment, the greater their CD4 count (Table 11).

Table 11: Antiretroviral treatment time period and CD4 count (N=502)

| Time on ARVs | | CD4 count | | |
|-------------------|---|---------------|---------------|---------|
| | | Less than 200 | More than 500 | Total |
| Less than a month | n | 1 | 0 | 1 |
| | % | 100.0% | 0.0% | 100.0% |
| 1-6 months | n | 28 | 1 | 29 |
| | % | 96.6% | 3.4% | 100.0% |
| 6-12 months | n | 30 | 7 | 37 |
| | % | 81.0% | 18.9% | 100.0% |
| 1-3 years | n | 143 | 56 | 199 |
| | % | 71.9% | 28.1% | 100.0% |
| 4-6 years | n | 114 | 88 | 202 |
| | % | 56.5% | 43.6% | 100.0% |
| 7-9 years | n | 18 | 13 | 31 |
| | % | 58.1% | 41.9% | 100.0% |
| 10-15 years | n | 2 | 1 | 3 |
| | % | 66.60% | 33.30% | 100.00% |

| | | | | |
|-------|---|-------|-------|--------|
| Total | n | 336 | 166 | 502 |
| | % | 10.8% | 33.1% | 100.0% |

3.5.3 Functional status as measured by the WHODAS 2.0

The functional status of participants is described below, starting with a description of their impairments, activity limitations and participation/social restrictions. Multivariate analysis is then presented to explore the interrelationship between activity limitation, participation/social restriction and impairment.

Note: The responses to some questions were missing or not applicable and these responses have not been included in the graphs. Consequently, percentages represented in the graphs do not always add up to 100.

3.5.3.1 Impairments

Impairments were present in all seven domains: (i) mental functions; (ii) sensory functions and pain; (iii) cardiovascular and respiratory system functions; (iv) digestive system functions; (v) reproductive functions; (vi) neuro-musculoskeletal and movement-related functions; and (vii) skin functions. Domains are presented below in separate figures, each figure giving detailed information of the areas in which most problems were reported.

Mental functions

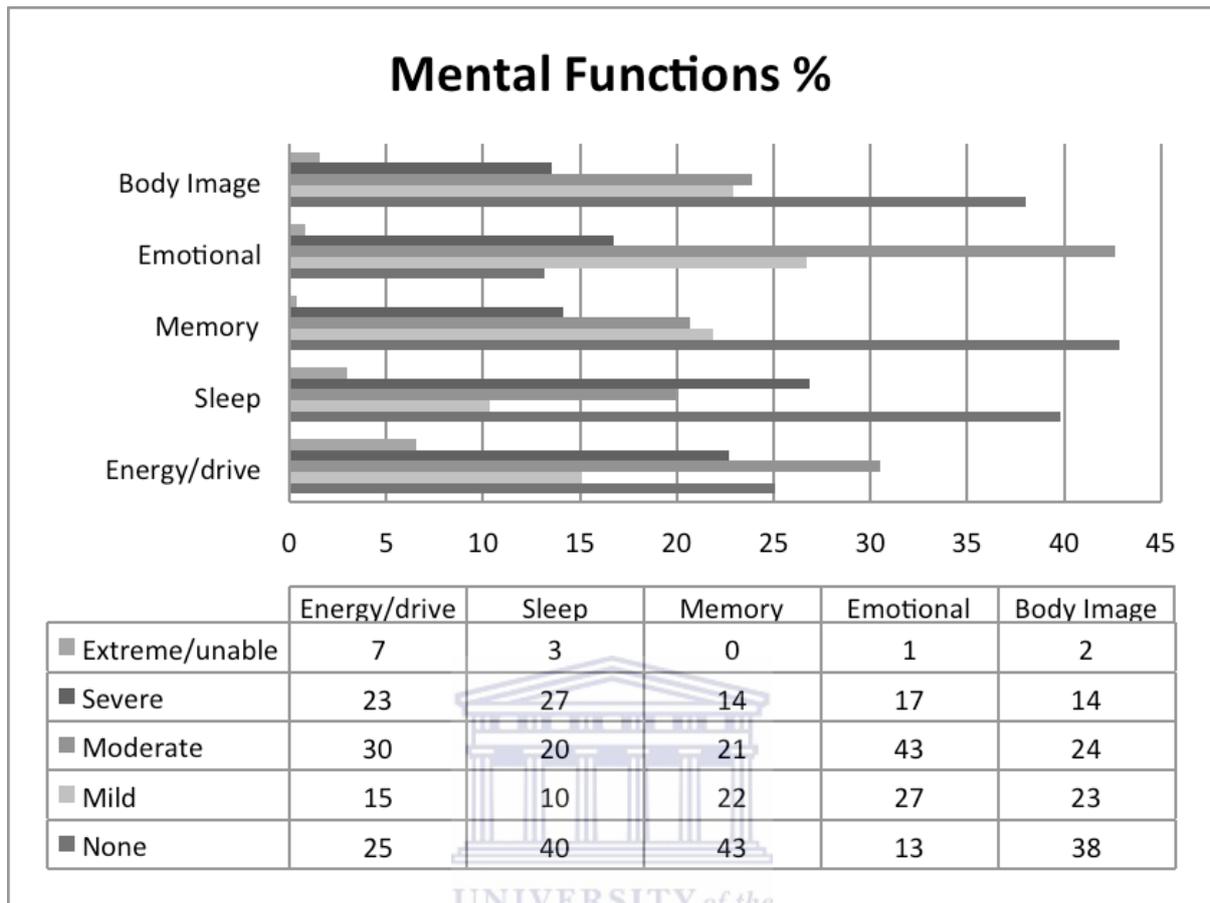


Figure 8: Percentage of participants reporting problems with mental functions (N=502)

Emotional functions were the most affected of the mental functions, with 61% reporting moderate, severe or extreme problems. This domain was followed by problems in the energy and drive category (60%). The area which gave the least problems was memory, with 35% reporting moderate or severe problems.

Sensory functions and pain

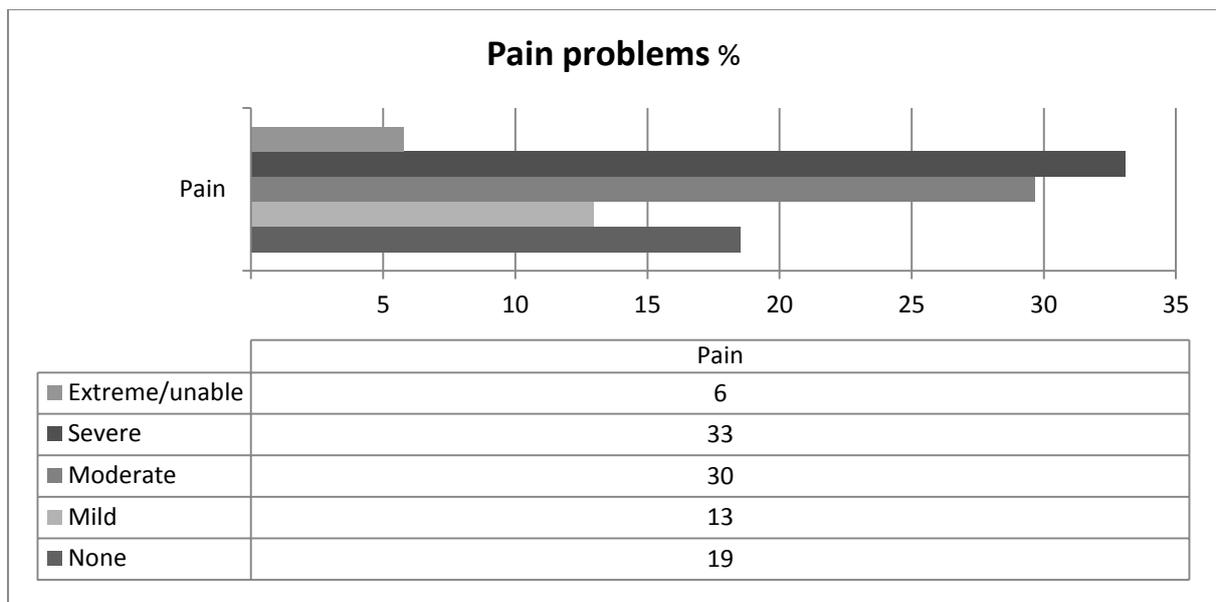
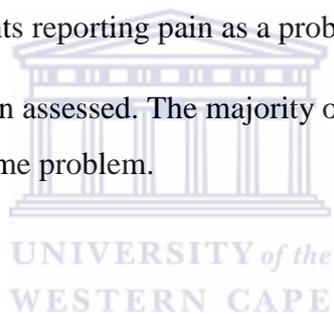


Figure 9: Percentage of participants reporting pain as a problem (N=502)

Pain was the only sensory function assessed. The majority of participants (69%) reported pain being a moderate, severe or extreme problem.



3.5.3.2 Cardiovascular and respiratory system functions

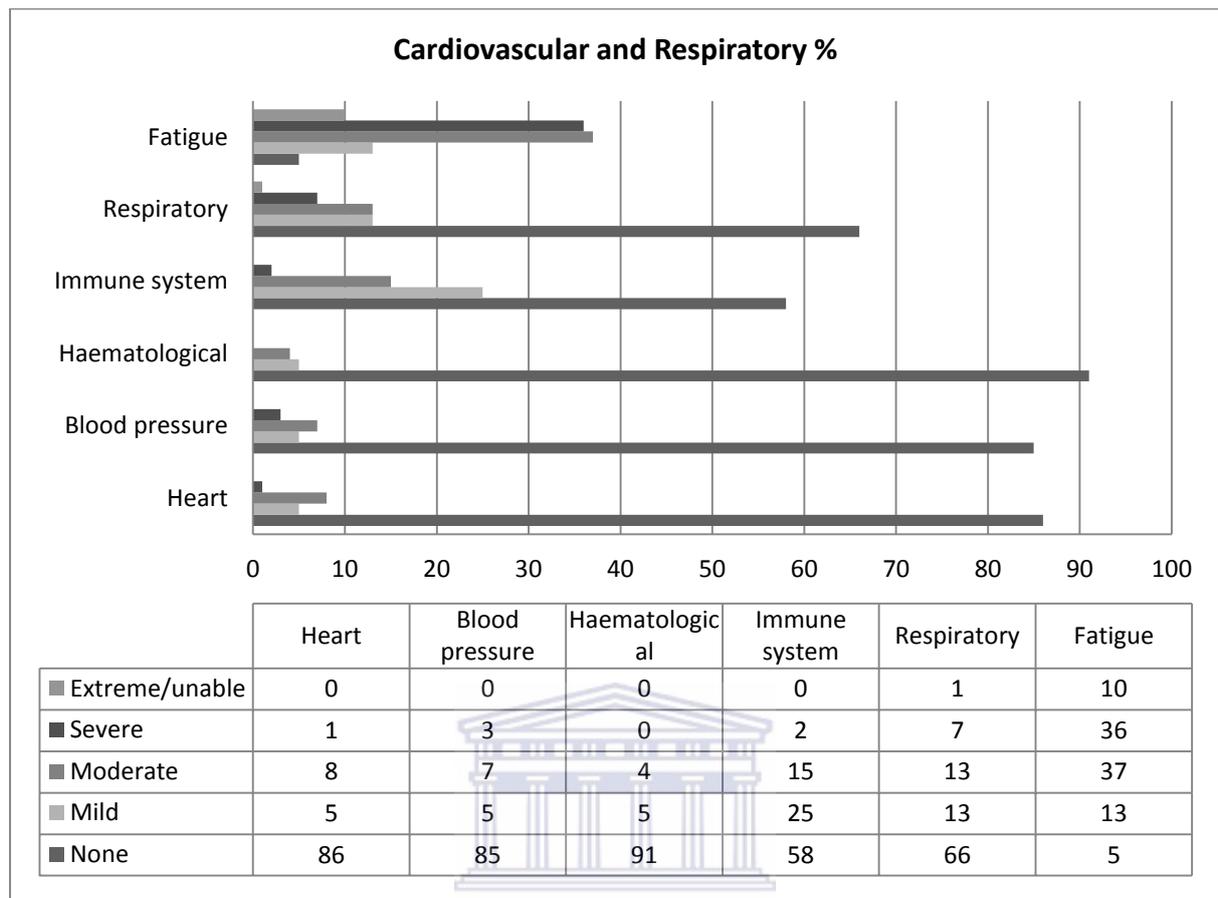


Figure 10: Percentage of participants reporting problems with cardiovascular and respiratory problems (N=502)

Under the cardiovascular and respiratory function, fatigue was the domain most affected, with 83% of participants reporting moderate, severe or extreme problems with fatigue, followed by respiratory problems (21%). The haematological domain was the domain with least problems, with only 4% reporting moderate problems.

Functions of the digestive system

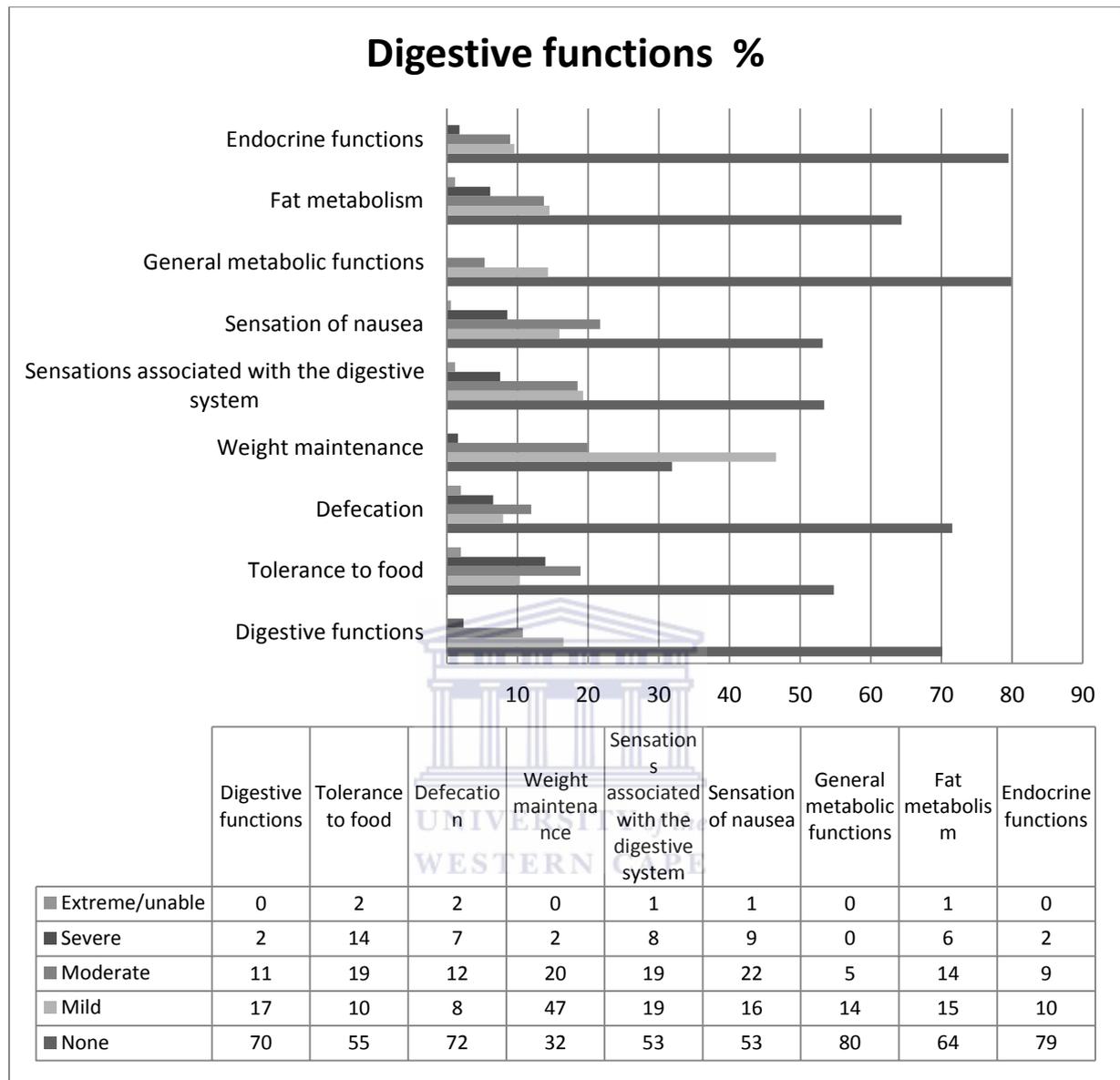


Figure 11: Percentage of participants reporting problems with digestive functions (N=502)

Among the digestive domains, tolerance to food was the most affected, with 35% reporting moderate, severe or extreme problems; this was followed by sensations of nausea (32%).

Problems with general metabolic functions were the least reported, with 5% of participants reporting only moderate problems.

Reproductive functions

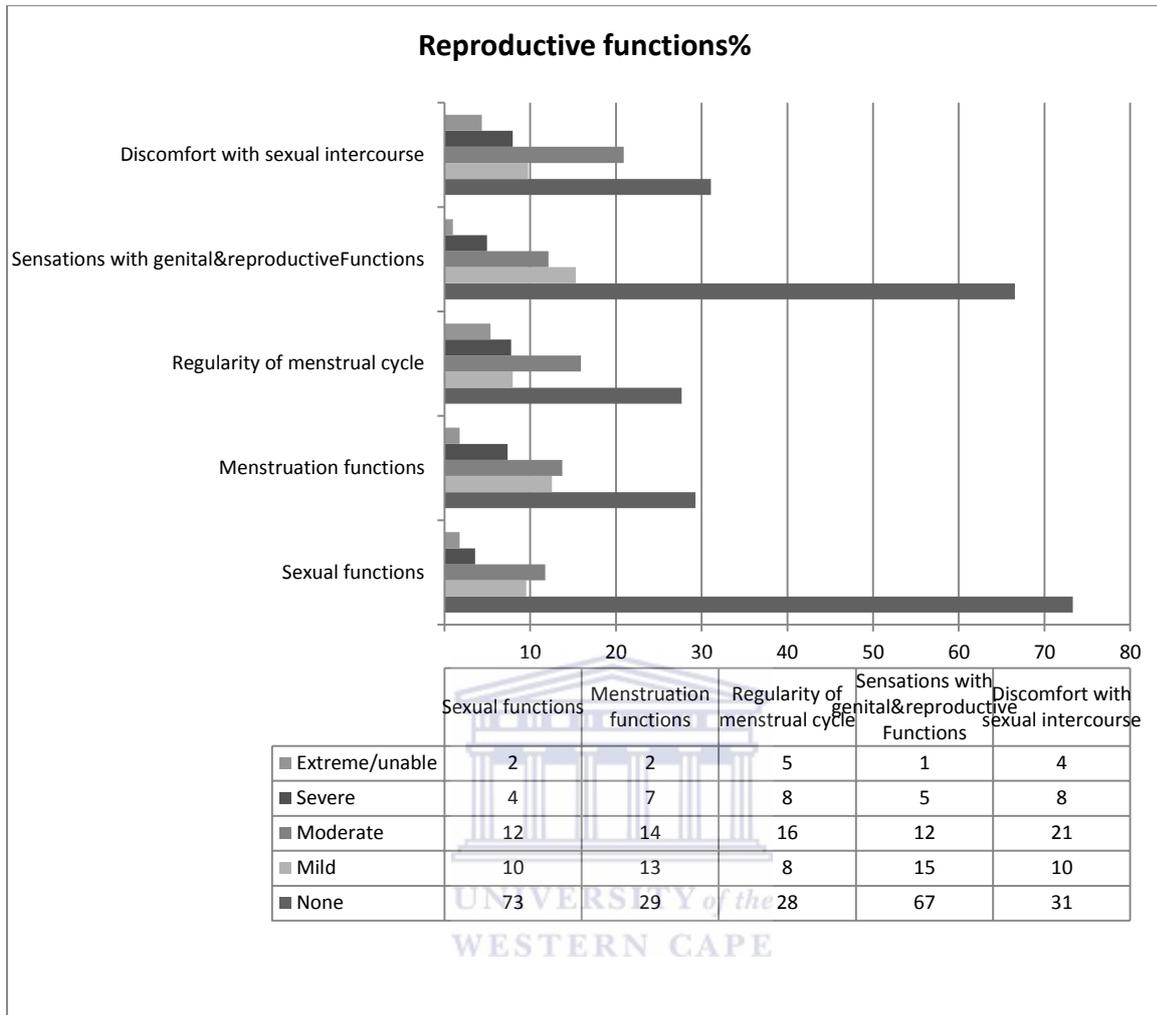


Figure 12: Percentage of participants reporting problems with reproductive functions (N=502)

Discomfort with sexual intercourse was reported by 33% of participants and was the domain most affected, followed by regularity of menstrual cycle, with 31% of female participants reporting moderate, severe or extreme problems.

Functions of the neuro-musculoskeletal and related movement

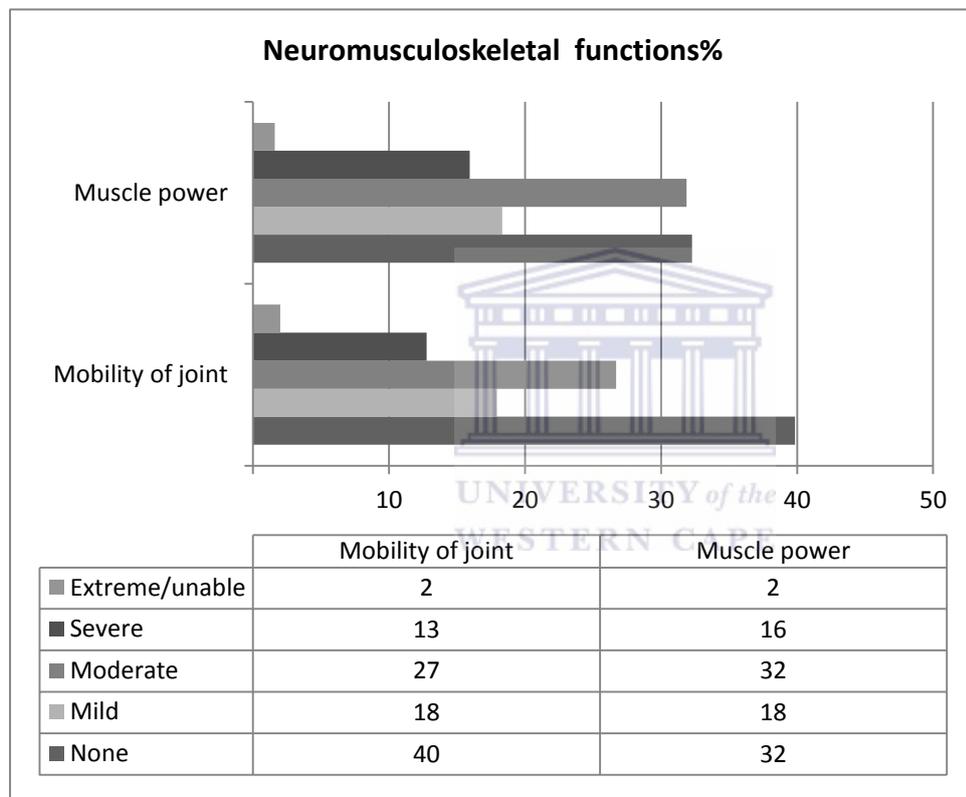


Figure 13: Percentage of participants reporting problems with neuro-musculoskeletal and movement-related functions (N=502)

There were two domains assessed under neuro-musculoskeletal and movement related functions: (i) muscle power and (ii) mobility of joints. Muscle power was most affected, with 50% of participants reporting moderate, severe or extreme problems. There was evidence of positive correlations between the two domains and pain (Table 12).

Table 12: Correlations among neuro-musculoskeletal functions domains and with pain

| | Mobility of joint | Muscle power | Pain |
|-------------------|-------------------|--------------|-------|
| Mobility of joint | 1.000 | 0.536 | 0.515 |
| Muscle power | 0.536 | 1.000 | 0.405 |
| Pain | 0.515 | 0.405 | 1.000 |

Note that all correlations were significant at a $P < 0.01$ level.

Functions of the skin

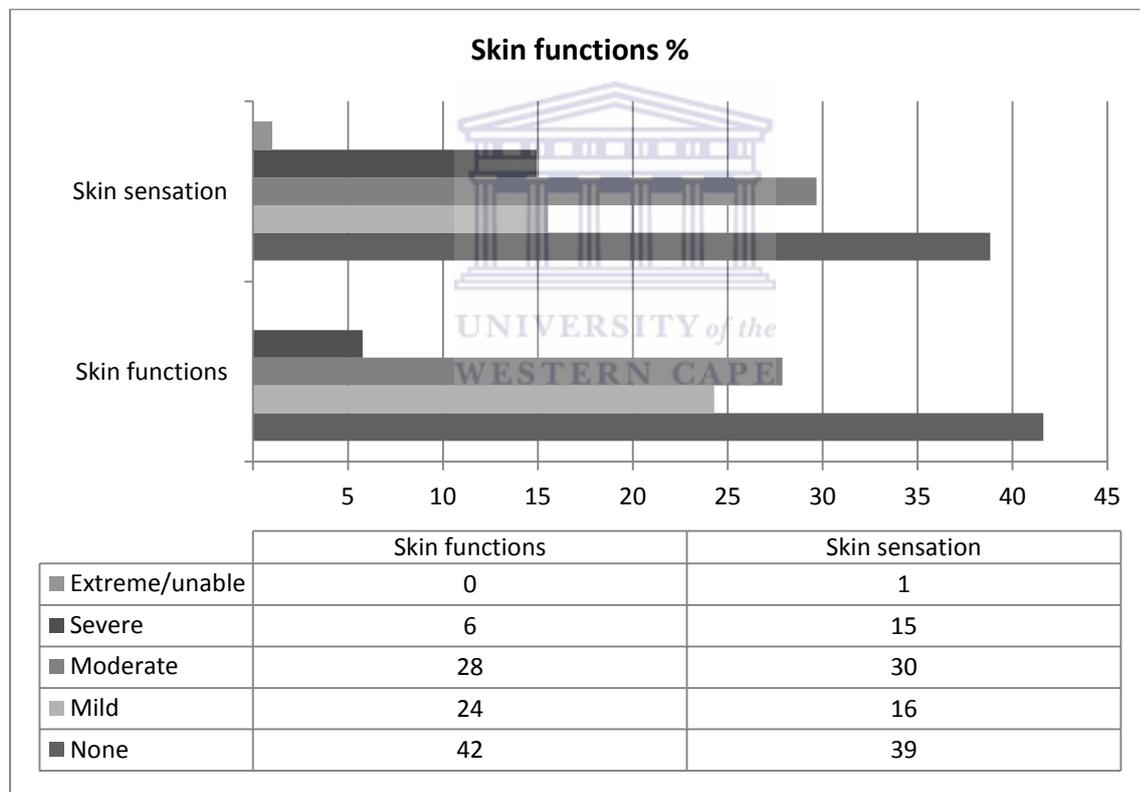


Figure 14: Percentage of participants reporting problems with skin functions (N=502)

Under skin functions, some participants (46%) reported skin sensations to be the most affected by moderate, severe or extreme problems. Positive correlations were found between the two domains and pain (Table 13).

Table 13: Correlations among skin functions domains and with pain

| | Skin function | Skin sensation | Pain |
|----------------|---------------|----------------|-------|
| Skin function | 1.000 | 0.676 | 0.407 |
| Skin sensation | 0.676 | 1.000 | 0.464 |
| Pain | 0.407 | 0.464 | 1.000 |

Note that all correlations were significant at a $P < 0.01$ level

3.5.3.3 Activity limitation and participation/social restriction

Activity limitations and participation/social restrictions are presented under the WHODAS 2.0 domains: these include the cognition domain, the mobility domain, the self-care domain, the getting-along-with-people domain, the life activities domain and the participation domain. Domains are presented below in separate figures; each figure provides detailed information of areas where most problems occurred.

Cognition functions

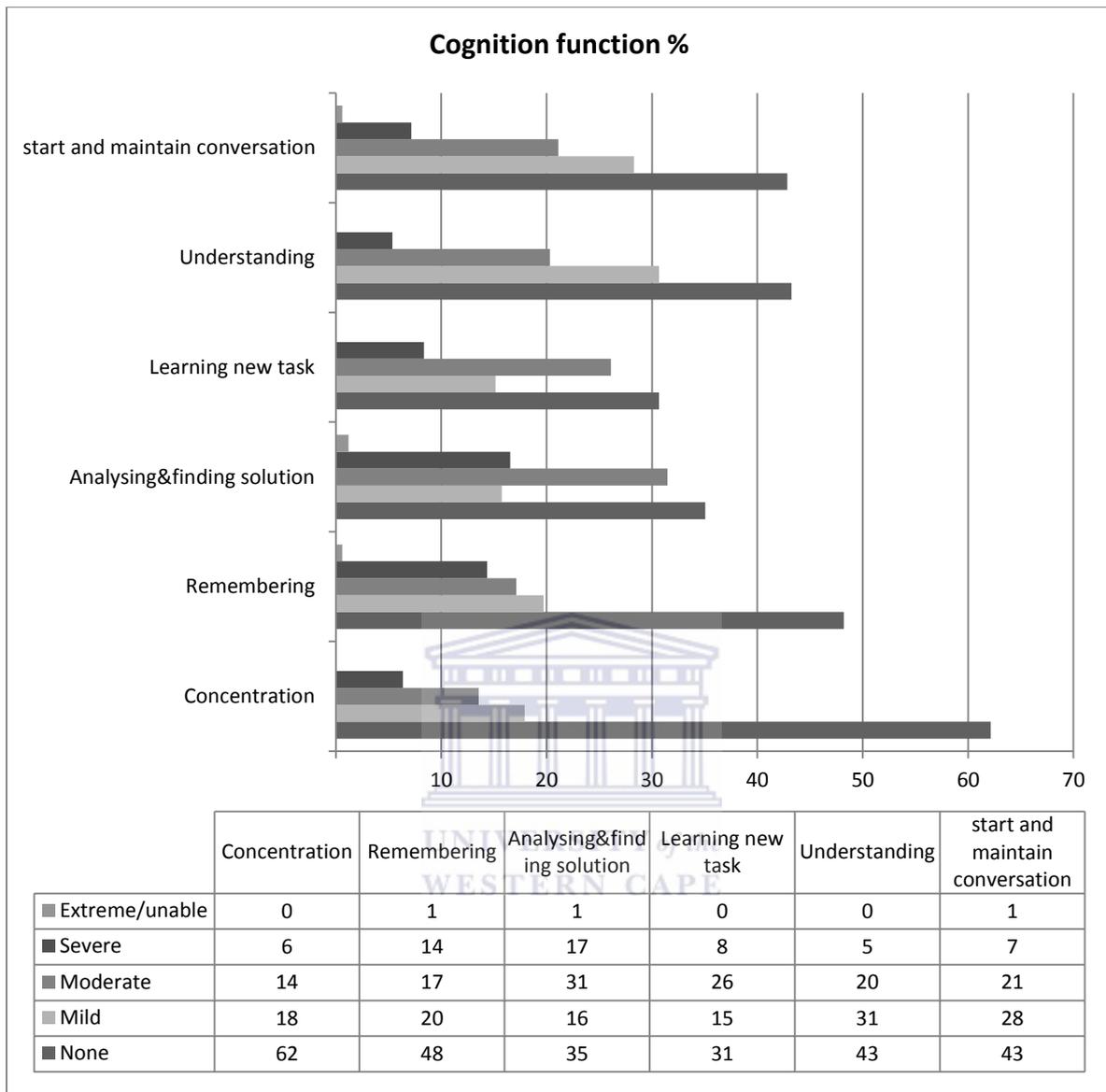


Figure 15: Percentage of participants reporting problems with cognition functions (N=502)

Analysing and finding solutions to problems in day-to-day life was the most affected domain, with 49% reporting moderate, severe or extreme problems. This was followed by problems with learning new tasks (34%). Concentration was the domain that showed least problems, with 20% reporting moderate or severe problems.

Mobility functions

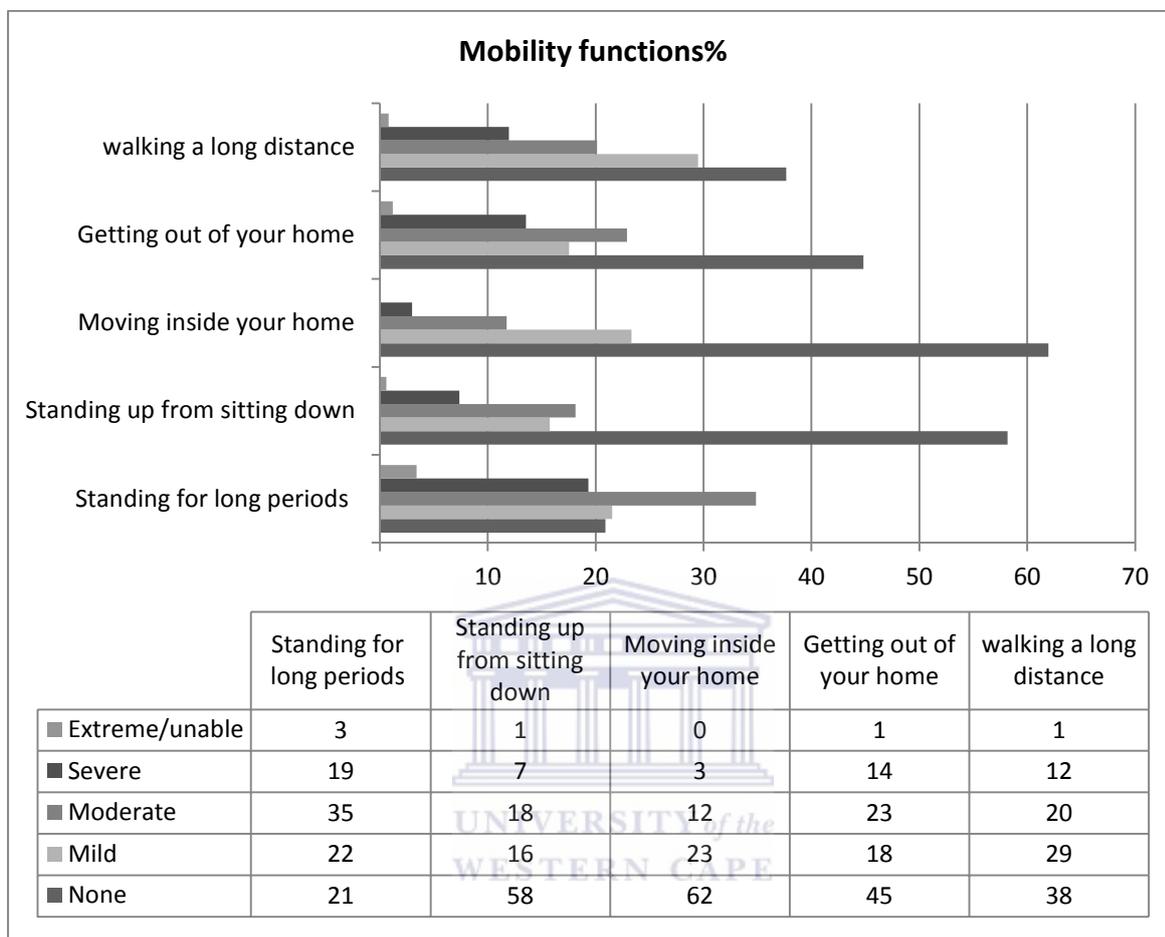


Figure 16: Percentage of participants reporting problems with mobility functions (N=502)

Among the domains of mobility functions, ‘standing for long periods’ was the most affected with 57% of participants reporting moderate, severe or extreme problems. This domain was followed by ‘problems in getting out of home’ (38%). ‘Moving inside your home’ was the domain which participants experienced least problems with: 15% reported moderate or severe problems.

Self-care

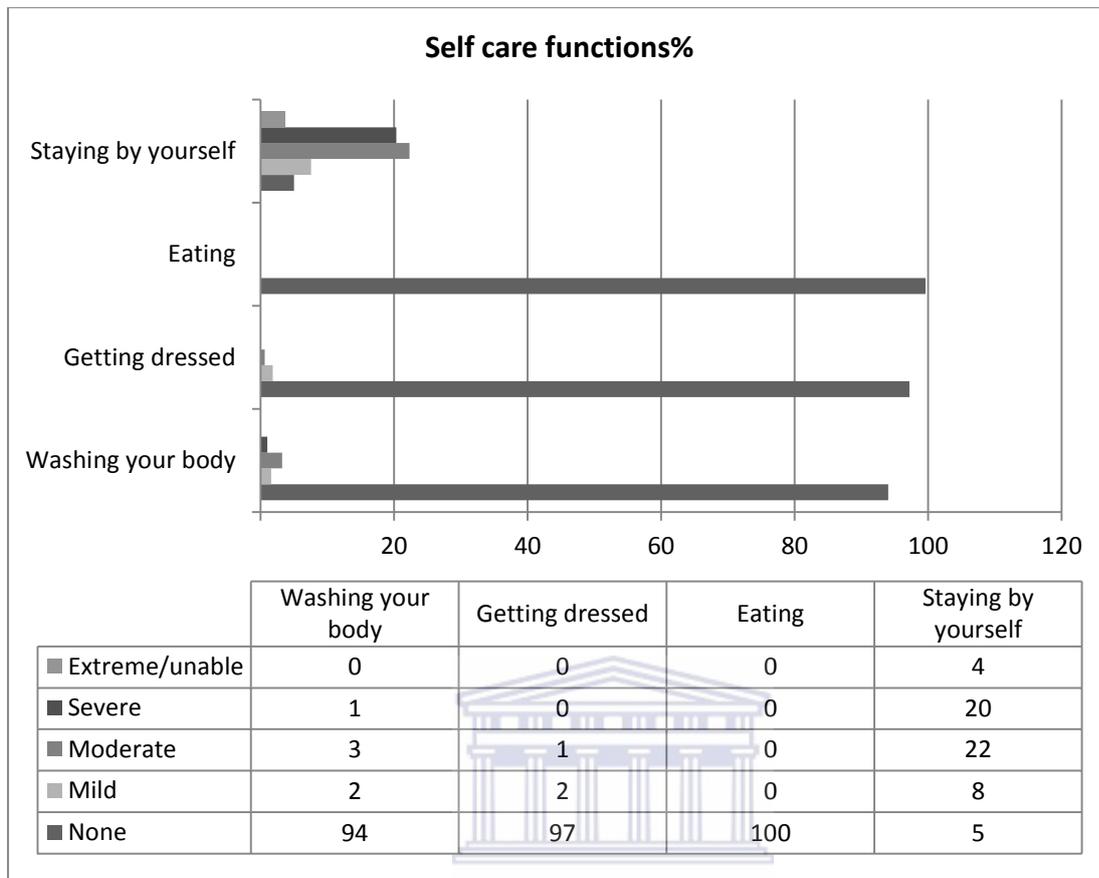


Figure 17: Percentage of participants reporting problems with self-care functions (N=502)

In self-care functions, the domain of ‘staying by yourself for a few days’ was the most affected, with 46% of the participants reporting moderate, severe or extreme problems. It was followed by ‘problems with washing the body’, with 4% reporting moderate or severe problems.

Getting along with people

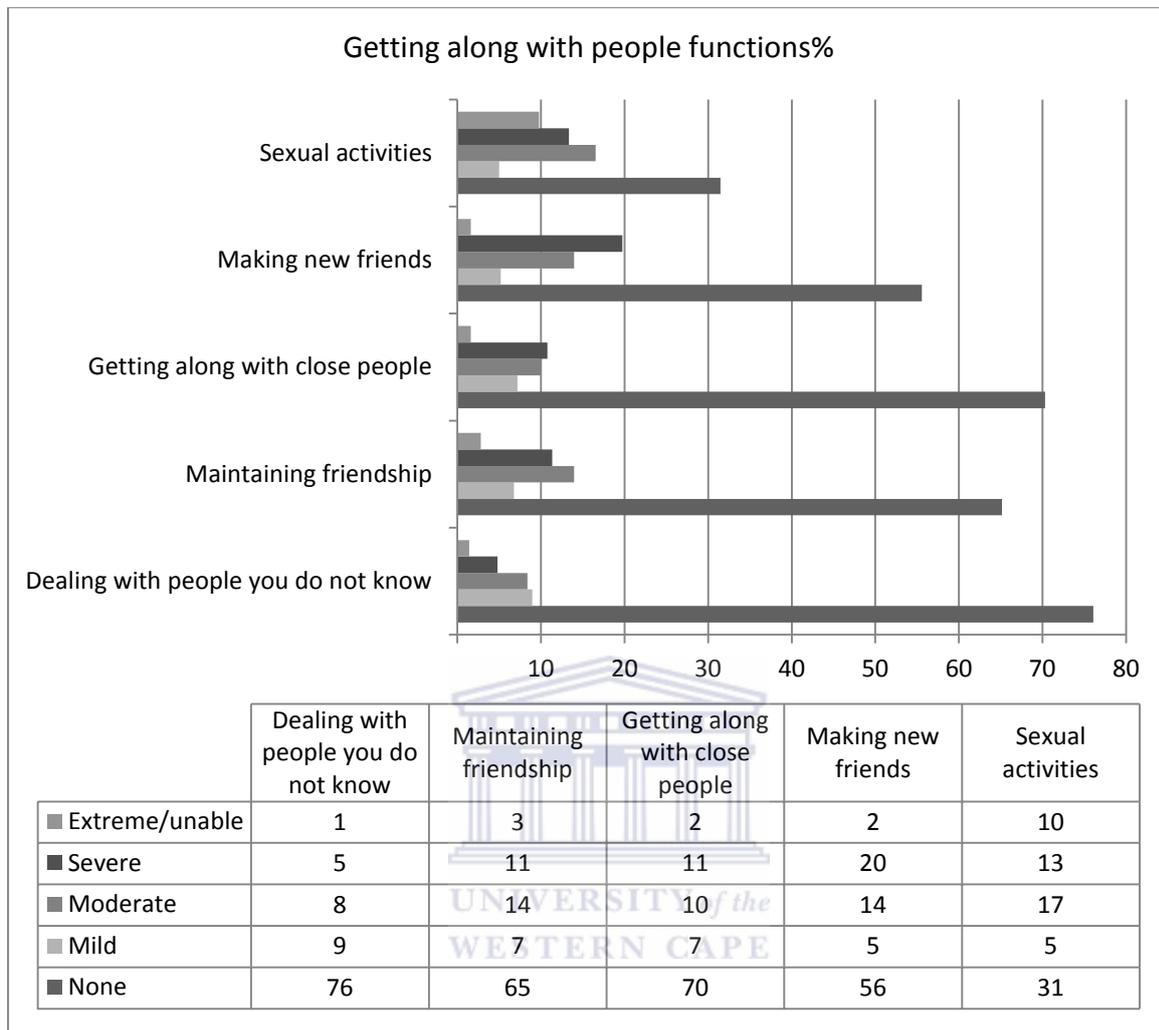


Figure 18: Percentage of participants reporting problems with getting along with people

‘Sexual activities’ were the most affected, with 40% reporting moderate, severe or extreme problems. This domain was followed by ‘problems with making new friends’, with 36% reporting moderate, severe or extreme problems. The domain which showed least problems was ‘dealing with people you do not know’, with 14% reporting moderate, severe or extreme problems.

Life activities

Household activities

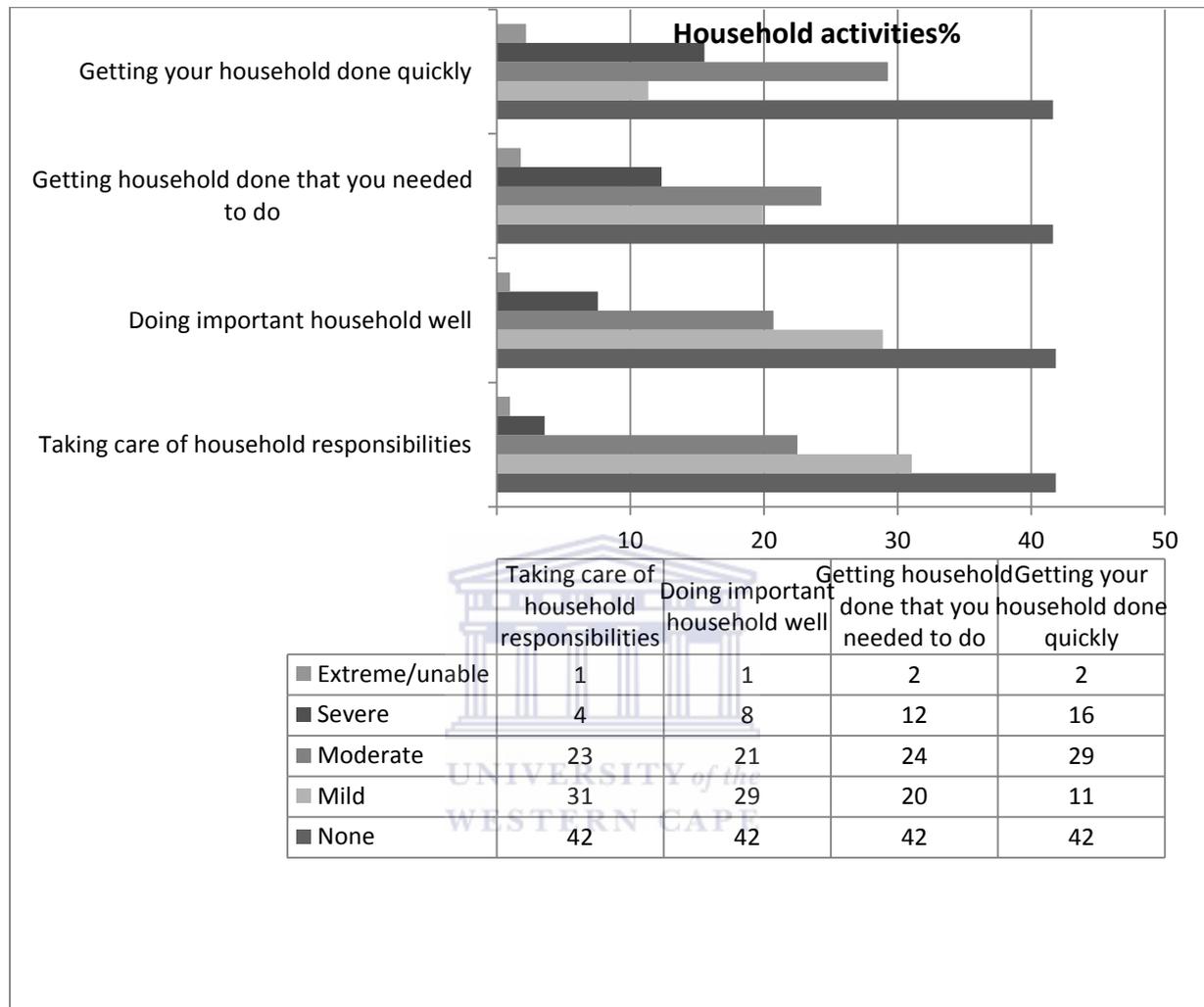


Figure 19: Percentage of participants reporting problems with carrying out household activities (N=502)

Among the activities involved in maintaining the household, ‘getting household activities done quickly as needed’ was the most affected, with 47% reporting moderate, severe or extreme problems. This was followed by ‘getting all needed household activities done’ (38%). The area which gave least problems was ‘taking care of household responsibilities’ with 28% reporting moderate, severe or extreme problems.

Work or school activities

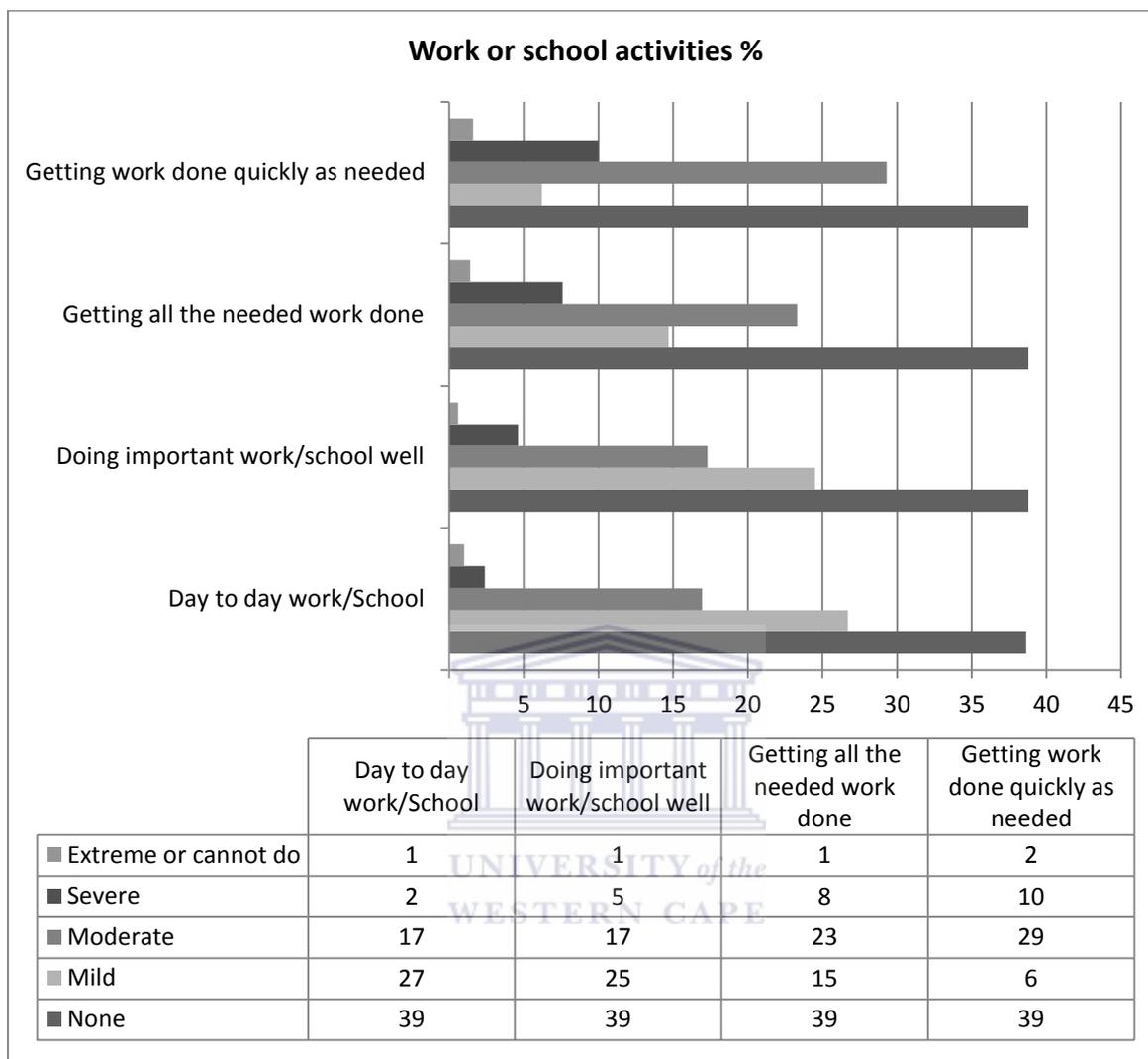


Figure 20: Percentage of participants reporting problems with carrying out work/school activities (N=502)

Under work or school activities, ‘getting work done as quickly as needed’ was the most affected, with 41% of participants reporting moderate, severe or extreme problems; this was followed by ‘problems in getting all the needed work done’, with 32% reporting moderate, severe or extreme problems. In addition, 44% of the participants, compared to 56%, worked at a low level because of their health condition and 45%, compared to 55%, declared that they had earned less money because of their health condition.

Participation

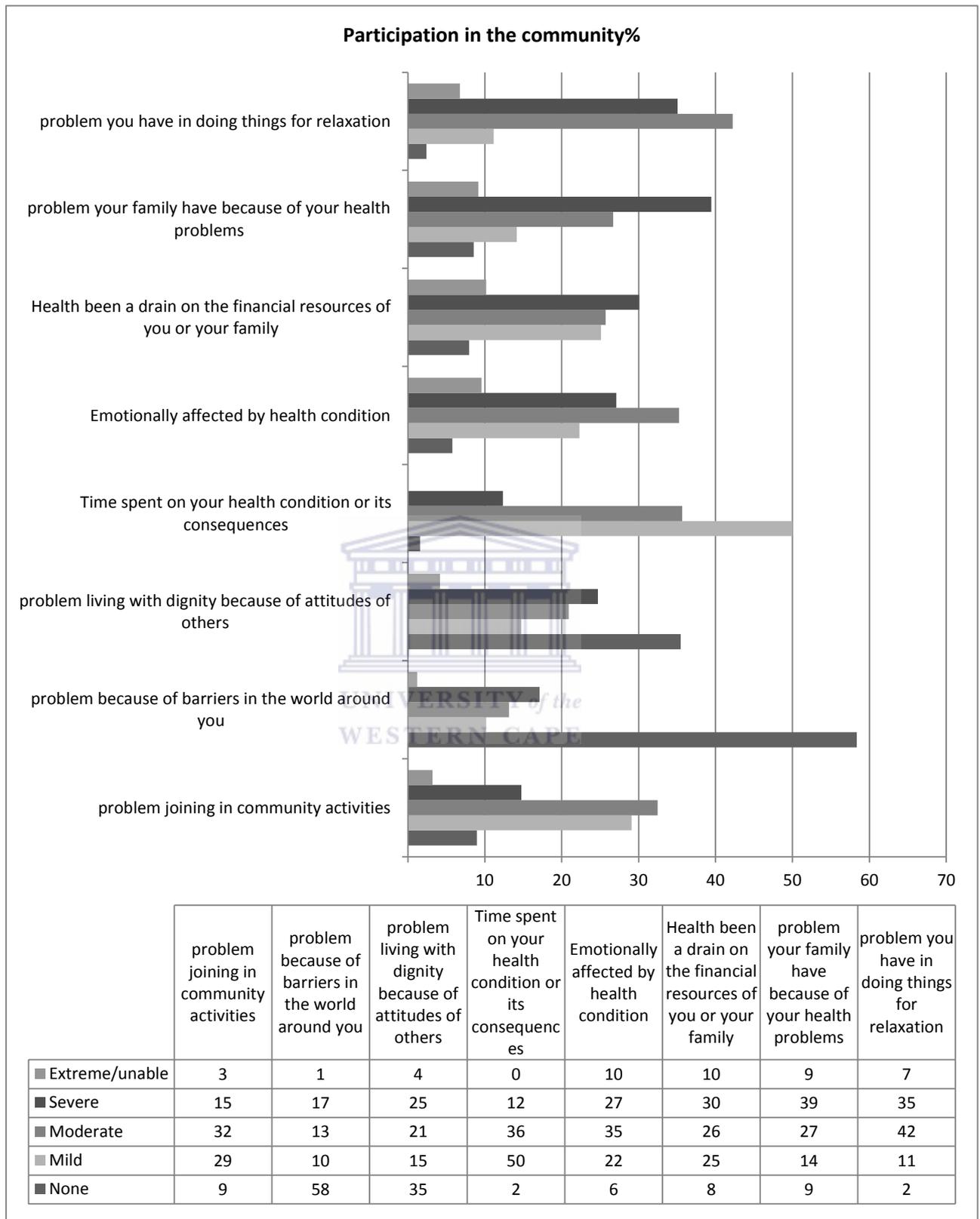


Figure 21: Percentage of participants reporting problems with participation in community (N=502)

Domains under participation/social restriction functions were the most affected, compared to other domains described above. Relaxation functions came first, with 84% of participants reporting moderate, severe or extreme problems. This was followed by ‘problems the family experienced due to the health condition of the patient’ (75%). Problems with emotional functions caused by the health condition’ (72%) and ‘financial problems the family had because of the health condition of the patient’ (66%) were also important. These were followed by ‘problems in living with dignity because of the attitudes and actions of others’ (50%), and ‘problems in joining community activities’ (50%).

3.5.3.4 Days when difficulties/problems were present and household/work activities were reduced or not carried out (N= 502)

Table 14: Days when household/work activities were reduced or not carried out

| Variable | Mean | Standard deviation |
|--|-------|--------------------|
| In the past 30 days, days when household work was reduced or completely missed because of health condition. | 6.82 | 7.212 |
| In the past 30 days, days when work /school activities were reduced for a half a day or more because of your health condition. | 5.48 | 5.993 |
| Overall in the past 30 days, days when all difficulties were present. | 15.92 | 6.934 |
| In the past 30 days, days when usual activities/work could not be carried out because of health condition. | 3.16 | 4.033 |
| In the past 30 days, days when work/usual activities were cut back or reduced because of health condition. | 5.09 | 4.531 |

Table 14 indicates that the participants experienced all the symptoms for approximately half of the days every month. Household /work activities were interfered with for about five days every month; there were three days in which the participants were completely unable to work because of their condition.

3.5.3.5 The most prevalent problems in each grouping of functions in the impairment, activity and participation domains

Table 15: The most prevalent problems in the impairment, activity limitation and participation/social restriction domains

| Function | Domain | % |
|----------------------------|---------------------|----|
| Relaxation | Participation | 84 |
| Fatigue | Impairment function | 83 |
| Problem to the family | Participation | 75 |
| Emotionally affected | Participation | 72 |
| Pain | Impairment Function | 69 |
| Financial impact on family | Participation | 66 |
| Emotional function | Impairment Function | 60 |
| Energy & drive function | Impairment Function | 60 |
| Standing long periods | Activity | 57 |
| Muscle power | Impairment Function | 50 |
| Community activities | Participation | 50 |
| Living with dignity | Participation | 50 |
| Sleep function | Impairment Function | 50 |

3.5.3.6 Table 16 Domains in which more than 50% of the respondents reported moderate to extreme problems/difficulties with particular function comparison of percentage scores across the WHODAS 2.0 domains:

Repeated measures ANOVA indicated that there was a significant difference between domains, with participation being the most affected (Current effect: $F(3, 975)=188.31$, $p<.001$). Table 16 illustrates how participation/social restriction is the most affected domain.

Table 16: Mean scores of the different domains (n=502)

| | Mean | Standard Deviation |
|-----------------------------|------|--------------------|
| Understanding/Communication | 23.1 | 21.3 |
| Life activities | 26.3 | 27.1 |
| Getting around | 25.5 | 20.4 |
| Participation | 46.0 | 17.9 |

A *post-hoc* Tukey test was performed which indicated that there were significant differences between the three domains (Understanding/Communication, Life Activities, Getting around) and Participation, and between Understanding/Communication and Life Activities.

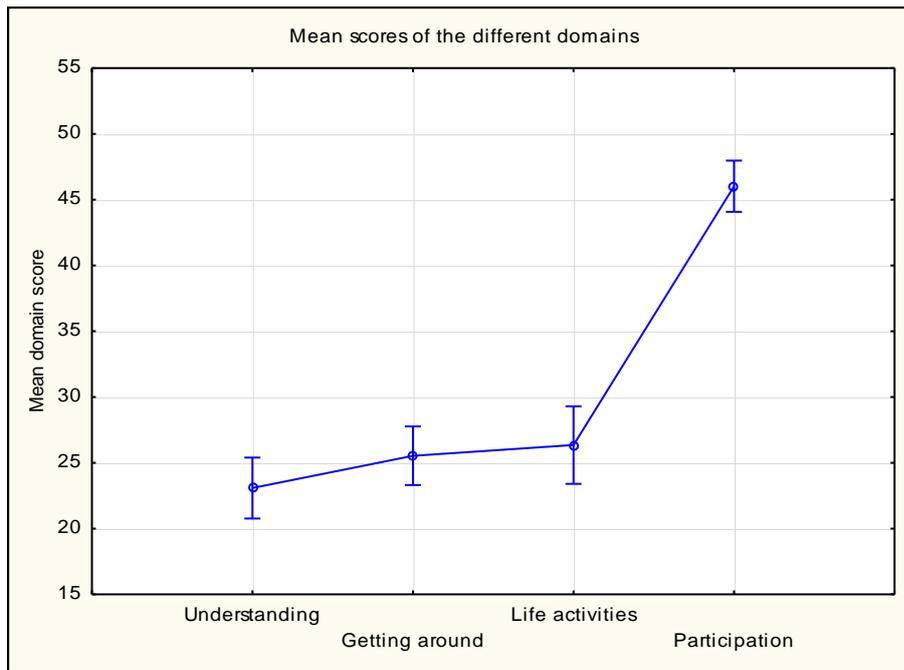


Figure 22: Post-hoc Tukey test for domains

Figure 22 shows the mean scores of each domain with 95% CIs. $F(3, 975)=188.31, p<.001$. Note that 'Self Care' and 'Getting along with people' are excluded.

Table 17 shows the difference between domains.

Table 17: Results of the Post-hoc Tukey test comparing the mean scores of the different domains (n=502)

| | Mean | Getting Around | Life Activities | Participation |
|------------------------------|------|----------------|-----------------|---------------|
| Understanding /Communication | 23.0 | 0.11 | 0.01 | <0.001 |
| Getting around | 25.5 | | 0.88 | <0.001 |
| Life activities | 26.3 | | | <0.001 |
| Participation | 46.0 | | | |

3.5.4 Determinants of scores in the different domains

Multiple regression analysis was used to establish which functions were the most predictive of the scores in each of the WHODAS 2.0 domains that demonstrated internal consistency.

3.5.4.1 Understanding and Communication/cognitive

The results of the forward stepwise regression analysis are shown in Table 18 below. The items that were entered by the programme first and which contributed significantly were subjected to further regression analysis using the enter method. Outliers whose residual scores were more than 2 SDs from the mean were excluded.

Table 18: Results of regression analysis predicting the score of understanding and communication (n=502)

| Understanding /Communication | Step-+in/- out | Multiple- R | Multiple- R-square | R- square- change | F – to- entr/rem | p-value |
|------------------------------------|----------------|-------------|--------------------|-------------------|------------------|---------|
| Memory functions | 1 | 0.60 | 0.36 | 0.36 | 221.56 | <0.001 |
| Energy and drive functions | 2 | 0.64 | 0.41 | 0.06 | 38.79 | <0.001 |
| Sensation related to the skin | 3 | 0.67 | 0.45 | 0.04 | 27.98 | <0.001 |
| Discomfort with sexual intercourse | 4 | 0.69 | 0.47 | 0.02 | 15.29 | <0.001 |
| Digestive functions | 5 | 0.69 | 0.48 | 0.01 | 7.74 | 0.01 |
| Skin functions | 6 | 0.70 | 0.49 | 0.01 | 5.90 | 0.02 |
| Respiratory | 7 | 0.70 | 0.49 | 0.01 | 5.07 | 0.03 |
| Muscle power | 8 | 0.71 | 0.50 | 0.01 | 3.67 | 0.06 |

| | | | | | | |
|--|----|-------|-------|-------|-------|------|
| Emotional functions | 9 | 0.71 | 0.50 | 0.00 | 2.44 | 0.12 |
| Sensations related to digestive system | 10 | 0.71 | 0.51 | 0.00 | 2.70 | 0.10 |
| Sensation of Nausea | 11 | 0.71 | 0.51 | 0.00 | 3.01 | 0.08 |
| Sexual functions | 12 | 0.716 | 0.512 | 0.003 | 2.687 | 0.10 |
| Body image | 13 | 0.717 | 0.514 | 0.001 | 1.004 | 0.32 |

Thirteen subjects were excluded as their standard residual scores were greater than 2*standard deviation. The final set of impairments is listed in Table 19 and accounted for 55% of the variance (Adjusted R²= .55 F(7,384)=69.04).

Table 19: Results of final regression analysis model predicting the score of Understanding and Communication (n=502)

| Understanding and Communication | B | Std.Err. - of b | t(384) | p-value |
|------------------------------------|------|-----------------|--------|---------|
| Intercept | 3.9 | 1.4 | 2.7 | 0.007 |
| Memory functions | 21.1 | 1.8 | 11.9 | <0.001 |
| Energy and drive | 8.6 | 1.7 | 5.2 | <0.001 |
| Discomfort with sexual intercourse | 6.7 | 1.6 | 4.2 | <0.001 |
| Digestive functions | 5.9 | 2.4 | 2.5 | 0.014 |
| Respiratory | 5.6 | 2.0 | 2.7 | 0.006 |
| Skin functions | 4.4 | 1.9 | 2.3 | 0.021 |
| Sensation related to the skin | 4.4 | 1.8 | 2.5 | 0.014 |

The items which caused the greatest increase in the Understanding and Communication domain (in other words, they ‘made it worse’) were problems with Memory, which increased the score by 21%. This was followed by problems in the Energy and Drive function item which added a further 9% to the score.

3.5.4.2 Getting around

The results of the forward stepwise regression analysis for getting around are shown in Table 20.

Table 20: Results of regression analysis model predicting the score of Getting Around (n=502)

| Getting around | Step - +in/-out | Multiple – R | Multiple - R-square | R-square - change | F - to - entr/rem | p-value |
|------------------------|--------------------|-----------------|------------------------|----------------------|----------------------|---------|
| Muscle power | 1 | 0.483 | 0.234 | 0.234 | 148.4 | <0.001 |
| Energy and drive | 2 | 0.601 | 0.361 | 0.127 | 96.9 | <0.001 |
| Memory functions | 3 | 0.658 | 0.434 | 0.073 | 62.2 | <0.001 |
| Mobility | 4 | 0.693 | 0.481 | 0.047 | 43.8 | <0.001 |
| Respiratory | 5 | 0.721 | 0.519 | 0.039 | 39.1 | <0.001 |
| Blood pressure | 6 | 0.744 | 0.553 | 0.034 | 36.3 | <0.001 |
| Digestive functions | 7 | 0.753 | 0.567 | 0.014 | 15.3 | <0.001 |
| Pain | 8 | 0.758 | 0.575 | 0.008 | 8.6 | 0.003 |
| Fat metabolism | 9 | 0.762 | 0.580 | 0.006 | 6.3 | 0.012 |
| Weight | 10 | 0.764 | 0.584 | 0.004 | 4.8 | 0.030 |

| | | | | | | |
|----------------|----|-------|-------|-------|-----|-------|
| maintenance | | | | | | |
| Haematological | 11 | 0.766 | 0.587 | 0.003 | 3.0 | 0.082 |

After the significant variables were entered, residual analysis resulted in the exclusion of 20 subjects. The final items accounted for 63% of the variance (Adjusted R²= .63 F(10,471)=82.070).

Table 21 shows the final set of impairments that significantly predicted Getting Around.

Table 21: Results of final regression analysis model predicting the score of Getting Around (n=502)

| Getting around | B | Std.Err. | t(471) | p-value |
|---------------------|-------|----------|--------|---------|
| Intercept | 5.11 | 1.253 | 4.075 | <0.001 |
| Blood pressure | 11.36 | 2.177 | 5.218 | <0.001 |
| Mobility | 11.25 | 1.448 | 7.773 | <0.001 |
| Memory functions | 9.13 | 1.473 | 6.202 | <0.001 |
| Respiratory | 7.83 | 1.616 | 4.842 | <0.001 |
| Energy and drive | 7.37 | 1.375 | 5.360 | <0.001 |
| Digestive functions | 7.29 | 1.907 | 3.820 | <0.001 |
| Muscle power | 5.12 | 1.432 | 3.574 | <0.001 |
| Weight maintenance | 4.80 | 1.651 | 2.905 | 0.004 |
| Pain | 4.38 | 1.398 | 3.135 | 0.002 |

| | | | | |
|----------------|------|-------|-------|-------|
| Fat metabolism | 4.13 | 1.522 | 2.714 | 0.007 |
|----------------|------|-------|-------|-------|

The items which caused the greatest increase in ‘getting around’ difficulties were problems with blood pressure and mobility, which increased the score, in each case by 11%.

3.5.4.3 Life activities

The results of the forward stepwise regression analysis for life activities are shown in Table 22.

Table 22: Results of regression analysis model predicting the score of life activities (n=502)

| Life activities | Step - +in/- out | Multiple – R | Multiple - R-square | R-square – change | F - to - entr/rem | p-value |
|-----------------------|------------------------|-----------------|------------------------|----------------------|----------------------|---------|
| Muscle power | 1 | 0.463 | 0.215 | 0.215 | 116.9 | <0.001 |
| Memory functions | 2 | 0.569 | 0.324 | 0.109 | 69.1 | <0.001 |
| Energy and drive | 3 | 0.613 | 0.375 | 0.051 | 35.0 | <0.001 |
| Pain | 4 | 0.643 | 0.413 | 0.038 | 27.2 | <0.001 |
| Respiratory | 5 | 0.668 | 0.447 | 0.034 | 26.1 | <0.001 |
| Sensation of nausea | 6 | 0.682 | 0.465 | 0.018 | 14.6 | <0.001 |
| Heart functions | 7 | 0.694 | 0.481 | 0.016 | 12.8 | <0.001 |
| Mobility | 8 | 0.703 | 0.494 | 0.013 | 10.8 | 0.001 |
| Sexual function | 9 | 0.712 | 0.507 | 0.013 | 11.4 | 0.001 |
| Weight maintenance | 10 | 0.718 | 0.515 | 0.008 | 6.9 | 0.009 |

| | | | | | | |
|------------------------------------|----|-------|-------|-------|-----|-------|
| Discomfort with sexual intercourse | 11 | 0.722 | 0.521 | 0.006 | 5.0 | 0.025 |
|------------------------------------|----|-------|-------|-------|-----|-------|

Life activities, after 17 outliers were excluded: the final items accounted for 60% of the variance (Adjusted R²= 0.59644608 F (11,400)=56.223). Table 23 shows the final set of impairments that significantly predicted life activities

Table 23: Results of regression analysis model predicting the score of Life Activities (n=502)

| Life activities | B | Std.Err. - of b | t(400) | p-value |
|---|-------|-----------------|--------|---------|
| Intercept | -1.61 | 1.793 | -0.899 | 0.369 |
| Heart functions | 15.68 | 3.431 | 4.571 | <0.001 |
| Mobility | 10.25 | 2.157 | 4.751 | <0.001 |
| Respiratory | 9.12 | 2.45 | 3.725 | <0.001 |
| Sexual functions | 8.98 | 2.426 | 3.7 | <0.001 |
| Memory functions | 8.24 | 2.155 | 3.825 | <0.001 |
| Muscle power | 8.04 | 2.089 | 3.848 | <0.001 |
| Pain | 7.34 | 2.011 | 3.648 | <0.001 |
| Energy and drive | 6.94 | 1.966 | 3.53 | <0.001 |
| Sensation of Nausea | 6.91 | 2.052 | 3.365 | 0.001 |
| Weight maintenance | 6.67 | 2.369 | 2.817 | 0.005 |
| Discomfort associated with sexual intercourse | 5.78 | 1.886 | 3.067 | 0.002 |

The items in the impairment function which most predicted problems in life activities were heart problems, which increased the score by 16%, followed by the mobility function item, which added a further 10% to the score.

3.5.4.4 Participation

The results of the forward stepwise regression analysis for Participation/Social Restriction are shown in Table 24.

Table 24: Results of regression analysis model predicting the score of Participation (n=502)

| | Step - +in/-out | Multipl e – R | Multiple - R-square | R-square - change | F - to - entr/rem | p-value |
|---------------------------------------|--------------------|------------------|------------------------|----------------------|----------------------|---------|
| Emotional functions | 1 | 0.480 | 0.231 | 0.231 | 127.2 | <0.001 |
| Discomfort with sexual intercourse | 2 | 0.583 | 0.340 | 0.109 | 69.6 | <0.001 |
| Memory functions | 3 | 0.631 | 0.398 | 0.058 | 41.0 | <0.001 |
| Pain | 4 | 0.656 | 0.430 | 0.032 | 23.4 | <0.001 |
| Energy and drive | 5 | 0.675 | 0.456 | 0.026 | 20.4 | <0.001 |
| Muscle power | 6 | 0.683 | 0.467 | 0.010 | 8.2 | 0.004 |
| Fat metabolism | 7 | 0.688 | 0.473 | 0.007 | 5.2 | 0.023 |
| Body image | 8 | 0.691 | 0.478 | 0.005 | 3.9 | 0.049 |
| Haematological functions | 9 | 0.695 | 0.482 | 0.004 | 3.6 | 0.059 |

Following the deletion of the data from 22 outliers, the model accounted for 57% of the variance (Adjusted $R^2 = .56785867$ $F(8,395) = 67.196$ $p < 0.0000$ Std.Error of estimate: 11.019).

Table 25 shows the final set of impairments that significantly predicted Participation/Social Restriction

Table 25: Results of final regression analysis model predicting the score of Participation (n=502)

| | B | Std.Err. | t(395) | p-value |
|------------------------------------|-------|----------|--------|---------|
| Participation | | | | |
| Intercept | 21.96 | 1.373 | 16.00 | <0.001 |
| Emotional functions | 10.24 | 1.294 | 7.91 | <0.001 |
| Discomfort with sexual intercourse | 6.96 | 1.196 | 5.82 | <0.001 |
| Energy and drive | 6.74 | 1.261 | 5.35 | <0.001 |
| Memory functions | 5.82 | 1.311 | 4.44 | <0.001 |
| Pain | 5.19 | 1.354 | 3.83 | <0.001 |
| Muscle power | 4.92 | 1.265 | 3.89 | <0.001 |
| Fat metabolism | 2.23 | 1.590 | 1.40 | 0.161 |
| Body image | 2.15 | 1.235 | 1.74 | 0.083 |

The items in impairment which significantly predicted problems in the participation domain were emotional problems, which increased the score by 10%. This was followed by problems in the sexual discomfort function item, which added a further 7% to the score.

Items contributing to decrease in WHODAS scores across the domains

As can be seen in the Table 26 below, which summarises the results of the regression analysis, problems with energy and drive, memory and digestive functioning were predictive of higher scores (that is, worse functioning) in all domains. Problems with digestive

functions, muscle power, pain, respiratory functions and sexual discomfort predicted higher scores in three of the four domains.

Table 26: Impairment items (X) significantly decreasing the different WHODAS domain functions.

| | Understanding | Getting Around | Life Activities | Participation | Total domains |
|---------------------------------------|---------------|-------------------|--------------------|---------------|------------------|
| Energy and drive | X | X | X | X | 4 |
| Memory functions | X | X | X | X | 4 |
| Digestive functions | X | X | | X | 3 |
| Muscle power | | X | X | X | 3 |
| Pain | | X | X | X | 3 |
| Respiratory functions | X | X | X | | 3 |
| Discomfort with sexual intercourse | X | | X | X | 3 |
| Fat metabolism | | X | | X | 2 |
| Mobility | | X | X | | 2 |
| Skin sensation | X | | | X | 2 |
| Weight maintenance | | X | X | | 2 |
| Blood pressure | | X | | | 1 |
| Body image | | | | X | 1 |
| Emotional functions | | | | X | 1 |
| Heart functions | | | X | | 1 |

| | | | |
|---------------------|---|---|---|
| Sensation of Nausea | | X | 1 |
| Sexual functions | | X | 1 |
| Skin functions | X | | 1 |

3.5.5 Summary of main findings

This chapter presents the results of the description of the profile and prevalence of impairment, activity limitation and participation/social restriction amongst people living with HIV. Males were in general older than females, with an average difference of five years. The most common marital status was ‘married’ for males and ‘widowed’ for females. There were more females unemployed compared to males, and males were found to be more educated than females. The longer the participants had HIV and had been on antiretroviral treatment, the more likely they were to be symptomatic. The longer since the participants had been diagnosed and had been on antiretroviral treatment, the higher the CD4 count. ‘Problems with pain and fatigue’ scored higher than problems found in other domains under impairment. Problems in Participation/social functions were the most commonly reported, compared to the other domains. Various impairments of body function predicted functions in activity limitations and participation/social restriction domains, with energy and drive and memory impairments contributing to an increase in scores across all domains and hence a decrease in function.

4 CHAPTER FOUR: PERCEPTIONS OF PLWH OF THEIR IMPAIRMENTS, FUNCTIONAL ABILITY AND ENVIRONMENTAL FACTORS – METHODOLOGY AND RESULTS

4.1 Introduction

Chapter Four provides the background and the aims and objectives of this sub-study. The methodology is described, and the findings are presented.

4.2 Background

Both physical and psychological functional limitations have been identified in PLWH (Harding, et al., 2012). Physical problems, such as lack of energy, fatigue and pain, are frequently reported (Wig et al., 2008), and it is claimed they contribute to functional limitations in many activities that are part of daily life; this also leads to reduced productivity (Crystal, et al., 2000; Nair, et al., 2009). Paraesthesia, reduced mobility, dizziness, skin hardening, lack of appetite, visual problems and lipodystrophy are also commonly found (Harding, et al., 2012).

Psychological problems related to the emotions appear to be the major functional problem encountered by PLWH (Wig, et al., 2008). Additionally, various studies have demonstrated that HIV stigma is experienced as an intrapersonal problem by PLWH, and can have a negative effect on their health, most importantly on their psychological and emotional functioning (Kalichman, et al., 2009). Stigma could also lead to low self-esteem and anxiety. It can also prevent people from disclosing their HIV status (Pearson, et al., 2009). However, it is possible to find PLWH who have overcome the stress of internalised stigmatization; and who try to accept their situation. They develop self- acceptance and try to cope with their new life; their new image is “being HIV-positive”. They are capable of avoiding the negative thoughts and attitudes which could prevent them from achieving their goal, which is, “living well with HIV” (Nam et al., 2008).

It has been observed that many PLWH have managed to disclose their health status; this is usually because they have developed a positive relationship with HIV. Most of those who deny their status have difficulties with disclosure and end up internalising the stigma

associated with HIV. There is evidence that PLWH are more likely to disclose to only a few people, usually those whom they are close to, for example to best friends or relatives, or those who have similar problems (Chaudoir, Fisher, & Simoni, 2011). However, although some PLWH have demonstrated positive attitudes towards their HIV serostatus and have decided to disclose, there is evidence that they continue to experience stigma and discrimination from their communities (Genberg, et al., 2009), and this could discourage disclosure (Duffy, 2005).

PLWH need quality care that responds to all their functional limitations, which are related to the infection or to the antiretroviral treatment; they should strive to improve their health status so as to live a better life with the disease. It has been indicated that most of the health care services for PLWH focus on medical and physical care and are orientated towards biomedical treatment; other domains such as psychological, social, community, spiritual and individual growth tend to be neglected. Health care planners ignore the complexity of HIV, which requires a more holistic approach (Taneja, et al., 2012).

It is important to explore the experiences of PLWH, in particular their functional limitations and the influence of the intrapersonal factors such internalised stigma, and of external factors such as family or community discrimination or the hospital environment. It is important to document the burden of this multifaceted and chronic health condition, and to monitor the effect of the antiretroviral treatment. This will enable one to evaluate antiretroviral treatment, in particular its effect on quality of care for PLWH. This will assist one to measure the return on health-care investments and the contribution and role of health-care providers as well as of the community. In addition, examining the perceptions of PLWH will help to determine what is required in terms of comprehensive care to address their many challenging needs.

4.3 Aims and Objectives

4.3.1 Aim

The aim in this part of the study was, among PLWH on antiretroviral treatment with associated disabilities, to explore the relationship between the impairments, functional limitations, participation restrictions and personal and environmental factors.

4.3.2 Objectives

- To describe the PLWH with associated disabilities' perceptions of the relationship between disease, medication and functional limitations and participation restrictions;
- To explore the effect of personal factors such as emotional and spiritual factors on their functional limitations and participation restrictions;
- To explore the effect of the medical environmental factors on their functional limitations and participation restrictions:
 - To describe the reported satisfaction with the hospital services;
 - To describe how the hospital services assist them with their functional limitations and participation restrictions.
- To explore the effect of the community environmental factors on their functional limitations and participation restrictions:
 - To describe if the community provides the support they need;
 - To describe the challenges they encounter in daily life in the community environment.

4.4 Methodology

In the following section the research design that was chosen to achieve the objectives of this study is described. The research settings, the study population, the sample size and the sampling techniques used are all described. The screening tool that was used to select participants for the discussion and the interview guide used for the discussion are described. The data collection method and procedure, the data analysis, the strategies to ensure rigour of research and ethical considerations are all discussed.

4.4.1 Research design

An exploratory study using focus group discussions (FGDs) based on the approaches of Boeije (2010) and Merriam (2009), was conducted utilising qualitative research methodology. It was considered an appropriate method for understanding and interpreting the experiences of PLWH (Babbie and Mouton, 2001; Denzin and Lincoln, 2000). As Morse (2012) has described, qualitative methodology can be used to explore health and illness and is useful for eliciting emotions and perspectives, beliefs and values, and actions and behaviours for the purpose of understanding the participants' responses to health and illness, and the

meanings they construct about their experience, and their subsequent actions. This methodology was also used to understand the influence of environmental factors on the functional limitations (Hennink, Hutter, and Bailey, 2010).

Furthermore, the qualitative methodology was used to explore and understand some of the findings in the survey (Chapter Three), for example; majority of the participants in the survey scored very highly in the “problems with participation/social restrictions” domain compared to other domains. Moreover, statistical tests revealed the likelihood of certain impairments, such as emotional problems and difficulties with sexual intercourse. From the survey alone, it was difficult to understand the reason for this high frequency or the relationships between these problems or to determine possible influences on the problem.

Additionally, by using the qualitative method the participants could also explore their experiences with regard to the health services and make suggestions for improvement.

4.4.2 Research setting

The study, using two FGDs, was carried out in two hospitals, one in each of two provinces in Rwanda.

4.4.3 Study population, sampling technique and sample size

Sampling was carried out to identify a diverse group of participants who would bring different experiences, perceptions and understandings to the group.

4.4.3.1 Selection of provinces and hospitals

One urban and one rural setting was selected to increase diversity. Kigali, the capital city of Rwanda, which forms an independent province was purposively selected as the urban setting as it reflects an urban setting most strongly. Simple random sampling was used to select one of the four other provinces that were involved in the survey (see Chapter Three), the Southern Province. Two hospitals that were involved in the survey were then purposively selected, one in each province. One hospital was in an urban area, Hospital A in the province of Kigali; the other hospital, Hospital B, was a hospital in the rural area of the Southern Province. The two hospitals are both public government hospitals; however, Hospital B is a partially church-run hospital. Both hospitals are district hospitals.

4.4.3.2 Study population, sampling technique and sample size

Participants were adult female and male PLWHs with associated disabilities and attending the ARV clinics at the selected hospitals.

As the results of the FGDs were to be used to validate the use of the WHODAS 2.0 and the Impairments Questionnaire, participants of the survey were not eligible to take part as they would have been “primed” by the items in the questionnaires. This would have introduced an *a priori* bias in to their discussion. Therefore a different sample was identified.

4.4.3.3 Sampling technique and sample size

At each hospital, the nurse responsible for the ARV clinic explained the purpose of the researcher’s visit and the activity to be carried out to all patients attending the clinic. The researcher then explained the purpose of the study to the patients.

All patients on antiretroviral treatment were invited to participate in screening for functional limitations. The patients who agreed to participate were screened using a screening checklist (See Section 4.4.4).

Purposive sampling was used to select the participants for FGDs from those who were screened. A diverse group of patients were selected with differences in relation to the gender, age, functional limitations and severity of disability. These patients were then invited to participate in the FGDs. The final groups at each hospital included eight participants, three male and five female.

4.4.4 Screening checklist and interview guide

4.4.4.1 Screening checklist

The screening checklist (Appendix V) (developed by the researcher) was adapted from the Washington Group on Disability Statistics: Short Set Questions on Disability (CDC, 2010; Madans, Loeb, & Altman, 2011). The Washington Group developed a short question set on disability in a form of checklist to be used in a national census to gather information about functional limitations in a population in short time. The rationale for this checklist was to identify, in a given population, people with similar types and levels of limitation with regard

to performing basic activities. The questions were designed to apply across nations, cultures and even across different economic statuses (CDC, 2010).

However, in order to make the process more holistic, the screening checklist was adapted to include some questions based on the functional limitations identified among PLWH in the survey presented in Chapter Three. The screening checklist differed from the long questionnaire we used for the survey: it was structured differently, and was designed to gather key information on functional limitations in a short time.

4.4.4.2 Interview guide

An interview guide (Appendix VI), developed by the researcher, was used for the two FGDs. It was based on the outcomes of and issues emerging during the survey (see Chapter Three). It contained open-ended and probing questions based on the approach of Patton (2002) to allow participants' experiences to emerge. Probes were used to deepen the discussion.

To understand participants' perceptions of the relationship between the disease, the medication and the functional limitations, the personal and the community factors:

1. Are there things that you could do in the past and are no longer able to do since you became ill?
2. How did taking medication change any of the things mentioned above?

To understand participants' experiences of the medical environmental factors:

3. Can you describe your experiences with how the hospital health care providers tried to assist you with the problems you have described above?
4. Can you give your opinions or views on what can be done to improve the hospital services so as to assist you with your problems and to improve your quality of life?

4.4.4.3 Translation of the screening checklist and the interview guide

All translators were fluent in English, while Kinyarwanda was their native language. Forward and backward translation was done of both the screening checklist and the interview guide. The rationale of this was to make sure that the questions asked were well understood in the language that would be used by the participants during the screening and FGDs. Additionally, the translation was intended to ensure that during discussion the interviewer would be

spontaneous and conversant with the questions posed in the language used by participants; when hearing their responses, he would remain focused and allow the discussion to flow naturally. Hennink et al. (2010, p. 148) indicated that “it is recommended that the discussion guide be translated into the language in which the discussion will be conducted. Using a translated discussion guide takes a lot of pressure off the moderator, who would otherwise need to translate each question as it arises during the group discussion”.

The forward translation was done by two people. The first person was a physiotherapy lecturer who had participated in the consensus meetings for the translation of WHODAS 2.0 (see Chapter Six). He had also participated in the screening and played the role of moderator in both FGDs. Additionally, he was consulted during the transcription and translation of the FGDs’ results from Kinyarwanda into English. The second forward translator was a Kinyarwanda teacher in a secondary school and an expert in linguistics. He also participated in the forward translation of WHODAS 2.0 (see Chapter Six) and in the consensus meetings (see Chapter Six) and he was the principal translator of the FGDs’ findings into English.

The backward translation was done by a qualified physiotherapist, who was also recruited as a research assistant for the screening of the participants for the FGDs; he also assisted in taking notes during FGDs and with the transcription and translation of the findings. Another linguistic expert, a lecturer at Kigali Health Institute, assisted with proofreading, both of the screening checklist and the interview guide. Hennink et al. (2010, p. 148) said; “it is extremely important to check the quality of the translated discussion guide and back translation is a common strategy for checking translations, whereby translated text is translated back into the original language and checked for accuracy”.

4.4.5 Data collection

4.4.5.1 Data collection method

Two FGDs were used to gather in-depth information from the participants. Eight participants were included in each group (Hennink, et al., 2010).

This method of data collection was chosen to allow all participants the opportunity to share, listen and understand one another’s opinions and to develop and generate ideas beyond their own original voices as the conversation progressed (Babour & Kitzinger, 2001; Patton,

2002). It was considered the best method for exploring the participants' experiences, opinions, needs and concerns. It gave the researcher the opportunity to discover how participants complemented each other, reached a consensus or opposed each other's ideas (Babour & Kitzinger, 2001). This allowed a dynamism to develop that gave participants the opportunity to interact and build on each other's ideas and opinions, enriching the information that emerged and enhancing the quality of the data (Denzin & Lincoln, 2005; Patton, 2002).

The method was chosen to enable people who might be intimidated by one-to-one/face to face interviews to participate in research by offering collective ways of communication (Patton, 2002). The participants who were from the same cultural background were encouraged to share their ideas, beliefs and attitudes towards HIV and functional limitations. The FGDs were also able to provide safety and build the confidence of people who seemed to be vulnerable when alone. The group gave them the opportunity to come together, with warm feelings creating bonding and the ability to share their own experiences with regard to particular functional limitations.

The FGDs were done at the hospitals in a social context where the participants could consider their own views in relation to the views of others and through this process generating high quality data (Patton, 2002). In a little over one hour, the researcher was able to gather very rich information from eight people instead of from only one (Patton, 2002).

4.4.5.2 Data collection procedure

Step1: Obtaining permission

In December 2011, prior to data collection, letters were sent to hospital managers to ask permission to collect data. Letters granting ethical clearance and letters from the same hospitals granting permission for the survey were attached. A letter to support the study was requested from the Ministry of Health/ Rwanda Biomedical Centre HIV division (RBC/HIV division) (see the ethical consideration, section 4.4.8). Permission was granted in February 2012.

This was followed by visits to the two hospitals; one day was assigned to each hospital to prepare for fieldwork and ensure that hospital managers and health care providers in the ARV clinics understood and supported the study.

Step 2: Identifying participants: Inviting PLWH to clinic

Visits were made to the two hospitals to prepare for data collection. The nurse responsible for the clinic assisted in choosing the day for data collection, based on the availability of the patients.

Step 3: Training the moderator and note taker

The site visits were followed by training over two days at the KHI to select the moderator and the note taker for the FGDs and to assist with screening. They were already familiar with the purpose of the study and the screening checklist as they had participated in its translation.

Step 4: Identifying participants for screening

Data collection took one day at each hospital. At both sites the FGD took place in the morning as this time was preferred by patients so they could go home early and continue with daily activities.

At each hospital the nurse responsible for the clinic had prepared three rooms for the screening, one for each interviewer, and a very comfortable room was prepared for the FGD. This nurse gave a general and brief introduction to all the patients at the clinic about the reason for our visit, and then the researcher explained the purpose of the study using the participant information sheet (Appendix VII). She ensured that the participants understood that there were two stages. It was explained that only those patients who had been on antiretroviral treatment from 2009 or earlier were eligible to participate. The researcher explained that participants were allowed to withdraw from the study at any time should they feel uncomfortable. They were further assured that their participation in the study would remain confidential.

Data collection started at Hospital A. A large number of patients attended the clinic that day for routine consultation and to receive antiretroviral treatment. Although the research team

arrived at the clinic opening time at 07h00, patients started arriving at 08h30. They were invited by the nurse to voluntarily join the screening after they had received their antiretroviral treatment. The patients signed the consent forms (Appendix VIII) prior to screening. At Hospital B the procedure was similar, the only difference being there were many patients at this clinic who wanted to take part in the screening.

Step 5: Screening to identify participants for FGD

A screening session took at least 7 to 10 minutes. In total, 40 patients were screened at Hospital A and 50 at Hospital B, where many more had volunteered. However for consistency, at each hospital up to 20 patients were selected to be invited for FGDs; most had functional limitations categorised as severe to extreme; following the screening checklist rating scale (Appendix V). After screening, if a patient was considered suitable for the FGD, he/she was requested to wait.

At Hospital A, the urban hospital, some people were reluctant to participate in the screening and in the FGD, despite the explanations by the nurse and the researcher. They spent time discussing this with one another, in the process affecting the time available for the screening and for the FGD. In addition, at first they did not want their voices to be recorded until they were sure about confidentiality. Things were different at Hospital B, the rural hospital, where the majority of people who were invited for the screening were enthusiastic, and even those who were not suitable to participate in the FGD asked if they could. Of the twenty people found suitable for the FGD, 15 were willing to participate. This was a challenge for the research team as only eight people could participate and the researcher had to explain this to them. After the screening, the 20 patients eligible for the FGD were gathered in one room and invited by the researcher and the moderator to participate in the FGD.

In both hospitals, more women than men volunteered to participate in the FGD. As a consequence at each hospital there were five women and three men in the final sample for each FGD.

Step 6: FGD

Before starting, the purpose of the research was again explained by the researcher in Kinyarwanda to the participants, by referring to the participant information sheet (Appendix IX). All participants were asked to sign a consent form agreeing to their participation in the FGD and allowing the use of the tape recorder in order to obtain accurate data (Appendix X). The researcher explained why each of the participants had been included and they were asked to feel free and relaxed during the discussion.

The moderator facilitated the discussion in Kinyarwanda. He started by introducing the research team, explaining the discussion procedure, and giving assurances that ethical issues would be considered throughout the process of data collection. He then welcomed all the participants and asked them to introduce themselves. Participants were thanked for accepting the invitation to participate in the discussion. The moderator opened the discussion with jokes and humorous stories to create a relaxed atmosphere. A bottle of soda was provided to each participant as in Rwandese culture, when you invite people for a discussion or gathering, it is customary that you share a drink. Participants could then freely share their experiences of living with HIV and of how the hospital assisted them to deal with their new lives.

Notes were taken by a trained research assistant. The researcher's role was to monitor the tape recording, to take notes using a pen and a notebook and to oversee what happened during the FGD. In the middle of the discussion, people who tended to be shy were encouraged by the moderator to contribute to the discussion. This was important, as certain participants were not very open about sharing their opinions, particularly at Hospital A.

Before closing the discussion, the moderator, note taker and the researcher reviewed and summarized the main points from the discussion and reviewed the notes taken. Each said something or read a summary of what he/she had written about the subjects under discussion. Participants were then asked if they agreed with this record of the discussion, and any corrections or addition information were considered. It was necessary to check if all the questions in the study had been covered and if the issues raised during discussion had been adequately dealt with. It was important to ensure the accuracy of the data before leaving the field, as this would to improve the reliability of the findings.

At the end of the review, the participants were thanked and were offered a transport ticket as a token of appreciation for their patience, as they would be leaving the hospital later than usual. This would enable them to travel by motorcycle which is faster (but more expensive) than a taxi bus and they would avoid arriving home too late. Participants at both sites, for their part, expressed their appreciation at being consulted and at being able to contribute to the improvement of their health care. The discussion lasted for one hour and forty minutes at Hospital A, while at Hospital B it took one hour and twenty five minutes. One of the reasons for this difference might be that one of the participants at Hospital A became emotional, and this caused a break and a moment of silence during the discussion.

4.4.6 Data analysis

4.4.6.1 Step 1: Transcription

Two days after data collection, verbatim transcription of the interviews commenced. This was done by the researcher, the research assistant, the moderator and the translator, who was an independent person who did not participate in FGDs. The moderator's role was to read all the notes from the two sources; the researcher's responsibility was to monitor the recording; the research assistant played the role of rapporteur. The translator was invited as an observer. The involvement in transcription of all the people who participated in the FGDs was interesting and made the task much easier. They distributed the various roles among themselves and together they made sure what was discussed was accurately transcribed. It was also important to invite the translator so that he became familiar with the format of the conversation before translation. For example; he was supposed to know that it was important to take into account body language and emotional expression.

The transcript included everything the participants said, taken directly from the tape recorder. Later handwritten notes that were made by the researcher and research assistant were integrated into this transcript text. These notes included observations about body language and emotional expression. The transcripts for the two hospitals were done separately.

4.4.6.2 Step 2: Translation from Kinyarwanda into English

After transcription, the transcripts were given to the translator to produce English versions. The researcher decided to choose a translator who was familiar with the rationale of the

study. He had participated in the translation of the WHODAS 2.0, the instrument used in the previous study, and in the translation of the screening checklist and the FGD interview guide.

Thereafter, the whole team met for four days of consensus meetings at KHI to critically review both transcripts, comparing the translated English transcripts with the Kinyarwanda originals. There was an attempt to assess the integrity of the semantic and conceptual meanings. The team also considered whether the results met the objectives of the study and were accurate representations of issues and questions raised during the discussion.

In discussing the translation into English, it was found that certain concepts or phrases, particularly medical terms, had lost their original meaning. Some words had been translated literally when this should not have happened. For example, participants used the word *abasirikari* in Kinyarwanda to mean ‘CD4’ when the literal meaning of *abasirikari* in English is ‘military’. The translator found the word did not fit in the sentence where it was used and decided to leave it for decision by the consensus meeting. Other words or phrases had been left out because the translator had found them problematic. All these problematic words were identified during this consensus meeting and appropriate translations were finally found. After this meeting the English version of the two transcripts was considered to be ready for further analysis. The experience gained during the process of translating WHO DAS 2.0 (see Chapter six) was extremely useful in the translation of FGD’s transcripts and in the organisation of the consensus meeting. It was also helpful because the moderator and the translator had both participated in the translation of WHODAS 2.0 (Chapter Six).

4.4.6.3 Step 3: Coding, categorising and creating themes

Content analysis was used to analyse the data. The use of the interview guide helped to structure the data gathering so data analysis was facilitated in such a way that participants’ responses were organised and relatively easily to identify, as they followed the questions formulated in the interview guide (Patton, 2002). Content analysis was used as results in categories which would describe the phenomenon under study (Elo & Kyngäs, 2008).

Merriam (2009, p. 205) indicated that

“in one sense, all qualitative data analysis is content analysis in that it is the content of interviews, field notes, and documents that is analysed. The process of content analysis

involves the simultaneous coding of raw data and the construction of categories that capture relevant characteristics of the document's content".

The two transcripts, one from each FGD, were combined into one document, but the identities of each FGD were retained as A or B. The researcher read and reread the original transcripts to make sure she understood and was able to interpret the participants' views. This was done using the method described by Boeije (2010), who says that repeated reading allows the researcher to enter into the participant's world and engage with the data.

The first step in the analysis was coding. The lines in the transcriptions were numbered. The researcher then wrote informative, exploratory and explanatory notes in the margins next to corresponding words or phrases to describe what the participant was saying. These notes were used to select codes (Creswell, 2009, 2013; Merriam, 2009). A table was then constructed to organise the codes and the corresponding data.

Column 1 comprised data organised by grouped words, concepts or phrases cut from the transcript; the grouping was based on similarity in meaning. Column 2 consisted of codes. Each code was put next to the matching grouped words or concepts or phrases.

There was a lot of line cutting and copying and pasting in the process of organising the data into sections identified by a code. Identification of the right code was considered essential, so before cutting and pasting sections of the text, transcripts were read critically several times to ensure the word or the phrase was assigned to the correct code. As the researcher reviewed the transcripts some new codes were created or possibly renamed.

Some codes were merged and this process continued and contributed to the identification of subcategories and then categories. From categories, themes were identified and appropriate words were found to name the themes (Creswell, 2009, 2013; Merriam, 2009). The identification of codes, categories and themes was initially done by the researcher, assisted by her supervisor. Subsequently the moderator and the research assistant were consulted for their input and to check that no idea had been left out or allocated incorrectly (put into the incorrect theme). For example, they suggested some of the participants "opinions" needed to be shifted from the theme "How the hospital services help me to cope with my problems as a PLWH" to "How the hospital services can improve, to respond to my needs as a PLWH".

Table 27: Example of coding and creating themes

| Data organised in grouped words/concepts | Code | Subcategory | Category | Theme |
|---|--------------------------|-----------------------|-----------------------------------|------------------|
| <p>L22 1A: I don't have the energy I had before!</p> <p>L25 3A: Ha!!! Afternoon I am already tired! Energy is longer there!!!</p> <p>L603 1B: In general, I feel getting weaker and weaker. This proves me that there is something wrong in the body, Hum! I just feel my body is longer the same!!</p> | Lack of energy/tiredness | Physical problem | Present from the onset of HIV | My body problems |
| <p>L700 6B: Heeee! I can tell; you the medicines have caused much memory loss! I now forget like an old person!</p> <p>L702 7B: I also have a big problem of memory loss.</p> | Loss of memory | Psychological problem | Occurred when started medications | My body problems |

| Data organised in grouped words/concepts | Code | Subcategory | Category | Theme |
|--|-------------------|-------------------------|--|-------------------------|
| <p>L707 6B: There is also non-proportional increased body weight. You notice that one body part swells excessively while another is very thin. Hum!! This makes us wear trousers or long clothes in order to hide very small legs with visible tendons and blood vessels. They sometimes change our medicines, but not much improvement.</p> <p>L 292 3B: (Speaking with sorrow) when I started medicines (Triviro), After sometimes, my legs, arms and buttocks got thinner, the face and the belly swelled. In short, the whole body was deformed.</p> | <p>Body image</p> | <p>Physical problem</p> | <p>Occurred when started medications</p> | <p>My body problems</p> |



4.4.7 Rigour

To ensure rigour of the study, the following strategies were followed:

4.4.7.1 Transferability

Merriam (2009) suggested that one of the strategies to enhance the transferability of qualitative results could include maximum variation in the characteristics of the sample; this could be applied when selecting the sites for data collection or the participants. As is described in the sampling section and in data collection procedure, in the present study, hospitals were selected from those chosen during the survey; one hospital was selected from an urban area and another from a rural area. Participants were men and women who varied in age, marital status, education and economic status and in length of time since starting on antiretroviral medication; however all had started on antiretroviral medication from 2009 or earlier. This was to ensure to allow consistency with the previous study (the survey). The use of purposive/judgement sampling was reported in Merriam (2009) and also in Babbie and Mouton (2001) as a way of enhancing transferability. Purposive sampling was used to select hospitals and participants eligible for FGDs from different demographic and socio-economic background.

4.4.7.2 Credibility

Babbie and Mouton (2001) and Merriam (2009) stated that credibility of the findings in a qualitative study is crucial, and that one of the most important strategies to enhance credibility is triangulation. This could be achieved through the use of various investigators for data collection and analysis, or through the use of multiple sources, methods and materials for data collection.

As it is stipulated in the sections on tools translation and the procedure for data collection, the researcher decided to involve the moderator, the research assistant and the translator (from the planning of data collection) to assist in preparation and with the translation, as they were familiar with the whole process of data collection and analysis, and they understood the objectives of the study; both the moderator and the translator had been involved in the elaboration of the instrument used in the survey and the research assistant had assisted in obtaining the necessary permission.

Thereafter, the moderator and the research assistant participated in the screening and in the FGDs and all three together participated in the data transcription and translation process. This consisted of consensus meetings to produce the final English transcript. The three experts were also consulted during other steps in the process, such as in the analysis and presenting and writing up of the findings. Additionally, all FGD discussions and observations were documented by the researcher and the research assistant; this included documenting participants' opinions, emotions, behaviour/attitudes etc. Discussions were also audio-recorded. All of these could influence the quality of the data obtained.

Furthermore, Thomas and Magilvy (2011), Babbie and Mouton (2001) and Merriam (2009) recommended member checks as another important strategy for ensuring the credibility of the findings obtained. Merriam (2009, p. 217) named this "respondent validation". According to Babbie and Mouton (2001, p. 277), "the aim of member checks is to assess the intentionality of respondents, to correct for obvious errors, and to provide additional volunteer information. It also creates an opportunity to summarize what the first step of the data analysis should be and to assess the overall adequacy of the data, in addition to individual data points".

For this current study, notes from both sources (the researcher and the research assistant) were compared for each site; before ending the session, data was repeatedly checked, and thereafter a summary was presented by the moderator to participants at the end of the FGD session. The participants' comments were solicited and considered to ensure that interpretation was valid and that nothing was left out.

In order to improve the credibility of the findings in this study, the researcher has written a section on reflexivity, which describes her position during the whole process of data collection and how she sometimes looked at things from her own perspective rather than from the participants' perspective. This was done as suggested by Thomas and Magilvy (2011) and also Merriam (2009, p. 219). Merriam commented as follows: "related to the integrity of the qualitative researcher; is another strategy to enhance credibility sometimes labelled researcher's position or reflexivity. The investigator needs to explain his or her biases, dispositions, and assumptions regarding the research to be undertaken. Such a clarification allows the reader to better understand how the individual researcher might have arrived at the particular interpretation of the data".

4.4.7.3 Dependability

Babbie and Mouton (2001) indicated that the dependability or consistency of findings in qualitative research means that if the study had to be repeated with the similar participants and in the same context; it would produce similar findings. Thomas and Magilvy (2011) emphasized that one important strategy to improve dependability in qualitative research was to involve peers in the analysis of data. Merriam (2009) summarised as follows: triangulation, peer examination, the researcher's position or reflexivity and the audit trail are the most important strategies to use to enhance the dependability or reliability of the findings in qualitative research. Methods used for triangulation and for clarifying the researcher's position have been already described.

In addition, to ensure the dependability or consistency of the findings; as recommended by Thomas and Magilvy (2011) and Merriam (2009), the researcher kept a research record where she recorded all the procedures for data collection, from the first day she visited the hospital to seek permission and to identify participants eligible for interview. All that she observed, as well as comments from participants or health care providers, and challenges encountered, were included in the record. In addition, the researcher's thoughts about the understanding and interpretation of participants' comments and decisions on certain issues were also considered and documented. In a recent article by Houghton, Casey, Shaw, and Murphy (2013) it was reported that in qualitative study, thoughts and ideas recorded throughout the data collection process could be useful for the development of themes, not only to enhance dependability but also to emphasize the transparency of the process followed. Some of this data is presented in the section on methodology. This describes how data was collected, transcribed, translated and then coded by the student researcher, assisted by her supervisor, before being entered in the final report. The moderator, research assistant and the translator were consulted for peer examination.

4.4.8 Ethical considerations

Ethical approval was given by UWC (see Chapter Three Appendix I), and ethical clearance was also obtained from CNLS (see Chapter Three Appendix I) and the KHI IRB. In addition, on request, a supporting letter was provided by the Ministry of Health RBC/HIV division ; this is the organisation that currently coordinates all HIV programs in Rwanda. Hospitals

needed this supporting letter in order to update the permission that had previously been granted by the CNLS (Appendix I) as the responsibility for coordinating HIV programmes had passed from the CNLS to the Ministry of Health RBC/HIV division during the period of the study. Permission from the two selected hospitals to conduct the FGDs was granted.

Two participant information letters (Appendices VII and IX) were used to explain the objectives and provide details of the study and to invite participants to take part in the study. The first letter was to invite their participation in the screening. The second letter was to invite their participation in the FGD. Participants were requested to sign consent form (Appendix VIII) agreeing to their participation in the screening, and those who were selected for the FGD completed another consent form agreeing to participate in the FGD and agreeing to the use of an audiotape recorder during the FGD (Appendix X). All forms were developed in English but translated into Kinyarwanda before use.

Participation was voluntary and participants were told that they had the right to withdraw from the study at any time and that this would not have any negative consequences for their care. Participants were guaranteed confidentiality but they were also requested to keep what was discussed in the FGD confidential. Prior to data collection, the interview team decided to use pseudonyms when reporting. At each site, immediately after the introductions, every participant was given a number and they were all understood that the numbers and the hospital label Hospital A and Hospital B would be used when reporting instead of their names: for example, participant A 2. Allocation of numbers followed the sitting arrangement.

There was one incident where a participant became very upset. During the discussion at hospital A, a woman cried while telling the story of how the husband had mistreated her after she tested HIV positive. The researcher was a trained counsellor, so prior to the discussion she was aware such reactions might happen. The counsellor at the HIV clinic had been asked make herself available if needed and the moderator was advised to allow a moment of silence if such a situation happened. When it occurred, the moderator stopped facilitating and immediately everyone in the room also kept quiet (without being asked) and seemed sad. The researcher utilised some counselling techniques for example, tapping on the back of the patient to assist her so she could continue to participate in the group. After a while, she

stopped crying and chose to continue sharing with others. At the end of the FGD she was referred to the clinic counsellor for follow up.

4.5 Findings

The purpose of the FGDs was to explore the perceptions of PLWH on ARV with associated disabilities the relationships between personal and environmental factors and the impairments and functional limitations. Sixteen participants took part in two focus group discussions, with eight participants per group.

The findings are presented according to the six themes that emerged from the analysis:

1. My body's impairments;
2. Functional limitations and participation restrictions I experience;
3. Personal factors that influence my functioning as a PLWH;
4. Social relationship or community environmental factors that influence my functioning as a PLWH;
5. Hospital environmental factors that influence my functioning as a PLWH;
6. How the hospital services could respond to my functional limitations.

The participants are not identified in the quotes. Interjections, such as “hum”, are included to assist the reader in understanding the contextual meaning and the emotions expressed by the participants.

4.5.1 Socio-demographic profile of the participants

The socio-demographic profile of the participants from Hospital A is presented in Table 28 and that of participants from Hospital B in Table 29.

Table 28: Focus Group A: Hospital A (Urban): participants (n=8)

| Participant Number | Age (Years) | Sex | Marital status | Employment | Years on ARV (n) |
|--------------------|-------------|--------|----------------|-------------------|------------------|
| 1 | 47 | Male | Separated | Assistant builder | 4 |
| 2 | 49 | Male | Married | Bank cashier | 5 |
| 3 | 45 | Female | Widowed | Tailor | 9 |
| 4 | 66 | Female | Widowed | Waiter | 7 |
| 5 | 30 | Female | Single | Assistant builder | 3 |
| 6 | 28 | Male | Single | Watchman | 3 |
| 7 | 46 | Female | Cohabiting | Vendor | 5 |
| 8 | 23 | Female | Married | Student | 4 |

Table 29: Focus Group B: Hospital B (Rural) participants (n=8)

| Participant Number | Age (Years) | Sex | Marital status | Employment | Years on ARV (n) |
|--------------------|-------------|--------|-----------------|------------|------------------|
| 1 | 36 | Female | Married | Farmer | 6 |
| 2 | 21 | Male | Single (Orphan) | Student | 3 |
| 3 | 38 | Female | Widowed (twice) | Farmer | 8 |
| 4 | 44 | Male | Separated | Farmer | 6 |
| 5 | 30 | Male | Married | Driver | 5 |

| | | | | | |
|---|----|--------|---------|-----------|---|
| 6 | 42 | Female | Married | Tailor | 8 |
| 7 | 45 | Female | Married | Housewife | 3 |
| 8 | 38 | Female | Married | Teacher | 8 |

4.5.2 Theme 1: My body's impairments

Participants described the many body impairments they experienced in everyday life. These included tiredness/fatigue, body weakness/lack of energy, pain (knee pain, abdominal pain, headache and backache), paraesthesia in the legs and arms, dizziness, lipodystrophy and body image, memory loss and lack of concentration. Nausea, lack of appetite, intolerance to food, a persistent cough, breathlessness, skin hardening, fever and herpes zoster were also mentioned by some participants. In urban and rural settings, the problems were similar.

Participants said that the problems started after being infected with HIV and/or after starting the antiretroviral treatment, and sometimes impairments/problems might change overtime, they might either get worse or improve. Participants also complained about two, three or more problems occurring concurrently, especially after starting antiretroviral treatment. For example 1B (a 36 years old rural woman, who had been on antiretroviral treatment for 6 years) said:

Yeah, medicines brought me many problems: such as paraesthesia in legs and arms as well as abdominal pain and headache.

3A: They have changed my medicines three times. Can you believe! At the last phase, my body weight decreased, I became weak, the knees started aching until now; I am worried! (Urban, female, 45 years old, 9 years on antiretroviral treatment)

7A: The medicines they give us made my muscles and nerves ache. I am getting thinner and I have continuous paraesthesia. When they change them [the medicines], sometimes the pain gets reduced. (Urban, female, 46 years old, 5 years on antiretroviral treatment)

4.5.2.1 *Lack of energy*

Participants described physical problems they experienced after being affected with HIV. They used the words lack of energy (*kubura imbaraga*), lack of force (*kubura ingufu*), tiredness or fatigue (*umunaniro*), and body weakness (*gucika intege*). Those terms were used interchangeably and frequently in both FGDs. Lack of energy was considered a chronic, but severe problem; it appeared to be a problem that had changed their bodies completely:

1B: *In general, I feel [I am] getting weaker and weaker. This proves that there is something wrong in the body, Hum! I just feel my body is no longer the same.* (Rural, female, 36 years old, 6 years on antiretroviral treatment)

4.5.2.2 *Pain*

Pain was described by many participants, who used various descriptions.

Pain experienced as severe

Some participants (male and female, urban and rural), complained that the pain was severe

5B: *Ah! ⁵I feel much pain.* (Rural, male, 30 years old, 5 years on antiretroviral treatment)

Pain experienced as chronic

Some other participants (male and female, urban and rural) described pain as chronic

8B: *I Always suffer from abdominal pain.* (Rural, female, 38 years old, 8 years on antiretroviral treatment)

1B: *I have suffered from headache for six months; until now it persists.* (Rural, female, 36 years old, 6 years on antiretroviral treatment)

⁵ Expression of emphasis

Pain experienced affecting many parts of the body

Participants (male and female, urban and rural) said that pain frequently affected almost all parts of the body. They complained about backache, headache, knee pain and abdominal pain.

Pain experienced after starting antiretroviral treatment

Many of the participants said they experienced pain after starting the antiretroviral treatment.

1B: *Hum!*⁶ *ARV brought chronic headache!* (Rural, female, 36 years old, 6 years on antiretroviral treatment)

4B: *Haaa!*⁷ *It is painful.* (Rural, male, 44 years old, 6 years on antiretroviral treatment)

3B: *Hum!*⁸ *The medicines (antiretroviral treatment) can cause many problems, I can tell you! For example dizziness and abdominal pain; it hurts like a wound!* (Rural, female, 38 years old, 8 years on antiretroviral treatment)

4.5.2.3 Paraesthesia

Participants in both FGDs complained also about paraesthesia and described it as follows:

Paraesthesia sensations

Participants described paraesthesia as being like itching with pins and needles sensations

5B: *I feel paraesthesia in the legs with pins and needles in the hips.* (Rural, male, 30 years old, 5 years on antiretroviral treatment)

Paraesthesia experienced with pain

Participants described paraesthesia as frequently occurring with pain; both were considered serious problems.

⁶ Expression of emphasis

⁷ Expression of emphasis

⁸ Expression of realisation and emphasis

3A: *Knee pain and paraesthesia are serious.* (Urban, female, 45 years old, 9 years on antiretroviral treatment)

Paraesthesia experienced as a chronic problem

Participants complained that paraesthesia, like pain, was a permanent problem.

1B: *I have suffered from paraesthesia for six months, until now it persists.* (Rural, female, 36 years old, 6 years on antiretroviral treatment)

Paraesthesia experienced as a localised problem

Many of the participants described paraesthesia that occurred frequently in the lower limbs.

For instance 8A said: *Yeah we often have much paraesthesia in the legs.* (Urban, female, 23 years old, 4 years on antiretroviral treatment)

Paraesthesia manifest in certain positions

Participants complained of having paraesthesia most of time; it occurred in specific positions, particularly when standing or sitting for long periods

7A: *I have paraesthesia when I am standing.* (Urban, female, 46 years old, 5 years on antiretroviral treatment)

Paraesthesia experienced after starting antiretroviral treatment.

Like pain, some participants said they experienced paraesthesia after starting antiretroviral treatment.

5B: *Since I have started having antiretroviral treatment, my legs got paraesthesia.* (Rural, male, 30 years old, 5 years on antiretroviral treatment)

4.5.2.4 Dizziness

Dizziness was also frequently experienced and particularly in a standing position. It was found to be exacerbated by hunger, thirst and the sun.

5A: *I very often feel dizzy when I am standing.* (Urban, female, 30 years old, 3 years on antiretroviral treatment)

8 A: *Dizziness comes most of the time when I am hungry.* (Urban, female, 23 years old, 4 years on antiretroviral treatment)

4.5.2.5 *Lipodystrophy and body image*

Two female participants (one at Hospital A and another at Hospital B) brought up the symptoms of lipodystrophy which they linked to the antiretroviral treatment. It had continued despite the change of antiretroviral treatment.

The one woman who complained about lipodystrophy was at Hospital A. She shared her experience with sadness and a lot of emotion, and said that despite many changes of medication, she had not seen any change or improvement.

3A: *Hum!*⁹ *When I started medicines (Triviro), I increased my body weight and felt very well. After some time, my legs, arms and buttocks got thinner, the face and the belly swelled. They have changed my ARV medicines three times!* (Urban, female, 45 years old, 9 years on antiretroviral treatment)

These women complained that lipodystrophy had disfigured their bodies and it led to stigmatization. For example, the woman at Hospital B explained that she was ashamed of her legs because they had become very thin compared to other parts of her body, so she hid them with trousers or a long dress.

6B: *There is also non proportional increased body weight. You notice that one body part swells excessively while another is very thin. Hum!*¹⁰ *This makes us wear trousers or long clothes in order to hide very small legs with visible tendons and blood vessels. They sometimes change our medicines, but there is not much improvement.* (Rural, female, 42 years old, 8 years on antiretroviral treatment)

3A: *In short, ... the whole body was deformed.* (Urban, female, 45 years old, 9 years on antiretroviral treatment)

⁹ Expression of regret and sadness

¹⁰ Expression of pity and regret

4.5.2.6 Memory loss and lack of concentration

Memory loss and a lack of concentration were also described. According to the participants, these two problems were exclusively a consequence of antiretroviral treatment; people had not experienced this problem while HIV positive but not on medication. One woman compared herself to an old person because of her increased forgetfulness:

6B: *Heeee!*¹¹ *I can tell you how the medicines have caused much memory loss! I now forget like an old person!* (Rural, female, 42 years old, 8 years on antiretroviral treatment)

8B: *Hum!*¹² *My sister is right; I think the memory loss and lack of concentration I am experiencing are caused by those medicines (antiretroviral treatment).* (Rural, female, 38 years old, 8 years on antiretroviral treatment)

Other addition problems described by a few participants were: fever, cough, breathlessness, herpes zoster, skin hardening, nausea, altered to tolerance to food, decreased body weight and paralysis.

4.5.3 Theme 2: Functional limitations and participation restrictions I experience

In this theme, participants discussed how body impairments affected their performance of activities in everyday life and their participation in social life. They expressed their frustration at living with these problems.

4.5.3.1 Functional limitations

Participants demonstrated how essential activities in everyday life, such as mobility activities, self-care activities, and household and work activities were limited and difficult to perform because of the body impairments.

Difficulties with mobility activities

Many of the participants in both FGDs reported how most of the time their mobility, including standing, climbing stairs and walking, was affected by pain, breathlessness, paraesthesia, and a lack of energy.

¹¹ Expression of regret

¹² Expression of realisation

For example, one urban woman of 45 years and who has been on for 9 years, said she experienced breathing problems and her heart rate increased when she climbed stairs:

3A: (Showing sorrow) *I hardly breathe when climbing up stairs. The heart pumps fast.*

One woman at Hospital B explained how she suffered from severe back pain and indicated how this had affected her walking:

3B: *Ah!¹³ back pain! It hurts too much! Hum!¹⁴ Sometimes I am unable to walk.*
(Rural, female, 38 years old, 8 years on antiretroviral treatment)

In FGD A, a man explained that he had difficulty with standing and walking due to knee pain, paraesthesia and a lack of energy.

2A: *I have difficulties with standing for a long time as well as to walk a long distance, because of knee pain, a lack of energy and much paraesthesia.* (Urban, male, 49 years old, 5 years on antiretroviral treatment)

Difficulty with self-care activities

This man (2A) continued to complain and explained that, because of pain and paraesthesia in his legs, he was unable to wear shoes:

2A: *Do you know what? Ah!¹⁵ Due to much pain and paraesthesia in the legs, even wearing shoes has become difficult for me.* (Urban, male, 49 years old, 5 years on antiretroviral treatment)

Two participants in the group agreed with him they could not wear shoes because of pain and paraesthesia:

3A: *Yeah! We all have the similar problem!* (Urban, female, 45 years old, 9 years on antiretroviral treatment)

¹³ Expression of emphasis

¹⁴ Expression of stress

¹⁵ Expression of regret

7A: *Hum!*¹⁶ *That happens a lot to us!* (Urban, female, 46 years old, 5 years on antiretroviral treatment)

Difficulties with life activities

This included difficulty in performing household activities and work activities. Many participants, at both hospitals indicated that after being infected with HIV their level of work performance has decreased because of a lack of energy and also sometimes because of pain. One participant at Hospital B also spoke of a loss of memory. Consequently, the participants found it difficult to perform certain household and work-related activities.

Household activities

A young woman of 23 years, demonstrated how difficulties with walking had affected fetching water, which is classified by ICF as a household activity. Although living in urban setting, water must frequently be collected from a long distance away. This tends to be a task done by women.

8 A: *I have difficulty doing a long walk. I could fetch water, but I cannot any longer*
(Urban, female, 23 years old, 4 years on antiretroviral treatment)

A 44 year old man (4B), from rural area, who has been on antiretroviral treatment for 6 years, and whose main work activity was farming, explained how his work performance had decreased since he has been infected with HIV: he was limited in almost all physical activities, even household activities, due to a lack of energy. In Rwanda, it is not common for men to get involved in household activities, except sometimes, like this participant, in rural areas, the type of household activity men might do is cutting wood.

4B: *We used to do work that required much energy before getting HIV infection and that has decreased ... The household activities, farming, and even carrying heavy bags (with farm produce), are all difficult for me because I always feel weak.*

¹⁶ Expression of realisation

Pain was also recognised by some participants as a factor that restricted their household activities.

8B: I always suffer from abdominal pain. Therefore, I hardly walk. Yet there is no possibility to do difficult [household] tasks. (Rural, female, 38 years old, 8 years on antiretroviral treatment)

Work activities

As it is shown in



Table 28: and **Error! Reference source not found.**, in both FGDs many of the participants said they were involved in work activities and indicated that they were self-employed but apparently this was occasional employment. The participants, including men and women, said their work performance was good before they were infected with HIV but their severely reduced levels of energy affected their work output overtime and they have not returned to the pre-HIV energy levels.

1A: *Work like building is reduced. Hum!*¹⁷ *I am saying this because I was a very good assistant builder! And for sure my performance has been reduced! I don't have the energy I had before!* (Urban, male, 47 years old, 4 years on antiretroviral treatment)

3A: *Hum!*¹⁸ *I am a tailor. Since I have been infected with HIV, I only work before noon. Ha!*¹⁹ *By afternoon I am already tired! My energy is no longer there!* (Urban, female, 45 years old, 9 years on antiretroviral treatment)

6A: (Holding his forehead, like someone who is desperate) *Hum!*²⁰ *To work for myself is reduced really!* (Urban, male, 28 years old, 3 years on antiretroviral treatment)

Some participants believed that activities that required a lot of physical activity led to health problems:

7A: *Work that requires much energy is the most causing problems.* (Urban, female, 46 years old, 5 years on antiretroviral treatment)

Some other participants avoided carrying out activities that required a lot of energy because of the potential health problems:

1A: *For sure we do not do the tiring ones to prevent problems.* (Urban, male, 47 years old, 4 years on antiretroviral treatment)

¹⁷ Expression of regret and realisation

¹⁸ Expression of regret

¹⁹ Expression of disappointment

²⁰ Expression of disappointment

Some participants recognised that overtime they had needed to adapt to the changes in their bodies, the reduced energy levels and the weakness and, to avoid health problems, they advised others not participate in tiring jobs:

2B: None can work as before because the strength is reduced. After being aware that you are infected with HIV, you need to change the way of working to minimize and prevent some health problems that can result from lack of energy and tiredness. (Rural, male, 21 years old, 3 years on antiretroviral treatment)

Participants indicated that they were advised by other people to avoid tiring jobs. Some said they have been told that tiring jobs could worsen their condition, so they had to be careful and be more health-conscious.

2A: At work, we are told to forsake the tiring tasks. (Urban, male, 49 years old, 5 years on antiretroviral treatment)

However, one woman stated that it was a challenge to accept and follow the advice to avoid tiring work. She said women had many responsibilities that required money and they did not have the option of any other work or any other financial support so they were obliged to carry on doing heavy work. Additionally they had childcare responsibilities and they ended up feeling very tired:

3B: I have three children. I am both their father and mother. I am always told not to work much and I feel I do not have enough energy. But I cannot find time to rest because of those children. I try to use the little energy I have and work! This leads me to an endless tiredness. (Rural woman, 38-year-old widow with three children, who has been on antiretroviral treatment for 8 years)

One married woman, only 42 years old, declared that she had lost her memory since she started taking antiretroviral treatment, but the most serious problem was that it had affected her usual work performance as a tailor:

6B: *Heeee!*²¹ *I have also lost memory since I started taking medicine! I very often forget and I wonder where I will get treatment. This has caused shortcomings at my work.* (Rural, female, 42 years old, 8 years on antiretroviral treatment)

Limitations in productivity

Participants complained that not only was their work performance reduced, but their productivity also decreased; they said it was evident that the one influenced the other:

7A: *Ha!*²² *I am telling you, since I was infected with HIV; my daily productivity has significantly reduced!* (Urban, female, 46 years old, 5 years on antiretroviral treatment)

In FGD B, a 45-year-old unemployed housewife was unhappy about how she lost her work because her health condition had become a drain on her business. Her performance and productivity were reduced and she had even lost her capital.

7B: *I was a vendor before, but I did not know my health status. I later knew about myself when I was pregnant. After giving birth, I often fell sick. The money I used for buying things to sell was finished. After getting better, I had no capital* (Rural, female, 45 years old, 3 years on antiretroviral treatment)

4.5.3.2 Restrictions in participation in social life

Difficulties with participating in leisure activities

The participants knew about leisure activities and recognised that they were good for their health and helped one to relax, but unfortunately they could no longer participate as one participant at the urban Hospital said and all the others voiced agreement with her.

4A: *Obviously! We most of the time watch [sport] and do not participate.* (Urban, female, 66 years old, 7 years on antiretroviral treatment)

²¹ Expression of regret and disappointment

²² Expression of regret

Participants pointed out that failure to participate in leisure activities was largely due to their body weakness or lack of energy:

3A: *We just watch people playing football or dancing, but it is difficult to participate. I feel weak!* (Urban, female, 45 years old, 9 years on antiretroviral treatment)

A 21-year-old boy born HIV-positive shared his bad experience with how his lack of energy had stopped him playing football:

2B: *I was a football player. I often felt dizzy and fell down in the playground because of body weakness and lack of energy. Now, I gave up playing.* (Rural, male, 21 years old, 3 years on antiretroviral treatment)

A few participants also indicated that sometimes they cannot participate in leisure activities because of their limited financial means.

2A: *To do leisure activities, sometimes depends also on one's financial means.* (Urban, male, 49 years old, 5 years on antiretroviral treatment)

My body impairments interfere with my social relationships

Some female participants explained that they were limited in their ability to connect with people around them due to a lack of energy.

4A: *I do not interact because of lack of energy.* (Urban, female, 66 years old, 7 years on antiretroviral treatment)

7A: *Because of the body weakness, we are not able to visit friends.* (Urban, female, 46 years old, 5 years on antiretroviral treatment)

My body impairments interfere with my spiritual practices

Some participants explained how their spiritual practices had changed since becoming infected with HIV. Their routine of praying had changed and the frequency had decreased. They said it was largely due to their body weakness or a lack of energy.

One female participant explained, while appearing sad:

8A: *Now to pray for a long time is not easy for me. I cannot afford to pray in the evening.* (Urban, female, 23 years old, 4 years on antiretroviral treatment)

Another woman said:

3A: *I go to pray before midday. But in afternoon I feel very tired and I am no longer able to, because of body weakness and I don't have strength.* (Urban, female, 45 years old, 9 years on antiretroviral treatment)

My body impairments interfere with my sexual relations

Participants in both FGDs revealed that they have problems in their sexual relationships; this was initially mentioned by men and who said it was because of decreased energy. At Hospital B, it was the very first problem that the participants started speaking about. At Hospital A, one man explained that increasing the frequency of sexual intercourse can decrease the amount of energy you have, even though it is already low.

5B: *Since I have known that I am HIV-positive, sexual relations with my wife have become difficult. The way I used to do it before has now decreased; it is because of my body weakness.* (Rural, male, 30 years old, 5 years on antiretroviral treatment)

1A: *You cannot have sexual relations several times, the force has decreased! If you frequently do it, you get worse.* (Urban, male, 47 years old, 4 years on antiretroviral treatment)

In both FGDs, women were not forward in talking about sexual relations. At the urban hospital, the doctor had to motivate them. The female participants who spoke about sexual relations indicated that not only was energy reduced, but there was no sexual desire, some women had been, threatened, disappointed and consequently were no longer interested in sex. This suggested that the problem was both physical and psychological:

1B: *Hum! Don't mention about sexual relationship! The desire is not there, I am not motivated and my husband is always weak.* (Rural, female, 36 years old, 6 years on antiretroviral treatment)

One female participant, a widowed (3A) explained how she had been infected by her husband, and then he died and also their only child. She said that she had been shocked by the two deaths. She associated sex with the deaths, subsequently, she has lost her sexual desire and this had a long lasting effect:

3A: For 12 years now I have not done it (sexual intercourse) and I can even say that I forgot about it ... I experienced how badly my husband died and gave up at once, I felt very threatened! I gave birth to a child who together with my husband got very sick before they died. (Urban, female, 45 years old, 9 years on antiretroviral treatment)

Participants pointed out that their doctors had advised them to reduce the frequency of their sexual relationships as this affected their energy levels.

2A: Doctors always tell us not to tire ourselves much because sexual relationship reduces the energy! It is already lowered. (Urban, male, 49 years old, 5 years on antiretroviral treatment)

One participant regretted this advice as he was still young and said that if it were not for the doctors' advice he would choose to have sex often.

This urban 28-year old man (6A), 3 years on antiretroviral treatment smiled, but appeared sad saying: *As I am still young, I would rather do it always but doctors tell us it weakens the body.*

4.5.4 Theme 3: Personal factors that influence my functioning as a PLWH

This theme describes the personal or intrinsic factors, that is, those factors within the participants that could either facilitate or hinder their ability to perform the activities of daily life and participate in social life.

4.5.4.1 Personal factors that act as facilitators of activity performance and social participation

Intrinsic factors identified as facilitators of activity performance and social participation included: spiritual beliefs, faith in God, and positive experiences with disclosure. These factors helped to overcome internalised stigma and to create awareness about HIV. Other

factors included: a sense of belonging at the ARV clinic, a sense of solidarity, trust in other people, and the use of coping strategies.

Participants' spiritual beliefs

Some participants said prayers had a positive effect on their health despite challenges regarding participation due to their lack of energy. They explained that when they were able to go to church, the church teachings boosted their strength and increased their motivation.

4A: I could go to pray when I was young. This became less frequent after being infected with HIV. When I feel like having strength, I manage to go to church and the preaching makes me stronger and motivated. (Urban, female, 66 years old, 7 years on antiretroviral treatment)

Participants' faith in God

One male participant said that after being infected with HIV, people had a stronger faith in God and might start attending church, even those who had not previously attended. They indicated that they might feel safe and secure to be near God.

2A: Hum!²³ Even those who could not go to church before may go now so as to get closer to God. (Urban, male, 49 years old, 5 years on antiretroviral treatment)

Another male participant In FGD B expressed her disappointment that on several occasions doctors were not available when he needed care. Nevertheless, he believed that Jesus could perform a miracle and still hoped he could heal their medical problems:

5B (with emotion): I have just told you that I feel much paraesthesia and pain. I am fed up with always coming and missing doctors here at Hospital B. I take my time and pray to my God! With hope, Jesus heals me! (Rural, male, 30 years old, 5 years on antiretroviral treatment)

The other participants joined in and said enthusiastically “*He also heals!*”

Positive experiences about disclosure as a strategy to improve psychological wellbeing

²³ Expression of realisation and emphasis

A few participants at Hospital B indicated that it was sometimes good to ignore what other people might have thought or said about their serostatus, and they decided to disclose their HIV status. This gave a sense of relief and enabled the person to relax. They commented that once they felt better and their minds were free they might be able to assist the non-infected people in their community to protect themselves:

3B: I think sometimes to disclose your status is very good because it makes you feel released in the mind. And then, you help those who are not infected with HIV as well.
(Rural, female, 38 years old, 8 years on antiretroviral treatment)

Positive experiences about disclosure as a strategy to overcome internalised stigmatization

Despite some community members' judgmental behaviour, some participants said that disclosure of their status helped them to accept themselves and move beyond their internalised stigma:

6B: To tell others that you are infected with HIV helps you to accept yourself. (Rural, female, 42 years old, 8 years on antiretroviral treatment)

One woman of 42 years who was a tailor shared how she believed, from her own experience, that disclosure of one's HIV status assisted people to move beyond being stigmatised. She said it could help someone to build trust in others, especially at their work places. It might prevent a person from being fired because of missing work when he or she went for routine consultation or for medication

6B: Haaa!²⁴ Honestly, you cannot tell [disclose to] everybody. But, sometimes, it is necessary to say it. For example, your co-workers who always missed you because you went to get examined or when you are sick or went to collect medicines. They can wonder much about you. To disclose sometimes enables you to get out of stigmatization; hence you cannot be expelled from the job. (Rural, female, 42 years old, 8 years on antiretroviral treatment)

²⁴ Expression of hesitation and perplexity

The same woman indicated that she had really accepted her health status and managed to disclose her status, but she thought this was mainly because of the self- acceptance training she had undergone in the past.

6B: But what helped me to achieve this [disclosure of my HIV status] was training aiming at self-acceptance that I did. It helped me a lot! (Rural, female, 42 years old, 8 years on antiretroviral treatment)

Many of the participants at Hospital B expressed the need for such training and suggested that it could be given in counselling sessions.

Positive thoughts about disclosure as a strategy to create awareness about HIV

Some participants said that disclosure was good and had to be encouraged as it could sensitize the community about the importance of HIV testing for those who were not infected and those who were already infected might be encouraged to seek care. They also said it would encourage people to adhere to the antiretroviral treatment. They said there were many people in the community, especially in rural areas, who were unaware of the availability and the benefits of antiretroviral treatment.

8B: Actually, this is not the illness to be kept as a secret. It must be said [disclosed] to raise people's awareness so that they can go to be examined and know their status. (Rural, female, 38 years old, 8 years on antiretroviral treatment)

Even though disclosure was encouraged, by certain participants, they said it took time for some people to take decision to disclose their status but that it becomes easier overtime. For example, a 38-year-old widow shared the experience of how she had lost two husbands. The second husband died because she did not disclose her status and she eventually infected him. After that experience she decided to disclose her status so that her partners could protect themselves.

3B: I became a widow when I was still young, and was left with HIV. I got married to a second man. While I was going to have sex with my husband, I did not reveal my status to him [looking sad]. He also died! But now, I first inform whom I am going to have sex with about my status. The important thing is that when you tell it to him, he

remembers to use a condom for protection. (Rural, female, 38 years old, 8 years on antiretroviral treatment)

Sense of belonging at ARV clinic

All participants felt secure and safe at the ARV clinic where they usually received care and they expressed their willingness to have their status known to these health care providers, but only to those in the ARV clinic. The participants knew that the ARV clinic health care providers knew their status as it was written in their files. They did not have to tell them. Thus there was no need for disclosure. However, there might not be the same sense of security outside the ARV clinic.

3B: I cannot tell to another doctor about my status; I only feel free with the one of ARV clinic... (Rural, female, 38 years old, 8 years on antiretroviral treatment)

Sense of solidarity

Participants expressed a sense of solidarity and said they felt free and disclosed to other PLWH

5A: One female participant, an assistant builder, (looking overwrought), said “I have never told it to anybody apart from people we share the same problem with, I mean other HIV infected [people]. (Urban, female, 30 years old, 3 years on antiretroviral treatment)

Trust in family, parents and close friends

Some male and female participants trusted only certain people and decided to disclose to them; this included their family, parents and close friends.

4B: We do not tell everybody that we are HIV positive, apart from someone with whom we feel free, like a close friend or a parent. (Rural, male, 44 years old, 6 years on antiretroviral treatment)

7B: Heeeeeeeee!²⁵ According to me, you cannot reveal your status to anybody except to your best friend. (Rural, female, 45 years old, 3 years on antiretroviral treatment)

Trust in hospital health care providers outside the ARV clinic

A few participants said that they decided to disclose their status to other health care providers outside ARV clinics when they fell sick and needed to be given medicine:

6B: *We disclose to other health care providers so that they give us medicines accordingly.* (Rural, female, 42 years old, 8 years on antiretroviral treatment)

Some participants mentioned they did not usually talk to the health care providers, not even those in ARV clinic, about issues concerning their functional problems. They believed these problems were related to HIV or the antiretroviral treatment, so they were destined to live with them. They did not think the doctors or other ARV health care providers could help.

6B: *Hum!*²⁶ *Really, I did not tell my doctor at all! I thought the functional problems I have are related to HIV or to drugs so it is there for life! Really! We do not always tell all our problems we face to doctors. However, maybe if we tell them, they can help us.* (Rural, female, 42 years old, 8 years on antiretroviral treatment)

Coping strategies

Participants explained how they strove to live normal lives. They did not want people to be suspicious of their status and might decide to change behaviour. One participant explained how sometimes she was invited by her friends to go for a drink. She would refuse and make an excuse without telling them the real reason, which was that she had been advised to stop drinking because of her health status:

4A: *Sometimes my friends invite me for drink. I never say that I do not drink anymore. I just apologize and say I am not in the mood today. Forgive me, forgive me!* (Urban, female, 66 years old, 7 years on antiretroviral treatment)

²⁵ Expression of mistrust and disagreement

²⁶ Expression of hesitation and confusion

8A: *Yeah! You take it as normal, as your own issue! What else can you do!* (Urban, female, 23 years old, 4 years on antiretroviral treatment)

4.5.4.2 Personal factors that act as barriers to activity performance and social participation

Personal factors identified as barriers to activity performance and participation in society included internalised stigma and age.

Internalized stigma

Many of the participants demonstrated that they had internalised the stigma relating to HIV. They had low self-esteem and they lacked confidence in themselves. They described how they lived with feelings of being hurt, and of regret and shame, and with the thought of being judged, stigmatised or discriminated against by (for example) being fired, chased away and even abandoned by other people in their community once they were discovered to be living with HIV. This made them afraid and had a big impact on their social participation. Some even refused to disclose their status to their families.

5A: (looking sad), *Hum!*²⁷ *For me, no one in my family knows that I am infected with HIV...* (Urban, female, 30 years old, 3 years on antiretroviral treatment)

Feelings of being hurt, feelings of regret and shame, guilt and remorse about HIV

Many participants expressed feelings of being hurt, and feelings of regret and shame once they were discovered to be living with HIV; this led them to fear disclosure. At rural hospital the 21 year old man who was an orphan expressed his worries about being hurt by negative comments which might be made by his peers or teachers at school – once they discovered he was HIV positive:

2B: *I am a student. When my colleagues and student supervisor notice that I cough too much, they ask me about my status, but I do not disclose because I think their comments cannot be good.* (Rural, male, 21years old, 3 years on antiretroviral treatment)

²⁷ Expression of revolt

One 45 year old woman who had lost her husband and her only child due to HIV, regretted what had happened and was ashamed of her status. She indicated how difficult it was to disclose her status:

3A (Looking nervous): *Hum!*²⁸ *It is hard to say it! [I have HIV]* (Urban, female, 45 years old, 9 years on antiretroviral treatment)

One young woman of 23 years indicated that immediately after being tested HIV-positive, she had not only felt terrified but also guilty, ashamed and wounded. At that time, when she thought about how she was infected through sexual intercourse it made her feel nauseous and she wanted to vomit when she looked at any man. Consequently, she had lost any desire for sexual intercourse. However, she did subsequently get married suggesting improvement overtime

8A: *Hum!*²⁹ *After being infected with HIV, I was about to vomit just after looking at any man* (Urban, female, 23 years old, 4 years on antiretroviral treatment)

Negative thoughts and imaginings

Participants expressed their thoughts and how they imagined being stigmatized, abandoned, chased and fired from work once they were discovered to be living with HIV.

Fear of being stigmatised

Many participants thought about how they would be stigmatised by others in the community once they were discovered to be living with HIV; they therefore chose to keep quiet about their status:

5A: *We don't disclose because we are afraid of being stigmatized!* (Urban, female, 30 years old, 3 years on antiretroviral treatment)

6A: *To tell other people that you are HIV positive is very difficult because they stigmatise you!* (Urban, male, 28 years old, 3 years on antiretroviral treatment)

²⁸ Expression of depression

²⁹ Expression of displeasure

Fear of being judged

Many of the participants were afraid of being judged once other people discovered they were HIV positive. This fear of being judged made them reluctant to disclose their HIV status. One participant expressed how people judged them by their appearance and explained how this affected their feelings:

6A: *Hum!*³⁰ *People sometimes suspect you before even you have undergone HIV testing! You know when you hear people judging your appearance, it hurts you more and then it becomes difficult to disclose.* (Urban, male, 28 years old, 3 years on antiretroviral treatment)

Fear of being chased away

Participants imagined being mocked and chased away by others in their community when these people found out about their HIV status. They explained that they felt comfortable and safe to be with others when these people did not know they were HIV-positive.

8A: *Hum!*³¹ *We manage to visit them because they do not know our problem. Once they are informed about it we can be chased away, stigmatized, or said to be useless. Truly, that is the problem we have. Not knowing our status makes them socialize with us; otherwise we cannot feel free with them!* (Urban, female, 23 years old, 4 years on antiretroviral treatment)

³⁰ Expression of depression and regret

³¹ Expression of depression and disappointment

Fear of being dismissed from work

One male participant expressed fear of being fired from work once his employer discovered his HIV status, although he believed it was a good thing to disclose his status. As a result, he was uncertain whether to disclose or not:

6A: When you do a monthly waged job, you are on antiretroviral treatment, and you have to go to a clinic every month, you have to tell your boss the truth to get permission. Sometimes, he/she may decide to suspend you because he/she knows your status. (Urban, male, 28 years old, 3 years on antiretroviral treatment)

Participants in both FGDs expressed their thoughts and worries about the spread of the information from one person to another in their communities once their HIV status was disclosed.

7B: We are afraid of people who may spread the information everywhere (Rural, female, 45 years old, 3 years on antiretroviral treatment)

Age

One participant at the urban hospital who was older than all others (64 years old) explained that apart from paraesthesia she did not normally have many health problems. She was confused whether she should attribute paraesthesia or any other health problem she might encounter to HIV or to her age.

4A: As for me I have a lot of paraesthesia when I stretch myself in the morning. (Smiling) but perhaps this is due to old age! (Urban, female, 66 years old, 7 years on antiretroviral treatment)

However, age did not deter this same woman from saying she would like sex if she found someone who was interested in her.

4A: (smiling) If someone proposes me to do it and caresses me, I may accept! (Urban, female, 66 years old, 7 years on antiretroviral treatment)

As mentioned in (sexual activity section) much younger participant in the group, FGD A, a 28 years old single man, found his age and parallel normal sexual desires were difficult to meet because of the HIV and his reduced energy levels.

4.5.5 Theme 4: Social relationship or community environmental factors that influence my functioning as a PLWH

This theme describes the extrinsic or social relationship factors in the community environment which could act as facilitators or barriers to activity performance and to participation in society. Participants in both FGDs, particularly women, spoke of facilitators, including support from other people and socialization with others, as being good strategies for maintaining psychological well-being. The barriers they spoke of included the negative behaviour and attitudes of other people around them once they discovered they were HIV positive, and conflict in their relationships with others.

4.5.5.1 Family relationship environment

This section includes factors that act as facilitators or barriers to function.

Family relationship factors that act as facilitators

A few participants said that their families had accepted them as PLWH and showed a positive attitude towards them, which included giving care and support. Sometimes, however, this amounted to overprotection, and led to some confusion between wanting and not wanting the support.

For example at the urban hospital, one 45 year old woman, a widow, had lost her child who was born HIV positive. She shared her experience with her siblings. She indicated that they protected her and cared for her. However, sometimes they were too caring, and the family prevented her from doing household activities and treated her like a disabled person even when she thought she was able to carry out the tasks.

3A: In my family, they really pay much attention, very much! They always make sure they know what is happening to me. I live with three of my sisters in the same compound; they give me what I need and even do all household activities for me ... I think I am able to do some work, but they consider me unable and always want me to

rest! They refuse to let me do some work, but I insist and do some [work] and tell them I am not a disabled. (Urban, female, 45 years old, 9 years on antiretroviral treatment)

4A: *Yeah, they try not to hurt her!* (Urban, female, 66 years old, 7 years on antiretroviral treatment)

2A: *Yeah that is the way it is. Hum!*³² *They pity her and do not want to hurt her!* (Urban, male, 49 years old, 5 years on antiretroviral treatment)

3A: *Yes! They have mercy.* (Urban, female, 45 years old, 9 years on antiretroviral treatment)

Family relationship factors that act as barriers

At Hospital A, a 46-year-old woman shared her experience of what happened to her immediately after being diagnosed as HIV positive. Her own family, including her father, mother and siblings, did not accept her as a PLWH. They ostracised her and abandoned her completely. They did not even care how she was coping: she was left alone when she was most in need of support. This made her very sad and caused her to become ill.

7A: (With great sorrow) *Just after getting informed that I am infected, my family was unhappy. I was always lonely, sick and even hospitalized. Because of much painful emotions and loneliness I had chronic headache and then, paralysis. They really showed negative attitude towards my status, they were even unable to come near me.* (Urban, female, 46 years old, 5 years on antiretroviral treatment)

The woman explained how her family, particularly her father, but also other family members, were particularly harsh; she felt emotionally abused.

7A: *Can you imagine, even my father used to tell me that I am a dead person ... Some [family members] managed to come and hurt me even more saying: "It is that bad illness! She will not survive..."* (Urban, female, 46 years old, 5 years on antiretroviral treatment)

³² Expression of sympathy

Speaking very emotionally, with a great deal of sorrow, this woman explained how she was infected by her husband. Later, after mistreating her, and demonstrating disrespect and dishonesty, he abandoned her and their three children to go to other women.

7A: I separated from my husband because of bringing other women, saying they were his sisters. He was telling me I was old and he was going to look for young ones. So, I felt crazy. I told him: "Now I have a problem with my parents because of the disease you brought to me. Instead of facing the consequences of the problem together, you are the one causing me troubles." (Urban, female, 46 years old, 5 years on antiretroviral treatment)

She indicated that the accumulation of all these deceptions was so difficult to bear that she considered committing suicide. Her story was conveyed with so much emotion that she cried afterwards. Other participants showed empathy and kept silent for some minutes.

7A: There was a time; I had an idea of committing suicide because of unhappiness. (Urban, female, 46 years old, 5 years on antiretroviral treatment)

At the rural hospital another woman said she and her husband had different opinions about whether to have a child. Her husband wished to have a child; however, she was worried and believed that giving birth could result in health problems. This had caused problems in their relationship.

6B: (Looking sad) I have another problem that overcomes my capacity until God only helps me. My husband always wishes he had a child, but it may cause me problems, I know! Hence misunderstanding! (Rural, female, 42 years old, 8 years on antiretroviral treatment)

A 46-year-old woman spoke of being mistreated, disrespected and of experiencing a lack of care from her partner. This interfered with her sexual arousal and had an effect on their sexual relationship.

7A: (Looking very sad) When you are in the misery, you cannot feel the desire to do it [sexual intercourse]! I have never been cherished by my partner; it is now deleted from my mind. (Urban, female, 46 years old, 5 years on antiretroviral treatment)

One participant at urban Hospital explained how her mother stigmatised and judged her according to her appearance. This made her disappointed in her mother's judgement of her appearance and this stopped her disclosing her HIV status.

5A: Hum!³³ You cannot believe! Even my mother judges me! I visited her and she said: "My child, have you been infected with HIV?" I replied: "I am really healthy."
(Urban, female, 30 years old, 3 years on antiretroviral treatment)

4.5.5.2 Community relationship environment

Community relationship factors that act as facilitators

In both FGDs, a few participants recognised that there were people around them who understood their problems, who showed a positive attitude and gave support, and who respected and accepted them the way there were as PLWH.

8A: There are people who are ignorant and have negative attitudes towards us; however, there are others who understand, take it easy, and even sometimes give us advice. Yet it depends on one's mindset (Urban, female, 23 years old, 4 years on antiretroviral treatment)

One participant at Hospital A explained that after being diagnosed HIV-positive, she was abandoned by her family; however some people in her community showed empathy and support and tried to convince her parents and siblings and advised them to show some care.

7A: People approached them [my family] saying: "you should treat her like others"...
(Urban, female, 46 years old, 5 years on antiretroviral treatment)

Some participants at the rural hospital appreciated socializing and entertaining with others in the community. They encouraged other people in the group to entertain and recognised that entertaining and socializing with other people in the community was a good strategy to improve psychological wellbeing and contribute to a good state of mind. They also stated that they felt happy when they were with other people, to the extent of wanting to stay with them.

³³ Expression of revolt

2A: *Hum!*³⁴ *I think we should sometimes forget about our problems and entertain, interact with others, and relax!* (Urban, male, 49 years old, 5 years on antiretroviral treatment)

3A: *Yes! We relax the mind!* (Urban, female, 45 years old, 9 years on antiretroviral treatment)

8A: *About entertainment, we do not feel upset when we are with others. We would rather stay with others.* (Urban, female, 23 years old, 4 years on antiretroviral treatment)

Community relationship factors that act as barriers

One participant indicated that PLWH experience extreme forms of stigmatisation in their respective communities. It is as if they are considered non-existent in their communities, despite the fact that they are struggling to survive.

5A: (very sad) *Yeah! People do not consider us like human beings. They comment that we are about to die.* (Urban, female, 30 years old, 3 years on antiretroviral treatment)

Certain participants at the urban hospital explained how the community stigmatised them according to their appearance. They explained how people in their community, even those whom they trusted and respected (for example, close friends) judged them or judged other people in their presence according to their appearance and concluded that they were HIV-positive. They indicated that this disappointed and confused them, and decreased their trust in people, including those who were close to them. For example, one participant explained how disappointed she had been by the attitude of her best friend, who was also her godmother. The friend had assisted her and encouraged her to go for testing, but when she learnt of her status she still judged other people by their appearance, even when they were together. This has led to her to lose her trust in other people.

4A: *My godmother helped me to know that I am HIV-positive. We used to live as friends. She really assisted me; she buys me medicines if I get sick, milk, and whatever I*

³⁴ expression of resilience

want. However when we are on the way to church if she sees someone, she says; “Look at him/her in face, is not that man/woman infected with HIV?” However, she knows she is with an HIV-positive person. Hum!³⁵ When she tells me so, I feel sad, unhappy and disappointed. Anyway, Hum!³⁶ I don’t know whom to tell anymore and when! (Urban, female, 66 years old, 7 years on antiretroviral treatment)

Participants revealed that they had experienced situations in their communities where people had disclosed their HIV serostatus and experienced stigma; this made disclosure even more difficult.

7A: *I know someone who said it and got stigmatized (Urban, female, 46 years old, 5 years on antiretroviral treatment)*

In addition to stigmatization, participants explained that they experienced situations where people in their community gossiped about a person’s serostatus, thereby indicating a lack of consideration and respect.

8A: (Speaking scornfully) Hum!³⁷ *How can you not help saying that someone has a problem. You do not respect him/her and you do not give him/her much consideration. (Urban, female, 23 years old, 4 years on antiretroviral treatment)*

Another participant indicated that some people not only showed a lack respect towards them but also did not care about them, and this contributed to a reluctance to disclose their HIV serostatus.

5A: *Also I refused to tell it to anyone because nobody cares for me! (Urban, female, 30 years old, 3 years on antiretroviral treatment)*

Participants shared how judgement and stigmatization in their communities had an impact on their friendships and on the deep feelings they had towards other people. The hurt and emotional abuse caused by other people contributed to the isolation of both men and women.

³⁵ Expression of perplexity

³⁶ Expression of doubt and mistrust

³⁷ Expression of revolt

5B: *When I was visiting people, I could hear them saying: “See, he has herpes zoster, you can see the symptoms of that terrible disease!” Then, I felt very sad and stopped going back there. Because of that, I do not visit people any longer (Rural, male, 30 years old, 5 years on antiretroviral treatment)*

7B: *In general, people stigmatize us. Love and friendship got cold! There are people who say; “Those are HIV positive”. Therefore, we are not motivated to visit each other. (Female, 45 years old, 3 years on antiretroviral treatment)*

4.5.6 Theme 5: Hospital environmental factors that influence my functioning as a PLWH

The following theme describes participants’ experiences with hospital services, including at the ARV clinic and other hospital departments.

4.5.6.1 Environmental factors: ARV clinic

This section discusses the factors that acted as facilitators and those that acted as barriers within the ARV clinics.

ARV clinic: environmental factors that act as facilitators

The facilitators included the service in the ARV Clinic, the antiretroviral treatment, and the referral procedure to other hospital services.

My satisfaction with the service in the ARV clinic

Service in ARV clinics was the most appreciated of all services offered at both the hospitals. Participants were satisfied with the service provided, and were very happy with and trusted the health care providers at the ARV clinic. Participants were very clear that they only considered the ARV clinic to be good but not all the other services within the hospitals.

One participant at the urban hospital, while emphasizing her appreciation of the health care providers at the ARV clinic, indicated that when PLWH visit other services, patients are not integrated and do not receive guidance

3A: *There is no problem with health care providers of this service. But when you go into other services you get lost and confused.* (Urban, female, 45 years old, 9 years on antiretroviral treatment)

7A: *Only the staff in the ARV clinic help us with a follow up and provide us with essential medicines.* (Urban, female, 23 years old, 5 years on antiretroviral treatment)

One young woman at Hospital B thought that patients' satisfaction with the service might influence their acceptance of their HIV status.

3B: *Yeah! Do you know what? I would like to add this; not everybody has already accepted his/her status. But I think if one gets satisfactory care, it might help so much with the acceptance.* (Rural, female, 38 years old, 8 years on antiretroviral treatment)

Satisfaction with the antiretroviral treatment

Participants were aware that, despite all the problems they had been experiencing, there was evidence that the antiretroviral treatment were very beneficial for their health. They believed that the health care providers at the ARV clinics were the most important people for them to relate to as they provided the most essential medicine, the antiretroviral treatment to treat the HIV infection. Participants said this solved their major life-threatening problem, and they could live with the other related problems.

2B: *The ARV doctor solves many of my problems by giving ARV drugs! Hum! Maybe it can be my mindset, when he gives me the medicines I feel other problems I can live with.* (Rural, male, 21 years old, 3 years on antiretroviral treatment)

Certain participants highlighted the benefits of antiretroviral treatment. They emphasized their increased energy, weight and improved general health status, and some participants indicated that the change occurs overtime.

2B: *After taking medicines, there was a change on my health. I got stronger compared to how I was before.* (Rural, male, 21 years old, 3 years on antiretroviral treatment)

5A: I do not have any problem because I take medicines. I have increased weight and my body functions well. (Female, 30 years old, 3 years on antiretroviral treatment)

Satisfaction with the referral procedure from ARV clinic to other services within the hospital

Most of the participants indicated that they were satisfied that the health care providers at ARV clinic who referred them to other services within the hospital when they were not able to manage the problem. At times they were referred to the general practitioner at the outpatient service, where they had to go through the general consultation procedure like any other outpatient, and be referred from there to a specialist, either within the hospital or outside.

2B: When we are ill, we come to get treated. We first pass by here at the ARV service and they directly refer us to other services. (Rural, male, 21 years old, 3 years on antiretroviral treatment)

6A: The ARV health care providers facilitate us; we can be transferred from here to a general doctor at the out-patient department. (Urban, male, 28 years old, 3 years on antiretroviral treatment)

Environmental factors that act as barriers in the ARV clinic

The barriers included a lack of assistance from ARV clinic with regard to functional problems, punishment by health care providers at the ARV clinic, difficulties regarding treatment of functional limitations, doctors who show a lack of concern about functional limitations, unavoidable functional limitations, a lack of awareness of specialist services, difficulties with the referral system and the use of multiple files.

Lack of assistance from the ARV clinic regarding care related to functional limitations

In both FGDs, participants said that, the health care providers from ARV clinic did not assist them with the functional problems they had described.

8B: *We realize that our doctors in the ARV clinic cannot solve other problems except by giving us the medicines, the ARV medicines.* (Rural, female, 38 years old, 8 years on antiretroviral treatment)

Participants added that they had complained about their functional limitations or problems and reported them to the health care providers at the ARV clinic, but participants were only given their usual antiretroviral treatment, or a different antiretroviral treatment, or additional drugs to the antiretroviral treatment. When the problems persisted or recurred and they complained again, they were told the problems would be alleviated with time. They were not referred to other services for treatment of these functional limitations.

3B: *I suffered from back pain and they did not refer me anywhere. They only gave me medicines. I was not healed and I am still living with it, whereas it hurts too much!*
*Hum!*³⁸ *Sometimes I am unable to walk!* (Rural, female, 38 years old, 8 years on antiretroviral treatment)

3A: *We are given drugs (antiretroviral treatment) in our clinic, but for paraesthesia, muscle and nerve pain, our doctors here tell us this will decrease and get better with time! They always say those problems do not go away immediately or they will be cured by themselves. There was a time, pain had become too much; this time, they had given me painkillers only and told me it [the pain] will finish slowly.* (Urban, female, 45 years old, 9 years on antiretroviral treatment)

Punishment by health care providers at ARV clinic

One male participant brought up an issue related to the negative behaviour and discrimination by some health care providers at the ARV clinic; this was due to a misunderstanding of the patient's functional limitation or problem. He explained that they did not understand his wife's problem with loss of memory and had refused to give her antiretroviral treatment.

³⁸ Expression of disappointment and emphasis

5B: Hum!³⁹ ... *One time, my wife forgot her appointment for ARV medicines because of memory loss. Health care providers from here (ARV clinic) punished her by refusing to give her the medicines and saying she should go and take them elsewhere! I found it is cruel! (Rural, male, 30 years old, 5 years on antiretroviral treatment)*

However, another participant in the group did not agree that this was discrimination and suggested it was rather a way of reminding and educating people about the benefits of medication and the importance of respecting appointments

8B: *Yeah! It is true. It happens doctors punish us, but it does not take longer. It happens sometimes, when we disrespect the appointment to come and take the medicines, whereas we are the beneficiaries. They punish us so as to make us change our mind. (Urban, female, 38 years old, 8 years on antiretroviral treatment)*

Participants' assumptions about treatment of functional limitations at ARV clinic

(1) My functional limitations or problems are difficult to treat

Many of the participants presumed that the functional limitations or problems they experienced were difficult to treat because they were the consequence of HIV infection or the antiretroviral treatment. Some were hesitant to report their functional limitations to their doctors at the ARV clinic or to ask for a referral to a specialist as they did not expect any improvement.

1B: *Our doctors manage what they are able to! But there are other conditions ... which might be difficult to treat. We always think maybe it is because there can be complications of the illness [HIV] or the medicines we take! (Rural, male, 36 years old, 6 years on antiretroviral treatment)*

(2) Our doctors are not concerned with our functional problems

Participants assumed that the doctors at the ARV clinic were not concerned about their functional limitations. They reported the problems that they understood were directly related

³⁹ Expression of regret

to HIV infection, and not the functional limitations, because they presumed their doctors could not manage the functional limitations.

3B: ... we decide to tell our doctor about problems related to the illness only, for example decreased CD4, but not those concerning our body function. (Rural, female, 38 years old, 8 years on antiretroviral treatment)

(3) My functional limitations are unavoidable

Certain participants accepted that HIV was a chronic condition and assumed that the associated functional limitations were inevitable and permanent. Consequently, they did not see the need to ask for specialist care.

4B: Yeah! We live with HIV infection. We set in mind [believe] that complications are unavoidable, and they are there for life! That is why we do not continue to seek [help] from specialists for specific health problems. (Rural, male, 44 years old, 6 years on antiretroviral treatment)

(4) I am not aware of specialist services

Most of the participants said that they did not know that there were specialist services that could manage some of their functional problems. Their health care providers at the ARV clinic had not told them about other services.

1B: I do not know there are services where they can cure, for example chronic headache and paraesthesia! (Rural, female, 36 years old, 6 years on antiretroviral treatment)

6B: Hum!⁴⁰ I know I have memory loss! I do not know that there is somewhere to be treated. I think I may live with it! (Rural, female, 42 years old, 8 years on antiretroviral treatment)

⁴⁰ Expression of realisation

I experience difficulties with referral system

Although participants recognised that the health care providers at the ARV clinic do refer them to various specialities, they said that there was no consistency in the procedure and method of referral, and this sometimes caused confusion. Usually they were referred to the outpatients department and from there to other services, but sometimes they were referred directly to specialised services. In other cases, there was no referral at all and they were given medicines at the ARV clinic. Sometimes rather than go to the ARV clinic they sought care at their own local health centre.

7A: Yes! But sometimes, for those problems they are not able to manage, they give us transfers directly to other services within the hospital without passing through the outpatient service for general consultation. (Urban, female, 46 years old, 5 years on antiretroviral treatment)

8A: Indeed you are right! It depends! Sometimes, we get transfer from our clinic here that allows us to go immediately to the specialists, but again there is a time, the transfer is to go through normal channel, which is from outpatient service then to specialists; this last option takes time!" (Urban, female, 23 years old, 4 years on antiretroviral treatment)

Many of the participants at Hospital A indicated that *"it [the referral process] is really a mess"*: there was no clear procedure to follow for referral.

A few participants in both FGDs mentioned departments they had been referred to including the ophthalmology clinic, the Ear, Nose, and Throat (ENT) clinic and the dermatology clinic.

Certain participants had never been referred though they had encountered various problems; they were not informed about the possibility of referral from the ARV service to other services, or they had been informed too late, when complications had already occurred.

However, in the course of the FGDs participants expressed the need for referral, including those who were not previously aware of the existence of these services.

4A: *Hum!*⁴¹ *This is my first time to hear about transfers. I had chest pain recently and I was given medicines here in ARV clinic. Until now, it is not well healed.* (Urban, female, 66 years old, 7 years on antiretroviral treatment)

5B: *Hum!*⁴² *It is not all the time they refer you! I have suffered from herpes zoster and it hurts! They only gave me ARVs and told me it will go! So I thought it is because it was related to HIV, so there is no any other medicine! Now it has left me with eye problems [and] they have decided to give me a transfer to the ophthalmology service. I have an appointment of going there next week.* (Rural, male, 30 years old, 5 years on antiretroviral treatment)

One participant shared her experience of the physiotherapy service and a few participants at urban Hospital, who had never been referred to physiotherapy, indicated that they thought that physiotherapy could help with the joint, muscle and nerve pains they experienced, however, to date they had only been given medicine.

We need a single medical file

Participants at the rural hospital pointed out that they had more than one medical file within the hospital, possibly a file for each service used, and this caused difficulties as all their medical history was not kept in a single file. They acknowledged that they contributed to this duplication when they went to the health centre/outpatient department without going via the ARV Clinic and so a new file would be opened.

6B: *For me, I have a medical file for each service I go through; I find it disturbing sometimes if I have to be interviewed all the time, like I am a new patient in this hospital!* (Rural, female, 42 years old, 8 years on antiretroviral treatment)

1B: *In fact, we contribute to this file mess. We are always told to contact the ARV doctor in case we face any health problem.* (Rural, female, 36 years old, 6 years on antiretroviral treatment)

⁴¹ Expression of realisation

⁴² Expression of realisation and regret

One participant explained that he or she might decide to go directly to the outpatient service when doctors in ARV clinic appeared to be overwhelmed with too many patients and did not have much time for them.

3B: *Normally what happens when we come here in the ARV service and find that our doctor is busy with many patients, we prefer to go to [the health centre] where they make us other medical files for another doctor.* (Rural, female, 38 years old, 8 years on antiretroviral treatment)

4.5.6.2 Environmental factors and services beyond the ARV clinic

The environmental factors in the hospital that act as facilitators and as barriers to function beyond the ARV clinic are described:

Services outside ARV clinic environmental factors that act as facilitators

The facilitators included rehabilitation services that assist with functional limitations or problems; involvement of PLWH community in their care, the extended care to the PLWH through the national medical insurance cover *Mutuelle de Santé*.

Rehabilitation services assist with functional problems

Very few participants with functional limitations or problems at either hospital had been referred to the appropriate rehabilitation service. At Hospital A one participant had been referred for physiotherapy at another hospital, and another participant to the mental health service. At Hospital B one participant had also been referred to the mental health service. These participants were satisfied with the care they received from the two rehabilitation services.

3A: (Showing happiness) *There was a time they gave me a transfer to CHUK for physiotherapy. I had much paraesthesia and paralysis (muscle weakness). They really helped me and I was healed!* (Urban, female, 45 years old, 9 years on antiretroviral treatment)

3B: *I told the ARV Doctor that usually I have memory loss, [and] he sent me to mental health doctors. I am now having their medicines.* (Rural, female, 38 years old, 8 years on antiretroviral treatment)

Involvement of my community in care

One woman explained how some health care providers in the ARV clinic think beyond the hospital environment and act holistically by considering not only the health care services at the hospital; they also seek to involve the patient's community, starting with their family, to provide further support. The nurses and doctors had assisted her by inviting her family members and the local leaders in her community for a discussion; the health care workers advised the family to give her as much support as possible, instead of mistreating her.

7A: *Three months ago, I came here, they examined me and found that the CD4 count has decreased. They asked me why and I explained that was maybe due to family problems I was facing. They called my family and the local leaders. They forbid them to ill-treat me. On the contrary, they should look after me as [they do] others.* (Urban, female, 46 years old, 5 years on antiretroviral treatment)

The national medical insurance cover - *Mutuelle de Santé* (Also see section 1.1.1)

Many of the participants indicated that they could afford to have the inexpensive medical cover, the Rwandan National Insurance, *Mutuelle de Santé*. They explained how it had many advantages for their health; for example, when somebody was recognised as a PLWH with *Mutuelle de Santé*, all treatment was free. They explained that it would be a good reason for them only to use the medical file from the ARV clinic at all clinics.

1B: *We have the advantage of going to other services with the ARV medical file, because if you have the *Mutuelle de Santé*, you are treated for free, whereas others pay 10% [of all services and drugs].* (Rural, female, 36 years old, 6 years on antiretroviral treatment)

Services outside ARV clinic environmental factors that act as barriers

The factors that acted as barriers included overcrowded facilities and long waiting times, participants' need for special consideration, participants' lack of awareness of the health care providers' responsibility to assist with functional problems, the inability of health care providers outside ARV clinic to assist with functional problems, poor communication, the negative attitudes of health care providers, the unavailability of doctors, the limitations of the national medical insurance and a preference for private rather than public facilities.

Facilities overcrowded and long waiting time

Many participants were not satisfied with the care they received from the other services they were referred to within the hospital. At the outpatient department and at the speciality services there were many other patients and they had to wait for a long time. This could have an impact on their condition.

3B: (speaking with sadness) *We have a problem! We sometimes go to see other doctors and find that they have many patients. Hum!⁴³ We are worried about a long line that we must make waiting for meeting a specialist whereas we are not like other sick people. Us, we are weak. Consequently, our health condition gets worse.* (Rural, female, 38 years old, 8 years on antiretroviral treatment)

Participants felt the need for special consideration as a PLWH

Several male and female also reported that one reason why they did not appreciate the care provided by the services they were referred to was that they were treated in a similar way to all the other patients. They said that they had special problems/needs related to their HIV status, which meant they were different from others; thus they expected to receive special consideration, or special care.

8A: (Looking nervous showing the seriousness of the problem) *The way they treat us in other services, is not different from other patients, whereas I think we are different. We even sometimes tell them that we are HIV-positive but we are treated and considered in*

⁴³ Expression of disagreement and worry

the same way as other patients. I usually ask myself why? (Urban, female, 23 years old, 4 years on antiretroviral treatment)

Likewise two other participants from Hospital A said that the health care workers in the other services gave them normal care, just like others, although they did not consider themselves as having the same needs as other patients: *“We are different, we are not like others”*.

Three other participants added; *“Yes! That is how it is, and sometimes we are in a severe condition!”*

6A: I think they should give us a special care! For sure, they do not care about us sufficiently. (Urban, male, 28 years old, 3 years on antiretroviral treatment)

Participants’ lack of awareness of the health care providers’ responsibility to assist with functional problems

Some participants were confused about whom they were being referred to. They were no longer certain who would look after them. They were not very sure which type of health care provider they were to be referred to, and who could assist them with the functional problems they were facing. In this situation, they ended up with a lot of extra stress (in addition to that usually associated with HIV).

6A: Truly we do not know which type of health care providers to go to for the problems we told you! Only what we know when we are referred, we do not have a person who looks after us in particular. This makes it more stressful! (Urban, male, 28 years old, 3 years on antiretroviral treatment)

Health care providers outside ARV clinic are unable to assist with functional problems

Various participants have mentioned that, as with the ARV clinic, health care providers at the other services did not always assist them adequately with their functional problems. They complained that the health care providers in other clinics were always overwhelmed with many patients and managed what they were able to by only prescribing drugs. The participants repeatedly brought up the issue of only having medicine prescribed: they said the medicines they were given were ineffective.

2A: *The services where we are referred to, they are always too busy with many patients and they manage what they can by only giving us medicines.* (Urban, male, 49 years old, 5 years on antiretroviral treatment)

2A: *Even for paraesthesia, nausea, backache and others, they prescribe medicines but we are not cured.* (Urban, male, 49 years old, 5 years on antiretroviral treatment)

8A: *Yeah! It is because the drugs we are given for the complications are not efficient.* (Urban, female, 23 years old, 4 years on antiretroviral treatment)

One male participant, at Hospital B, suggested another reason for their difficulty with other services was that patients were not familiar with the health care providers working there.

4B: *Sometimes the care we receive from doctors from other services is not effective because we are not familiar with them.* (Rural, male, 44 years old, 6 years on antiretroviral treatment)

Poor communication

The health workers did not communicate in the ways male and female participants in both urban and rural areas wanted. They wanted to be listened to, to have their health problems explained, and to be involved in decision-making about their health care.

1B: *Doctors do what they can! I mean their best! But I think and wish really if we could have more doctors who can take time to listen to our problems it could be better.* (Rural, male, 47 years old, 6 years on antiretroviral treatment)

8A: *We are not getting the detailed explanations of what we are suffering from.* (Urban, female, 23 years old, 4 years on antiretroviral treatment)

2A: *The doctor just judges and takes decisions for you. He/she does not ask you many questions.* (Urban, male, 49 years old, 5 years on antiretroviral treatment)

Participants related the issue of communication to self-acceptance, saying good communication could improve acceptance of being HIV-positive. They wanted “*be given special consideration*”

8A: *We need communication more than others do, because we have special needs ... Really, we are not considered differently from other patients. (Urban, female, 23 years old, 4 years on antiretroviral treatment)*

1B: *Through interaction, they can teach us self-acceptance since many among us have not yet accepted their situation. (Rural, male, 47 years old, 6 years on antiretroviral treatment)*

Some participants attached so much importance to communication that they avoided being seen by particular doctors who did not interact with them or to listen to their problems.

1B: *For example, you may hear someone saying that I cannot get in if such a doctor is inside, just because he knows the doctor does not always have time to talk or to listen to his problems. (Rural, female, 36 years old, 6 years on antiretroviral treatment)*

They thought one reason doctors did not listen was because they were so busy.

5B: *I personally know one doctor, he is a friend of my brother, but he is very busy at work like others. I prefer to meet him at home and explain all my problems to him and then, he gives me appropriate advice. (Rural, male, 30 years old, 5 years on antiretroviral treatment)*

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Health care providers' negative attitudes to PLWH

Certain participants complained that at some health centres they visited, the health care providers did not show compassion; instead they discriminated against them once they discovered that they were PLWH.

8B: *When you go to a health centre and tell them the problem you have, they look in the file and tell you to go to the doctor who follows you. You realize that you are coldly received just because you are a person with HIV. (Rural, female, 38 years old, 8 years on antiretroviral treatment)*

Doctors not available

Sometimes, even on referral, doctors were not available for the patient despite having an appointment. This might be because the doctor has been called to an emergency. The patients would then have to continue with only the antiretroviral treatment or go to a private clinic, if they had the money.

3B: You may frequently come to see a doctor, on appointment given and miss him whereas you are suffering much. This makes you either go to private clinics, if you have money or keep on taking the medicines (ARV). (Rural, female, 38 years old, 8 years on antiretroviral treatment)

Limitations of the national medical insurance, *Mutuelle de Santé*

At the rural hospital, some participants explained that *Mutuelle de Santé* had its limitations, and not all their needs could be met. It did not cover all the necessary medication, especially expensive medication, and did not include some specialists' services. Sometimes they paid separately for these services.

8B: Some medications are not covered by Mutuelle de Santé so we buy them 100% with our own money. (Rural, female, 23 years old, 8 years on antiretroviral treatment)

3B: Heeee!⁴⁴ I had a problem of the eyes. The ARV service gave me a transfer to ophthalmology. Then, my medical insurance was refused. So, because I was suffering much, it required me to pay by myself for consultation. (Rural, female, 38 years old, 8 years on antiretroviral treatment)

Comparing care in private and public facilities

Some participants, particularly men, had considered seeking care at private clinics. They had the impression that private health services were better than those in the state sector. They suggested that the public sector needed to recognise its weaknesses and refer them to these private clinics.

⁴⁴ Expression of disappointment

1A: *They prescribe inefficient drugs, instead of referring us to private clinics where we would get efficient treatment.* (Urban, male, 47 years old, 4 years on antiretroviral treatment)

They said they would go to private clinics if they were informed that appropriate drugs were not available at the hospital.

1A: *They [the government hospital] would tell us that they do not have the appropriate medicines for the problems we have. Thus, we would seek help in private clinics.*

(Urban, male, 47 years old, 4 years on antiretroviral treatment)

Some male and female participants said that, at times, the quality of care in private services was better; some health care providers in the private sector had attended to their functional problems but participants appeared reluctant to discuss this, as if they feared being reported to the ARV clinic. Other participants did not agree that the care was better at the private clinic:

7A: *I had pain in shoulders and back. I was given medicine here at this hospital, but there was no improvement. I went to private clinic where they also gave me medicine, but until now nothing changed. So it depends!* (Urban, female, 46 years, 5 years on antiretroviral treatment)

Care in private clinics was much more expensive, unless one had additional private health care insurance, for example RAMA.

2A: (Seemed to hesitate, murmuring, like someone thinking of what he is going to say); *Hum!*⁴⁵ *I prefer to go to private clinics because it is where I get treatment and recover. Really medicines they give us here ... do not help! And I think if one has means, to get treatment in private clinics it is not a problem. I use RAMA. In fact, all clinicians there [at the private clinic] receive patients with care.* (Urban, male, 49 years old, 5 years on antiretroviral treatment)

⁴⁵ Expression of hesitation

3A: *You are right! Long ago, pain in muscles and nerves became too much. I had some money and decided to look for a doctor in private. He had prescribed me a medicine; I went to buy it in a private pharmacy. It was expensive, but helped me much! It was the efficient medicine!* (Urban, female, 45 years old, 9 years on antiretroviral treatment)

4.5.7 Theme 6: How the hospital services could respond to my functional limitations

This theme describes participants' recommendations regarding improvements in the hospital services to respond to their functional needs and improve their quality of life. This included recognition of their vulnerability, providing counselling, improving their human resources, and making use of appropriate treatment planning and management.

4.5.7.1 Recognise the vulnerability of PLWH

Participants felt that they were extremely vulnerable, with special needs, and emphasized that they needed to be given special consideration by the doctors and other medical staff; they required more attention than other patients, including referral to other services. They wanted to be treated by people who would understand their problems and who would support them.

8A: *I suggest, doctors where we are referred to, should take more care of us than they do for ordinary patients. They should know that we have our special needs related to our health condition. Thus, we need special care.* (Urban, female, 23 years old, 4 years on antiretroviral treatment)

The participants wanted the health care providers in the services beyond the ARV clinic to understand their health condition and the problems they were facing and in particular to take more time to listen to them than they did with the other patients.

4A: *We need health care providers from this hospital to understand our condition and the related problems, to listen to us more than they do for ordinary patients.* (Urban, female, 66 years old, 7 years on antiretroviral treatment)

4.5.7.2 Establish counselling programmes

Many of the participants wanted a counselling programme offered daily or at least once a month, as this was how often they attended the ARV clinic. They believed that group counselling sessions could help PLWH change their behaviours. This support should not only

include psychological care but should also include their quality of life and adherence to antiretroviral treatment.

3A: There is a problem with counselling here! There should be group counselling every morning. There are some cases that shock me. For example, there are women who are continuing getting pregnant every year when they are HIV-positive. They are not well fed; they are poor, really they should be given some advice in particular. (Urban, female, 45 years old, 9 years on antiretroviral treatment)

3A: We also need the group counselling for nutrition and dietetics. It would help us have our own control on body weight. (Urban, female, 45 years old, 9 years on antiretroviral treatment)

8A: And it (counselling) also teaches us the importance of medicines. (Urban, female, 23 years old, 4 years on antiretroviral treatment)

In FGD B, one participant said the counselling would strengthen them, and she related counselling training to self-acceptance. All other participants expressed the need for training.

6B: Yeah; counselling is good. During sessions; they should teach us about health care, rebuild our hearts, and give us advice concerning self-acceptance. (Rural, female, 42 years old, 8 years on antiretroviral treatment)

4.5.7.3 Human resources

Most participants emphasized the need for health care providers to be available.

Availability of medical doctors in ARV clinics

At Hospital A, they wanted a medical doctor at the ARV clinic because there was not one. They said that if there was a doctor they would be examined and treated at the ARV clinic, and the doctor would only refer those cases he or she could not manage, and referral would be to the right specialists. They said this should improve the referral procedure.

6A: The obstacle to referral is the lack of our own doctor here in our clinic. (Urban, male, 28 years old, 3 years on antiretroviral treatment)

2A: They complicate our life when they include us in the normal hospital referral procedure without first being examined by a doctor here in our clinic. It could be better if a doctor examines us here and refers to others if needed. (Urban, male, 49 years old, 5 years on antiretroviral treatment)

Participants at the rural hospital said they had one medical doctor at the ARV clinic. However they wanted for a second one to assist because the doctor was so busy. The doctor needed to attend to patients in other departments or to attend workshops and meetings. At times patients who came to get treatment left without receiving any because the doctor was not available.

1B: In this ARV service, [it] would be better if we had another doctor who could work once the one we have is absent. He may have gone to attend training or work in other services, [or] to care for other patients, and sometimes, when one amongst us falls severely sick and comes to seek care and finds that the doctor is not there, sometimes he goes home without any treatment and his condition gets worse. (Rural, female, 36 years old, 6 years on antiretroviral treatment)

Participants wanted to be treated by the doctor they were familiar with.

4B: Sometimes, the care we receive from different doctors is not effective because we are not familiar with them. (Rural, male, 44 years old, 6 years on antiretroviral treatment)

Availability of rehabilitation specialists

At both hospitals most of the participants wanted to be referred to the appropriate specialists to assist with their functional problems.

3A: We would wish to have specialists for all the problems we have mentioned earlier; such as headache and paraesthesia. (Urban, female, 45 years old, 9 years on antiretroviral treatment)

At Hospital B, the discussion was extremely vibrant and participants came up with interesting propositions. Most indicated that they would prefer to have specialists provide them with all the necessary care in the ARV clinic.

6B: *It could be better if we have the specialists for the complications we told you, like paraesthesia, chronic headache, eye problems, back pain, and so on. We wish they [the specialists] could be close to us in ARV service.* (Rural, female, 42 years old, 8 years on antiretroviral treatment)

Participants assumed that this would solve the lengthy waiting time experienced at the other services.

7B: *Yeah! We would like the specialists here, close to us in this service, so as to avoid the long appointment.* (Rural, female, 45 years old, 3 years on antiretroviral treatment)

However, one participant at the rural hospital disagreed saying it would be unfair for other patients who needed to see that specialist.

1B: *According to me that is not possible! Instead, they can group together all patients with similar health problems and connect to the right specialists who can help them, because if he /she come here in this ARV service, other patients can miss him/her whereas they are also suffering.* (Rural, female, 36 years old, 6 years on antiretroviral treatment)

Team of health care providers exclusively for PLWH of the
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Participants not only wanted their own medical doctor but an entire team of health care providers in the ARV clinic or in any other service they visited within the hospital or outside the hospital. They explained that as they would always be patients they wanted health care providers whom they could trust and who would look after their problems, always to be there for them, and give them special consideration. They said this on-going contact with the health care providers would improve the quality of care.

3B: *Since we are permanent patients, we would rather have our own health care providers, who follow us and we tell them our problems. Otherwise, complaints are always there! We will always have problems.* (Rural, female, 38 years old, 8 years on antiretroviral treatment)

Increased numbers of hospital health care providers

Without specifying the profession, participants at both hospitals wanted an increase in the number of health care providers in both hospitals. This would improve service delivery by reducing the waiting time, which was a serious problem.

3A: Health care providers are few. They should increase their number. (Urban, female, 45 years old, 9 years on antiretroviral treatment)

2B: For me, I think care delivery in this hospital can be improved by increasing number of health workers. Service delivery needs to be improved really. (Rural, male, 21 years old, 3 years on antiretroviral treatment)

3B: Yeah, moreover, this hospital receives so many patients in the way that, sometimes they become intolerant [of] prolonged waiting periods which, therefore, may lead to grumbling and insulting the health care providers. If possible, there should be more health care providers who could quickly solve the patients' problems. (Rural, female, 38 years old, 8 years on antiretroviral treatment)

Because of the shortage of health care providers, and the increased number of patients, some patients were referred to other hospitals and again might need to wait for an appointment. This waiting for an appointment had a negative impact on their health condition.

5B: Indeed it is important that the number of health care providers be increased. Do you know that it sometimes happens to be sent to another hospital and then, be given another appointment from that hospital because of many patients? This exacerbates the disease we are suffering from. (Rural, male, 30 years old, 5 years on antiretroviral treatment)

Nurse to be responsible for ARV medication at the health centre

One male participant spoke about care outside the hospital and suggested that a nurse be made responsible for the ARV service at each health centre so as to improve services for PLWH from the primary level.

4B: *At each [health centre], there should be a nurse who is in charge of ARV service.*
(Rural, male, 44 years old, 6 years on antiretroviral treatment)

4.5.7.4 Treatment planning and management for PLWH

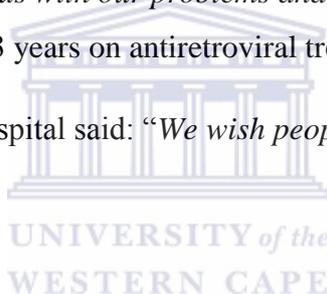
Participants spoke of the need for collaboration between health care providers, improved referral, and having a single medical file.

Collaboration

Participants at both hospitals said it would be good if the health care providers at the ARV clinic could work closely with those from other services within the hospital. They should have frequent meetings to identify the problems of PLWH and collaborate in planning effective care.

2B: *I think all health care providers in this hospital should work together; it is an important strategy to assist us with our problems and improve their service delivery.*
(Rural, male, 21 years old, 3 years on antiretroviral treatment)

Three participants at the urban hospital said: *“We wish people could work together. It can solve many problems”*.



Referral

Male and female participants wanted the health care providers at the ARV clinic to recognise their limitations in managing the patients' problems and refer them to other departments. The health care providers needed to consult with each other when deciding who the most appropriate person was to whom they should refer the patient.

2B: *They should think about referring us when they cannot manage the condition.*
(Rural, male, 21 years old, 3 years on antiretroviral treatment)

6A: *Really it would be better if they discuss our problems together with others and send us to particular specialists who can give us appropriate treatment for specific sicknesses.* (Urban, male, 28 years old, 3 years on antiretroviral treatment)

3B: If the Doctor realizes that he or she is not able to cure the disease, he/she should refer us to another who [would be] able to manage it. That is what collaboration means! (Rural, female, 38 years old, 8 years on antiretroviral treatment)

Participants wanted appropriate referral so they did not need to find their own specialists. One woman at urban Hospital indicated that if the referral was well organized from the ARV clinic, patients would not need to look for specialists as they did not have the background to find the appropriate people.

3A: We would like to be transferred to specialists from here if there is a need; without [having to use]our own initiative to look for them. We sometimes look for them by ourselves and do not find the right people. (Urban, female, 45 years old, 9 years on antiretroviral treatment)

A single medical file

Participants did not like to have a separate medical file in each department. They wanted to use one medical file for all services, regardless of where they were being referred to. The use of one medical file could foster collaboration and improve the referral procedure. It could improve patients' relationships with health care providers throughout the hospital. It could improve follow-up and the quality of service delivery.

2B: We would like also to propose one medical file should be sent to the service a patient is transferred to. This would help the specialists refer to the progress notes of the ARV doctor or other doctors. It would then make us feel free with them like our ARV doctor. (Rural, male, 21 years old, 3 years on antiretroviral treatment)

7B: This would be much better because one medical file can be used in every service we go through and we then have no difficulties with the treatment process. Even that mess of many medical files we mentioned earlier, would be over. (Rural, female, 45 years old, 3 years on antiretroviral treatment)

The moderator wanted to know if participants did not have problem with their status being known when moving the medical file from one service to another. Contrary to what they said earlier, participants indicated that they did not mind their HIV status being known by all the

health care workers and that they would rather give priority and consideration to the quality of care.

4.5.7.5 Improve the quality of National Medical Insurance: *Mutuelle de Santé*

At both hospitals the participants wanted the quality of *Mutuelle de Santé* to improve so it would provide more benefits. Alternatively, they wanted another type of medical insurance that would cover their medical needs as PLWH.

2B: If the quality of the National Medical Insurance is not improved they should find us a particular health insurance that enables us to have all diseases treated as happens for HIV/AIDS. (Rural, male, 21 years old, 3 years on antiretroviral treatment)

A mother, 38 years old, wanted the poorer people to be assisted with the medical insurance fees of their children as they were not always able to pay.

8B: It is better you helped us find health insurance for our children because we have much difficulty paying it for them. (Rural, female, 38 years old, 8 years on antiretroviral treatment)

Participants at the urban hospital, were concerned about PLWH who were very poor, and thus unable to afford the medical insurance payments. They wanted them to be assisted and provided with medical insurance to cover their health needs.

2A: It would be better to assist PLWH, especially those who do not have medical insurance because of poverty, to get it. (Urban, male, 49 years old, 5 years on antiretroviral treatment)

3A: Yeah, for sure it could be a good thing really, they cannot afford [it] by themselves, they are miserable! (Urban, female, 45 years old, 9 years on antiretroviral treatment)

Other participants: “*Hum!*”⁴⁶ *They really suffer much!*”

⁴⁶ Expression of sympathy

Participants wanted the hospital pharmacy to be well stocked. One participant said that sometimes the hospital pharmacy lacked essential drugs so the patients had to buy medicines from a private pharmacy without medical insurance. This was expensive.

2B: However, the hospital also should be empowered to find enough medicines. Sometimes, we are prescribed medicines [when] they cannot be found in the hospital store. We are, then, required to buy them in private pharmacies at a higher price.
(Rural, male, 21 years old, 3 years on antiretroviral treatment)

4.5.7.6 Implementation of nutrition or food programs

Participants at the rural hospital wanted nutrition and food support programmes for PLWH. Good nutrition was recognised as important for a healthy lifestyle for PLWH. They said that food was provided to PLWH in the past by non-government organisations (NGOs), through PLWH associations, and this was still needed.

1B: There were associations through which donors supported people living with HIV infection by giving them food. We wish the programme to be restored and help us because these medicines require adequate diet. (Rural, female, 36 years old, 6 years on antiretroviral treatment)

There was a suggestion to revisit the *Girinka* or “One cow to one poor family” policy in Rwanda; this had been initiated to eradicate poverty. This was a national programme aimed at giving a cow to every poor Rwandan family to ensure that they would have some food. They wanted PLWH to benefit from this programme.

6B: I suggest you advocate for us that “Girinka” should reach our associations so as to access milk which would help get proper diet. (Rural, Female, 42 years old, 3 years on antiretroviral treatment)

Financial support for orphans

One male student, an HIV orphan, wanted other HIV orphans who had stopped going to school due to a lack of school fees to be assisted financially so they could resume their studies.

2B: *I suggest that you should help HIV- infected orphans who [have] stopped studying. You could help them find supporters who can pay their school fees.* (Rural, male, 21 years old, 3 years on antiretroviral treatment)

Youth HIV clinic

The young male student wanted to separate the children/youth service from the adult service. He said youth had different interests from adults and sometimes, when they were together waiting for treatment, children complained of being bored and annoyed by the adult conversation. He wanted school children to be provided treatment before other people so they could report in time for school.

2B: *We children, when we sometimes come here to take medicines, we normally become annoyed with uninteresting parents' stories. And also our wish as students is that they should let us be treated before other patients so that we can go back to school early.* (Rural, male, 21 years old, 3 years on antiretroviral treatment)

Time management

One female participant, at the urban hospital wanted health care providers to improve their time management, to respect the starting time of work and to avoid mixing social and work activities

8A: *We would like to request health care providers to start work on time. They begin when they want and when they are there at time; they keep on telling stories, just wasting time.* (Urban, female, 23 years old, 4 years on antiretroviral treatment)

Need for privacy

At the urban hospital, the male participants wanted privacy. For example one man indicated how he wanted more privacy at the ARV clinic, and complained that there was a family planning clinic at the ARV clinic and he wanted this separated from the ARV clinic.

6A: *There is another problem; we used to be alone at this service. Now, we are with another service [family planning] which is bothering. We wish we could have some privacy.* (Urban, male, 28 years old, 3 years on antiretroviral treatment)

4.5.8 Summary

The themes that emerged are presented in these findings. The first theme described the impairments that manifested in patients, due to HIV infection or to the antiretroviral treatment. The impairments mentioned were: lack of energy, pain, paraesthesia, dizziness, lipodystrophy, body image and memory loss and lack of concentration. Male and female participants, in both urban and rural hospitals, spoke of similar impairments. They indicated how severity might change overtime.

The participants' impairments, especially lack of energy, which gets worse overtime, pain, paraesthesia, breathlessness and loss of memory, affected their function and performance of daily activities and their participation in social life. The activities most affected were: mobility, self-care, and life activities, including household and work activities. All activities, except households, were reported by men and women equally.

Reduced activity performance contributed to decreased productivity, which affected livelihood, and this occurs overtime. Impairments, particularly lack of energy, restricted male and female participation in social life, including leisure activities, social relationships, spiritual practices and sexual relations. Males participants compared to females, spoke more about lack of energy causing decreased engagement in sexual intercourse. The female participants who talked, complained about lack of desire as a cause of decreased involvement in sexual intercourse rather than lack of energy.

The third theme described the personal factors that either facilitated or limited participants' functioning. Personal factors that facilitated functioning included spiritual beliefs and faith in God; positive thinking about disclosure was identified as a strategy to improve psychological well-being, or to overcome internalised stigma and to create awareness about HIV. Other facilitating factors were: a sense of belonging at the ARV clinic; a sense of solidarity among PLWH; and trust in other people, especially parents, close friends and health care providers (this facilitated disclosure). Coping strategies that participants developed were described. Personal factors that limited functioning were also discussed. These included internalized stigma, expressed by feelings of being hurt, and feelings of regret and shame, and guilt and remorse about HIV. The participants had thoughts about being stigmatized, being chased away, being judged or being dismissed from work. Age was identified as personal factor that

could influence the ability to function well. Very few men were engaged in the discussion on disclosure. Although female participants spoke of positive and negative effects of disclosure the only man who spoke of disclosure indicated that it would lead to stigmatisation and it was not clear that he had disclosed his status to anyone beyond the ARV clinic. This was similar in both rural and urban areas. Certain women shared how disclosure becomes easier overtime. Likewise women dominated the discussion on stigma, in rural and urban areas. Other factors were spoken about by both men and women, in rural and urban areas.

The fourth theme described the social relationship or community environmental factors that influenced the participants' functioning. Social relationships included participants' relationships with their families and with their communities. Family relationship factors that facilitated functioning included good family support and positive attitudes. Family relationship factors that hindered functioning were the negative attitudes of family members. Community relationship factors that acted as facilitators included good community support and positive attitudes, that could lead to improvement overtime. Community environmental factors that limited functioning included community stigmatisation and discriminatory attitudes. Female participants compared to male, expressed easily their feelings and experiences regarding family and community relationship. It was not easy to know male participants' living experiences and relationship with their family and community after contracting HIV.

The fifth theme described the factors in the hospital environment that influenced the functioning of PLWH. The hospital environment included the ARV clinic and services outside the ARV clinic environment. Environmental factors in the ARV clinic that facilitated functioning included the service provided by the ARV clinic, trust in these health care providers, and the referral procedure from the ARV clinic to other services within the hospital. Environmental factors in the ARV clinic that acted as limitations to functioning included a lack of assistance concerning functional problems, the participants' lack of knowledge about specialist services that could help to manage the functional problems, the inconsistent referral procedure, and the use of multiple medical files for one patient within the same hospital. Environmental factors related to services beyond the ARV clinic that facilitated functioning included assistance with functional problems from the rehabilitation

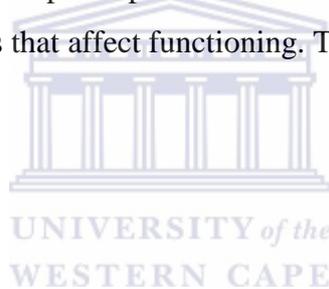
services, involvement of the community in care, and aspects of the national medical insurance, *Mutuelle de Santé*. Environmental factors related to services outside the ARV clinic that limited functioning included overcrowding, long waiting times, the absence of any special consideration for PLWH, participants' lack of knowledge of health care providers who may assist with functional problems, the health care providers' inability to assist with functional problems, a concern about whether the private service was better than the public service, and this was more spoken about by male participants, poor communication, health care providers' negative attitudes, the unavailability of doctors and inability of *Mutuelle de Santé* to respond to all the health care needs of PLWH.

Theme six described the participants' recommendations for improving services at the hospitals. These included: recognition of the vulnerability of PLWH, the establishment of a counselling program, an increase in the number of health care providers, strengthened collaboration and an improved referral system within the hospital, a single medical file, improved quality of service by *Mutuelle de Santé*, a food programme, a dedicated youth HIV clinic, education support for PLWH orphans, health care providers to respect time management, and consideration for privacy at ARV clinics. Only male participants spoke about the need for increased privacy.

5 CHAPTER FIVE: DISCUSSION OF RESULTS OF THE QUANTITATIVE AND QUALITATIVE STUDIES

5.1 Introduction

This section discusses the findings of the quantitative survey and the FGDs. The findings are discussed using the conceptual framework of the ICF presented in Chapter One (Figure 3). The key findings of the survey that relate to the profile and prevalence of disability among PLWH were obtained through the measurement of impairments, activity limitations and participation restrictions among PLWH who were on antiretroviral treatment. Where relevant, the results of the survey are also triangulated with those of the FGDs. The discussion includes: the participants' personal factors, including the demographic profile and the impact of personal factors on functioning; the participants' HIV status (health condition); the impairments, activity limitations and participation restrictions profile; and the community and the hospital environmental factors that affect functioning. The chapter ends with reflections and the limitations.



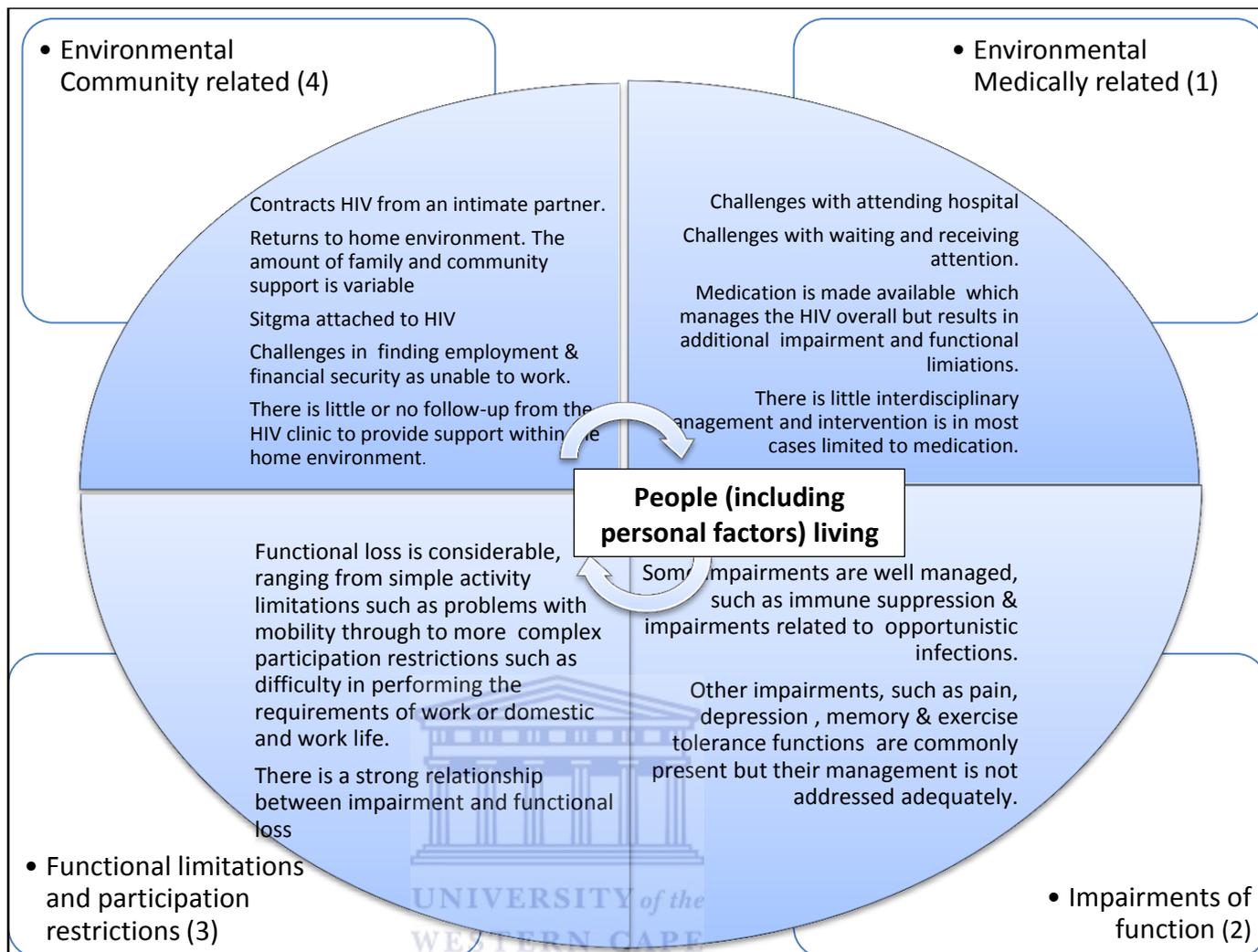


Figure 23: The bio-psychosocial model of management for people in Rwanda

5.2 Personal Factors

In this section the socio-demographic profiles of the participants are presented and the effect on functional limitations and participation restrictions is discussed. The sample of over 500 is large in comparison with that in a number of other studies on function in HIV (Anandan, et al., 2006; Myezwa, et al., 2009; Van As, et al., 2009), and is likely to be large enough to allow for generalization of the results of those attending public clinics and receiving antiretroviral treatment for more than one year in Rwanda.

5.2.1 Gender

On the days of data collection at the ARV clinics for the survey 35.7% of all patients attending the clinics were males and 56.6% females. Of these, 48.3% of these patients were willing to participate in the survey and met the inclusion criteria of being on ARVs. These participants were interviewed in the final sample.

In each of the FGDs, although there was an attempt to have an equal number of males and females in the group, the proportion was 3:5 male: female participants. Other men declined to participate. Although the socio-demographic findings of the FGD participants are not considered generalizable they are presented in the relevant sections.

The survey sample shows an over-representation of women, as 75% of the respondents were female. More women than men came to seek care on the days of data collection, and a greater proportion volunteered to participate in the study. This over-representation may be because women are more at risk of being infected with HIV, or because more women than men attend public sector facilities, or it may be the result of a combination of both factors. Likewise in the FGDs a greater proportion of women volunteered to participate. Two other studies on HIV conducted in Rwanda also showed samples dominated by women (Mutimura, Stewart, Crowther, Yarasheski, & Cade, 2008; Uwimana & Struthers, 2008). Similarly, several other studies conducted in sub-Saharan Africa have demonstrated an over representation of women (Freeman, et al., 2007; Harding et al., 2012; Makoae, et al., 2008; Makoae et al., 2005; Myezwa, et al., 2009; Pearson et al., 2009; Van As, et al., 2009; Wanyama, et al., 2007). In contrast, a review of various other studies on HIV from different places in the world, such as India, USA, Canada and Brazil, showed a higher proportion of men in their samples (Coleman, et al., 2006; Devnani, Gupta, Wanchu, & Sharma, 2012; Emler, 2007; Gaidhane, et al., 2008; George, et al., 2009; Miaskowski, et al., 2011; Rusch, et al., 2004a; Taneja, Dixit, Yesikar, & Sharma, 2012; Toro, Burns, Pimentel, Peraza, & Lugo, 2006).

There is a higher prevalence of PLWH in sub-Saharan Africa than other countries in the world (UNAIDS, 2012a, 2012b), and this mainly affects women (UNAIDS, 2012a).

Findings from the recent demographic health survey in Rwanda have confirmed a higher rate of HIV infection in women than in men (4% vs. 2%, a ratio of 2 to:1) (National Institute of Statistics Rwanda, et al., 2012). This could explain why, in the current study and in other

similar sub-Saharan Africa countries, women have dominated the sample. In addition, as Uwimana and Struthers (2008) state in their article, women have specific health issues or conditions, such as gynaecological and obstetric conditions, that lead them to seek health care more often than men. It thus appears as though a combination of the higher prevalence of HIV infection in women and the lower attendance of men at public health facilities could account for the higher rate of female participation. If this were not so, the ratio of female to male presenting with HIV would be 2:1 (according to the national figures), or 66.6%: 33.3%.

Another possible interpretation could be the influence of the masculinity characteristic of men: the traits associated with masculinity could also explain their lower rate of attendance and participation in the study. It has been observed that, unlike women, men often only access health care when their health condition becomes severe and they are no longer in control of their health (Mavhu et al., 2010).

In terms of generalizability, the findings are more likely to reflect the experience of women than that of men, and future research is needed to establish why men with HIV are less likely to attend clinics and volunteer for research projects in Rwanda.

5.2.2 Age

The mean age of the sample in the survey was 39.7 years. In the FGDs the mean age was 41.8 years for FGD A and 36.8 years for FGD B. A study of HIV conducted in Rwanda by Mutimura et al. (2008), as well as several other studies on HIV conducted in other African countries, such as Kenya, South Africa, Tanzania and a multicentre study involving South Africa and Uganda, present the mean age of their samples as being between 36.5 years and 38.6 years (Cettomai, et al., 2010; Harding, et al., 2012; Mullin, et al., 2011; Myezwa, et al., 2009). Studies reviewed from Western countries have shown a greater mean age (\Rightarrow 40 years) in their samples (Aouizerat, et al., 2010; George, et al., 2009; Holzemer, et al., 2009; Miaskowski, et al., 2011; Toro, et al., 2006).

Worldwide, the prevalence of HIV has drastically decreased and the number of those newly infected has been significantly reduced. Between 2001 and 2011, Rwanda achieved a reduction of more than 50% in new infections (UNAIDS, 2012b). This might be the reason why there were fewer participants in the youngest group (15 to 30 years old) in the survey;

this group would otherwise have been expected to have more cases of HIV infection due to the recognised increase in sexual activity among this age group. Moreover, in Rwanda there has been a large investment in the prevention of HIV. Various approaches have been used, such as mass media education campaigns; behaviour change programmes, such as voluntary testing and counselling; ensuring that condoms are available and accessible; and programmes to encourage male circumcision, among others (Ministry of Health (MoH) Rwanda, 2011b).

Findings from the recent Rwanda national demographic health survey demonstrated that the HIV infection is most prevalent among women between the ages of 35 and 39 years old (7.9%), whereas for males it is most prevalent between the ages of 40 and 44 years (7.3%) (National Institute of Statistics Rwanda, et al., 2012). This could be one of the reasons why, in this survey, men were approximately five years older than women, the mean age for the males was 43.4 years, whereas for the females, 38.4 years. This is similar to a study conducted in South Africa which showed that men were almost five years older than women (Myezwa, Stewart, Mbambo, & Nesara, 2007). In a study in Mozambique, the difference was slightly higher as the mean age for men was seven years more than that for women (Pearson, et al., 2009). In a study conducted in India, the difference was even greater: the mean age of men was ten years more than that of women (Devnani, et al., 2012).

Another possible interpretation for this phenomenon (the men being older than the women) could be that, in general, younger women are more likely to be more exposed to HIV infection than men when they have sex with an older man. Factors, such as poverty, particularly among females, may help to explain this. One should also take into account the influence of culture, which contributes to the women's inability to negotiate with regard to sex or the use of condoms. Sexual violence which may be linked to women having sex with older men, exposes women to unsafe sex and HIV infection (UNAIDS, 2010).

5.2.3 Marital status

In the survey, the most common marital status among males was 'married' (65%) while 'widowed' was most common among females (41%). In the FGDs the commonest marital status among the men was 'married' (40%), the others were single or separated. No men indicated they were 'widowed'. Among the women, the commonest marital status was married (60%), widowed (30%). 'Widowed' was highest (48% and 44%) in two other Rwandan

studies, with similar samples, but this applied to both sexes (Mutimura et al., 2008; Uwimana & Struthers, 2008). In contrast to this survey, findings from the national demographic health survey found that most women with HIV were married (50%), 47% men were married, 5% of women were widowed, and fewer than 1% of men were widowed (National Institute of Statistics Rwanda, et al., 2012).

There are a number of reasons for these discrepancies. Firstly, the number of married men may reflect the belief that the respect, dignity and recognition of a man in the Rwandan culture is influenced by his marital status. Men may identify as married (whether legally or not) because they want to be recognized by the society as responsible, mature and respectable adults. Secondly, the survey indicates that many married women become infected; in some cases, their husbands have died and they are widowed. A widow may choose to live her life alone with her children, rather than getting married to another man. In contrast, most men remarry after losing their wives. Thirdly, the aftermath of the 1994 war and genocide could also explain these findings. During the genocide, many men were killed, leaving behind many widows (Jones, 2002; Newbury & Baldwin, 2000); many women were sexually abused during this period (Cohen, et al., 2009; Mukamana & Brysiewicz, 2008) and sometimes contracted HIV (Donovan, 2002). Among those women, there might have been young girls. A higher rate of widowed women was also found in one group of PLWH in India (Devnani, et al., 2012).

The findings on marital status from the survey suggest the need for further research to test these assumptions and to provide more insight into the reasons for the significant difference with the findings of the national demographic survey.

5.2.4 Education and employment

In the survey findings, employment and education were associated with gender. Men were more likely to be employed and involved in regular, paid work (12% vs. 4%) than women; they were also found to be more educated (above secondary level, 13% vs. 5%) than women. These findings are in accordance with those of the national demographic health survey (National Institute of Statistics Rwanda, et al., 2012), and with those of another study conducted in India: in this study, in a group of PLWH reporting to an ARV clinic, most of

the men were found to be involved in paid labour; they were also more educated than women (some up to Masters level and above) (Taneja, et al., 2012).

In Rwanda, as in other countries, employment, particularly paid work, depends on one's level of education. Furthermore, traditionally in Rwandan culture, a young girl has to do the housework; this includes cleaning the house, fetching water, preparing food, etc. In contrast, education is a priority for boys. This is because a boy is viewed as having the responsibility for the continuity of his family, while a girl is expected to leave her family one day when she gets married and joins her husband's family. Currently, the government is striving for greater gender equality in both the education and employment sectors. The national demographic health survey reported that 18% of men have completed secondary school vs. 15% of women, while 91% of men and only 73% women indicated they were employed (National Institute of Statistics Rwanda, et al., 2012). The lower levels of education and employment in the survey sample (compared to the recent national demographic survey) might be because the participants were older.

Further research is needed to provide evidence as to why, in the era of promoting girls' education and equal employment opportunities in Rwanda, the gender difference for both education and employment was found to be more than double in the survey.

5.2.5 Impact of personal factors on functioning

Personal factors can act as both facilitators and barriers to activity performance and social participation. Factors such as age, gender, coping styles, and social background could have an influence on individual functioning (Geyh, et al., 2011; Threats, 2007). The FGDs participants described factors within themselves that contributed positively to their functioning and participation and those which were barriers to functioning and participation.

5.2.5.1 Spiritual beliefs

Participants' spiritual beliefs and faith in God were highlighted. The practice of praying was described as a positive strategy that brought strength and motivation and contributed to their psychological well-being. Participants expressed a strong faith in God, and wished to surrender all their problems to God; they were certain of God's healing power. They felt more secure when they felt close to God. This is similar to other findings that some PLWH

use spiritual beliefs and practices as coping strategies to help them deal with the HIV infection and its complications (Dalmida, et al., 2009; Freeman, et al., 2007; Litwinczuk & Groh, 2007; Makoae, et al., 2008; Maman, et al., 2009; Pittiglio & Hough, 2009).

Participants in a qualitative study by Pittiglio and Hough (2009) indicated that they had a strong faith in God and that their relationship with God was so powerful that it gave them the confidence to live with HIV; they believed that their survival was part of God's plan. Like our participants, they indicated that they considered their relationship with God to be a source of hope; they had decided to surrender their illness to God. Maman et al. (2009) also found the participants had hope and a strong faith in God; like our participants, they believed in God's miracles and that He could cure them of their illness. However, these participants reported that their counsellor encouraged them to pray, suggesting that God may have the power to cure HIV (this was not the case in the present study).

Two studies have demonstrated the effect of such spiritual beliefs on psychological functioning and well-being and on HRQL (Dalmida, et al., 2009; Frame, et al., 2005), and on social functioning (Frame, et al., 2005). Coleman et al. (2006) report that their participants used prayer as a self-care management strategy for the following impairments: fatigue, nausea, depression and anxiety.

These findings suggest that consideration needs to be given to an intervention in the form of a spiritual programme to improve the psychological and social functioning of PLWH.

5.2.5.2 Resilience

In order to cope with the disease, participants built their inner strength and resilience through strategies that might assist them to appear normal and to live normal lives like anyone else in their society. They tried to avoid suspicion or the discovery of their status as a PLWH, and went to the extent of changing their appearance or behaviour. Nam et al. (2008) found participants had developed a new image of "self" with the virus. Ownby and Dune (2007) found participants also tried to live a normal life despite the severe pain they were suffering from (a symptom of peripheral neuropathy). They would explain their condition as gout because peripheral neuropathy was a known complication of HIV, and if revealed, people might suspect that they had HIV.

Makoae et al. (2008) focused on identifying coping strategies that could assist in living a normal life with the HIV infection. Viewing the self as normal or “okay” was courageous in the face of the illness and was highlighted among the possible strategies. Other coping strategies included using humour, educating others, letting go, remaining hopeful and keeping oneself active. These strategies seemed important in assisting PLWH to cope with the challenges of HIV infection and its multiple side effects, particularly stigma.

Although these findings have similarities there is a need for further research to understand how to individualise coping strategies, and to understand the benefits or disadvantages of these strategies for the health of PLWH, particularly for their psychological functioning.

5.2.5.3 Internalised stigma

Despite an orientation towards positive strategies that help to build resilience, participants in both urban and rural area, particularly women, did not appear to have accepted their HIV status and lived with the internalised stigma. This was expressed through feelings of being hurt by other people’s attitudes, and through behaviour and comments once the participants discovered they were PLWH. It was also expressed through feelings of regret, shame, guilt and remorse about their HIV serostatus. They imagined being judged, being discriminated against at their workplaces, and being abandoned by other people in their community once their status became known. All this had a significant impact on the disclosure of their status and their participation in the society. Participants feared that people in their community might tell others their status once they had disclosed it.

Other studies have also demonstrated the presence of considerable internalized stigma among PLWH and their reluctance to disclose their status. Simbayi et al. (2007) reported that their participants expressed shame and feelings of guilt about their HIV serostatus. Lee et al. (2002) found that PLWH felt embarrassed about having the HIV infection and consequently avoided others as they were not ready to disclose their status. Likewise Emlet (2007) found that PLWH wanted to keep silent because they feared they would be stigmatised and discriminated against by others in their communities. Gaskins et al. (2012) also found PLWH were worried about stigmatization and rejection and about other people spreading the news of their HIV serostatus.

Li, Wang, He, Fennie and Williams (2012) found that when PLWH learnt that they were infected, they felt hurt and became very sensitive to other people's judgmental comments and behaviour. They expected other people in the community to be afraid of them and to discriminate against them once they found out they had HIV. They avoided others in their community. They blamed themselves for getting the virus and felt distressed for causing shame and becoming a burden to themselves and also to their families. This led to extreme negative thoughts, including the wish to die soon. Gaskins (2006), on the other hand found that participants were reluctant to disclose their status because they thought their community lacked knowledge about the HIV infection and as result would not accept them.

In support of these views, our findings on internalised stigmatization among PLWH suggest an urgent need for a psychological intervention. This would help PLWH to accept themselves and develop strategies that could assist them in coping with the disease and adjusting to an environment in which they feel insecure and discriminated against because of their HIV serostatus. The engagement of the community might also be needed. Here the intervention could also focus on disclosure and perhaps assist people in the community to understand both its positive and negative consequences.

5.2.5.4 Internalised stigma and disclosure

Interestingly, some participants believed that disclosing their HIV status might be a good strategy that could improve psychological well-being and encourage self-acceptance. This could help combat the internalized stigmatization described above that many participants had been experiencing. Participants also believed disclosure was a good strategy for creating awareness about HIV; it could assist in disease prevention and encourage those who were already infected to seek care.

In keeping with our study, several previous studies have reported on the willingness of PLWH to disclose their HIV serostatus and on their opinions of the possible benefits of this, or of the reasons for disclosure. Makoae et al. (2008) describe how participants said disclosure was beneficial because it reduced gossip and rumours. They decided to disclose in order to seek support from loved ones and other people in the community, and to create awareness about the HIV infection. Emler (2007) says some participants thought that disclosing to others was helpful because these people could provide social support. Gaskins et

al. (2012) describe how participants believed disclosure could relieve stress, encourage social support and assist in education about prevention.

Although our participants emphasised their willingness to disclose, and the good reasons for doing this, they thought they should not disclose to everybody, and insisted on the importance of trust. Several studies have made similar findings on the issue of confidentiality (Gaskins, et al., 2012; Sowell, et al., 2003). Participants mentioned groups of people whom they trusted and felt able to disclose to. They trusted some of their family members and close friends. All of them trusted their fellow PLWHs and felt secure in revealing their HIV serostatus to them. This sense of solidarity and willingness to disclose is not surprising as PLWH all know that they have a similar problem and it might be helpful to share challenges and to comfort one another.

In keeping with the findings our study, participants in Gaskins et al. (2012) agreed while they could disclose to all their family members, the mother was the most likely first recipient. They also mentioned PLWH counterparts and friends, but (like our participants) they trusted only very close friends. However, in contrast to our study, the sexual partner was identified as a person who was not always informed. Participants in Sowell et al. (2003) also agreed with the need to tell family members, including trusted relatives and close friends; however, in contrast to our study; their participants mentioned employers and also sexual partners as among the people they would disclose to. Participants who agreed to disclose their status to their sexual partners said this was important because of the risk of HIV infection. Participants in the study by Maman et al. (2009), trusted their partners, and unlike our participants, they also thought church leaders could be trusted because they could keep secrets and pray for them.

Our participants said that they trusted and would disclose their status to the health care providers at the ARV clinics, but not to other medical staff in the hospital. Apparently, this was because they appreciated the care received at the ARV clinic, compared to that provided by other services within the hospital. They felt they belonged to ARV clinic. It was their own service provider and their entry point to the hospital. However, this should not be interpreted as disclosure as the health care providers from ARV clinic knew about the participants' HIV serostatus from the day of diagnosis. Some participants indicated that they sometimes trusted

health providers outside the ARV clinic and disclosed their HIV status when they needed medication. However, it appears that our participants may not have needed to disclose their status to any health care provider. Participants in other similar studies also agreed to tell health care providers, but (unlike in our study), they agreed to tell all their health care providers without exception (Gaskins, 2006; Sowell, et al., 2003).

It is important to say that, in this study, in both urban and rural areas, women dominated the discussion about disclosure and internalised stigma and it not clear that some of the men in the FGD had ever disclosed their HIV status beyond the hospital. The findings around disclosure suggest that it is a useful strategy to fight internalised stigma, in addition to raising awareness regarding HIV. This is needed among both non-infected and infected people. PLWH did not always understand the importance of informing their sexual partners of their status, which could result in passing on the infection. This implies that any intervention that targets the management of internalised stigma needs to incorporate the need for disclosure. A health promotion programme would be recommended, and if possible it should utilizes a peer education strategy. Disclosure could also improve PLWH's psychological and social functioning if based on an effective psychological intervention.

The findings related to disclosure to health care providers highlight important issues. There was particular trust given to ARV clinic health care providers, while disclosure of their HIV status to health care providers outside ARV clinic only happened because of the need to obtain medication. Functional limitations or problems were often not reported, despite the need for treatment. This suggests there is a need to inform PLWH about rehabilitation services, such as physiotherapy and psychology, and their effectiveness in the management of functional limitations. Perhaps ARV clinic health care providers, as identified key caregivers, could play a role in advocating this.

5.2.5.5 Age

Age was mentioned as a possible contributing barrier to the optimal functioning of PLWH. This supports the findings of Crystal et al. (2000), where older participants demonstrated higher levels of physical impairment and functional limitation, compared to younger participants. The present study did not explore the impact of age on the functional limitations of PLWH. Future research is needed to provide a clearer understanding.

5.3 HIV status and health – Health condition

The findings of the survey show that among the participants there was no significant difference in the CD4 count (above and below 500) between those who declared that they were symptomatic and those who were not. This information is consistent with findings from another study by Willard et al. (2009). In addition, Willard et al. (2009) suggested in their article that the term “asymptomatic HIV disease” is not valid: findings from their study, as was the case with ours, revealed that PLWH experience symptoms regardless of their CD4 count level. Furthermore, they recommended that clinicians should do a thorough subjective examination regarding the presence of symptoms, unrelated to the level of CD4 count, and plan for management of the symptoms.

This survey showed that the longer the participants had been on antiretroviral treatment, the more likely they were to be symptomatic. If we refer to Chapter Two, the review of literature, this is not surprising, as many studies have demonstrated that antiretroviral treatment significantly increases the risk and incidence of symptoms. This finding was supported by several of the FGDs participants, women and men, in both urban and rural areas and who attributed their functional limitations to the medication rather than the underlying pathology and indicated that increasing symptoms occurred overtime.

However in the survey, those who had been on antiretroviral treatment for a long period showed a higher CD4 count. Despite the side effects of antiretroviral treatment, and in line with the findings of previous research, these findings confirm the positive impact of antiretroviral treatment on the CD4 count (Heaton, et al., 2011; Howard, et al., 2002; Ma, Chen, Chau, & Saberi, 2010; Smith et al., 2004).

The survey findings have confirmed that the manifestation of symptoms of impairment among PLWH is not related to the CD4 count, but it is likely to be associated with the longer duration of antiretroviral treatment. Furthermore, the study strongly supports the evidence from several other studies that adherence to antiretroviral treatment for a long period is positively associated with increased CD4 count and with the manifestation of symptoms.

The increase in symptoms over time, despite the increased CD4 count, may be linked to PLWH not reporting symptoms. As the FGD participants described, they did not necessarily

report their symptoms to the health care workers because they thought that as their problems were associated with HIV and the antiretroviral treatment, they could not be cured. As a result, they did not receive the appropriate medication or treatment.

5.4 Impairments in PLWH

5.4.1 Impairments in mental functions

5.4.1.1 Energy/drive

Mental/psychological functions were frequently affected among respondents in the survey and discussed in the FGDs. This is similar to the findings of several previous studies (Alexander, 2011; Ciesla & Roberts, 2001; Collins, et al., 2006; Freeman, et al., 2007; Myezwa, et al., 2009; Newshan, et al., 2002; Rusch, et al., 2004a; Van As, et al., 2009), including one also conducted in Rwanda (Uwimana & Struthers, 2008).

According to Van As et al. (2009), the most common mental/psychological problems were emotional problems, problems with energy and drive, and sleep disturbances. However, in our study, among the mental/psychological functions assessed, emotional problems were most commonly reported, with 61% of the sample reporting moderate, severe or extreme problems. The problem least reported was memory loss (35%). Emotional, energy and drive, and sleep problems were also reported as significant by the participants in Myezwa et al. (2009); however, all three problems scored higher than the scores in our study. Moreover, energy and drive was reported to be the most serious problem (75%), followed by problems with sleep (71%) and then by emotional problems (62%). However, these other studies used the categories 'no problems' and 'some problems', whereas our study used the categories of 'no' or 'mild and moderate' to 'severe', and this might account for the lower numbers in our study. In addition, it is relevant to note that 'fatigue' is not included in the ICF checklist, which was the instrument used in their study, and that 'energy and drive' maybe expressed as 'fatigue' (Myezwa, et al., 2009). Notably, in the present study, fatigue was assessed under the cardiovascular and respiratory domain and, as it is described below, it was found to be the most commonly reported impairment.

The impact of fatigue was clarified during the FGDs. In both urban and rural areas, women and men participants used the terms fatigue, lack of energy, tiredness and body weakness interchangeably. As it is discussed in literature section (2.4.1.12), similar descriptions were made by participants in other studies with similar study populations (Aouizerat, et al., 2012; Corless, et al., 2002; Siegel, et al., 2004; Sullivan & Dworkin, 2003). For example, in Corless et al. (2002), participants described fatigue as “being tired, weak and [having] just no energy”. Many of our participants recognised that they had experienced a lack of energy from the onset of the HIV infection, and viewed this as an immediate effect of the HIV infection. Similarly, in another qualitative study by Siegel, Bradley, and Lekas (2004), participants described the lack of energy associated with HIV infection and said: “it is a symptom of the virus” or “it comes with the virus”.

According to the literature, many factors may affect energy levels. For example; Siegel et al. (2004) indicated that age, being overweight, poor adherence to antiretroviral treatment, sleep problems, stress and poor nutrition could also be considered as contributing to the lack of energy. Poor adherence to antiretroviral treatment was also described by Corless et al. (2002) as a factor that exacerbated a lack of energy. They also found that a lack of energy or fatigue was associated with depression, sadness and difficulty with concentration (Corless, et al., 2002).

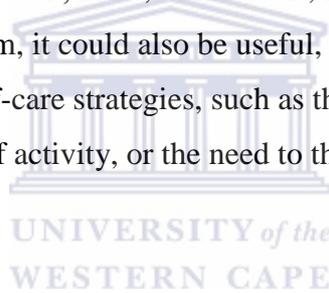
Although the participants did not mention other factors contributing to their lack of energy, many factors might have contributed to their chronic lack of energy. A deep understanding of the aetiology of HIV-related lack of energy, from the patients’ perspective, is important. Women and men, in both FGDs in our study described lack of energy as a permanent problem that had transformed their bodies, and indicated that lack of energy might get worse overtime. Siegel et al. (2004) described a lack of energy as a symptom of disease’s progression, especially because of its persistence after the initial HIV diagnosis. For example, one of their participants indicated: “I felt the virus was getting more active in going through my body because I was feeling too tired...” (Siegel, et al., 2004, p. 216).

Two other studies with a similar sample, but utilising quantitative methods, also reported a lack of energy as permanent problem. Participants in Aouizerat et al. (2012) experienced a lack of energy as a serious problem, with almost half of them describing it as constant, and

others describing it as severe, and a small number indicating that it was very distressing. Findings from a prospective study by Pence et al. (2009) highlighted the persistent lack of energy among a similar sample of PLWH. The study, conducted over a fifteen-month period, demonstrated that participants with the highest baseline lack of energy scores were assessed as having significant scores over time, indicating that a lack of energy was a problem throughout the period of assessment.

The findings in this study support the evidence that a chronic lack of energy is experienced by PLWH, including those on antiretroviral treatment. This is likely to have a serious effect on their physical and social functioning and would interfere with livelihood and their quality of life.

Regular exercise, such as walking, jogging and other aerobic exercise as recommended in various studies, could assist in countering the chronic fatigue or the lack of energy experienced by PLWH (O'Brien, et al., 2010; Smith et al., 2001). As this lack of energy appears to be a permanent problem, it could also be useful, as suggested by Corless et al. (2002), to educate patients on self-care strategies, such as the need for rest, good nutrition, sleep, and adjustments to levels of activity, or the need to think positively and exercise appropriately.



5.4.1.2 Sleep

Although more than 60% of the survey respondents reported that sleep was a problem, this was not mentioned by the FGDs participants.

5.4.1.3 Memory

Over 55% of the survey respondents reported problems with memory. The FGDs participants similarly reported memory loss and a lack of concentration as two cognitive problems and attributed these to the antiretroviral treatment. These problems have been reported in previous surveys with similar samples (Rusch, et al., 2004a; Simioni, et al., 2010). There is evidence that memory deficits or forgetting can lead to poor adherence to antiretroviral treatment (Becker, et al., 2011; Harzke, et al., 2004). However, according to participants in the FGDs it appeared as if ARV clinic health care providers did not understand the impact of forgetting

on adherence to antiretroviral treatment. If they had understood this they would have been unlikely to punish patients when they forgot their appointments for antiretroviral treatment.

This finding also points to the need to train ARV clinic health care providers on the need for memory assessment of among PLWH in order to document changes and evaluate the risk of poor adherence. The training needs to emphasize the effect of a positive attitude and the need for support of by health care providers to improve patients' adherence to antiretroviral treatment, as is demonstrated by Harzke et al. (2004). ARV clinic health care providers need to work closely with psychologists, as specialists in the management of cognitive problems, in order to assist patients with memory and concentration problems.

5.4.1.4 Emotional stress

Similar to the survey in which over 60% of respondents reported emotional problems, a high rate of emotional problems was also found in another group of PLWH in Rwanda (Uwimana & Struthers, 2008). Some FGDs participants displayed emotional distress in the group, evident by the exclamations of sadness and dismay. One woman reported contemplating suicide and many reported distress at ill treatment by family members and others. Worries and fears about the HIV infection and its related pathologies, along with stress arising from the complex side effects of antiretroviral treatment, could explain the high incidence of emotional problems in the survey population (Catalan, et al., 2000; Ciesla & Roberts, 2001). In addition, it should be noted that the 1994 war and the genocide in Rwanda have left many people, young and old, with severe psychological problems (Uwimana & Struthers, 2008), mostly caused by the loss of relatives and close friends, and also by the various methods of torture used by the perpetrators. This included rape, which would have increased the risk of HIV infection among women (Uwimana & Struthers, 2008). The consequences of HIV infection and the side effects of its treatment, combined with the lingering effects of the genocide, could explain the prevalence of emotional problems, as found in this study.

The findings demonstrate a need for regular screening for the presence of emotional problems among PLWH; this could lead to referrals to mental health workers and would have the potential to improve the psychological rehabilitation of PLWH in Rwanda.

5.4.1.5 Body image and lipodystrophy

Body image was identified by both the survey and the FGDs as being a problem. Body image was identified as being a problem by 40% of the survey respondents. Signs of lipodystrophy were also mentioned as a problem by some women in the FGDs who associated it with the antiretroviral treatment. This finding is similar to that in other studies (Miller, et al., 2003; Mutimura, et al., 2007; Power, et al., 2003). The FGDs participants explained how the lipodystrophy, including a distended abdomen and rounded face, with thin buttocks, legs and arms, had disfigured their bodies. In a qualitative study by Power et al. (2003), participants described similar lipodystrophy characteristics and explained how it had changed their bodies, making it difficult to recognise themselves.

There is evidence that exercise has the potential to alleviate some of the physiological and physical side effects of lipodystrophy (Fillipas, et al., 2010; Mutimura, et al., 2008). However, no participants in the FGDs indicated they had participated in exercise for this purpose.

The findings indicate that lipodystrophy affects the body image and the physical, psychological and social functioning of the individual. Any intervention that seeks to overcome lipodystrophy and body image should consider all these areas.

5.4.2 Sensory impairments

5.4.2.1 Pain

Pain was the only impairment assessed under sensory functions in the survey and was present in 80% of respondents, who reported intensity and prevalence of pain as 'high'. It was also mentioned by many of the FGDs' participants. A number of previous studies have also reported pain as being very common among PLWH (Del Borgo, et al., 2001; Dobalian, et al., 2004; Gray & Berger, 2007; Hughes, Jelsma, Maclean, Darder, & Tinise, 2004; Miaskowski, et al., 2011; Myezwa, et al., 2009; Rusch, et al., 2004a; Uwimana & Struthers, 2008; Van As, et al., 2009). Pain was also found to affect quality of life of PLWH, with both their physical and psychological well-being affected (Gray & Berger, 2007; Larue, et al., 1997; Nair, et al., 2009; Newshan, et al., 2002). Compared to other studies, the high prevalence of pain among

PLWH in our study could be related to the HIV infection and its associated pathologies and to the side-effects of antiretroviral treatment (Hewitt, et al., 1997; Larue, et al., 1997).

As in other studies, the FGD participants said pain was caused by both the HIV infection and the antiretroviral treatment (Hewitt, et al., 1997; Miaskowski, et al., 2011; Singer, et al., 1993). These participants described the pain as severe and chronic. As discussed in literature section, this finding is similar to that of other several studies. Richardson et al. (2009) reported that the participants in their sample experienced persistent pain, which most characterised as severe to extreme. Miaskowski et al. (2011) also reported that many participants in their study experienced chronic pain, lasting longer than six months, while the majority complained of moderate to severe pain. Participants in a study by Del Borgo et al. (2001) reported that the intensity of pain ranged from moderate to unbearable.

The FGDs' participants indicated that pain affected many parts of the body; they often mentioned backache, headache, knee pain and abdominal pain. Men and women both spoke of pain. Likewise in Anandan et al. (2006), participants reported pain in different parts of the body: abdominal pain, painful joints and aching muscles. The description of pain as chronic and severe implies that pain was a very serious disabling problem, and the involvement of multiple body parts could have worsened the disability among our participants. It is likely that these levels of pain would have affected both the physical and psychological aspects of health, as well as social functioning and would have an impact on quality of life.

There is a growing body of evidence that physiotherapy techniques such as massage and exercise can alleviate the pain experienced by PLWH (Hillier, et al., 2010; O'Brien & Nixon, 2010; Ownby, 2006). Physiotherapists need to educate other health care providers about the benefits of their techniques for the relief of pain. This might improve referral to physiotherapy services and contribute to better management of pain. There is also a need for physiotherapists and other health care providers to educate patients about self-care strategies that could assist them to deal with their problems linked to pain.

5.4.2.2 Paraesthesia

Paraesthesia was not one of the specific items on the Impairment Questionnaire, which was an omission, in the light of the responses from the FGDs' participants who described a

sensation of itching or pins and needles that often occurred with pain. They said it was chronic and frequently localised in the lower limbs, and mostly occurred when they had been standing or sitting for a long time. Like pain, paraesthesia was associated with antiretroviral treatment. This description of paraesthesia reflects the symptoms of peripheral neuropathy, particularly distal symmetrical peripheral neuropathy, which has been identified as a side effect of antiretroviral treatment. For example, participants in a study by Luma et al. (2012), 96.9% of whom were on antiretroviral treatment, were found to have peripheral neuropathy during assessment. They experienced the following symptoms: pain, numbness, and pins and needles, with the latter being the most common symptom. Similarly, Nicholas et al. (2002), and Van Oosterhout et al. (2005) found that pain and numbness in the lower limbs and symptoms of peripheral neuropathy were the most common complaints; they maintained that these were side effects of antiretroviral treatment. Mullin et al. (2011) found that people in their sample commonly experienced numbness, pins and needles and pain, which they described as an aching or burning pain.

Several studies have demonstrated how peripheral neuropathy is a very serious and uncomfortable condition, particularly on account of the terrible pain it causes; it can lead to physical and social functional limitations among PLWH (Mullin, et al., 2011; Ownby & Dune, 2007). Participants in a qualitative study by Ownby and Dune (2007) explained that they had experienced so much pain that they characterised it as a sign of death or a punishment from God. One participant said: "...it makes you feel like Lord; Jesus is my days getting short? Is it coming to be my time?" Another participant indicated: "... I thought that was God's way of punishing me for the things I had done in my life" (Ownby & Dune, 2007, p. 51)

Our finding suggests that future research needs to include an assessment and exploration of the manifestation of paraesthesia combined with pain in PLWH. Additionally, the link with peripheral neuropathy should be explored.

5.4.2.3 Dizziness

Certain FG participants reported that they experienced dizziness, another omission from the Impairment Questionnaire. This was worse in standing and was exacerbated when

participants were hungry or thirsty or when they were in the sun. Dizziness was also mentioned by Lee et al. (2009).

An intervention to control dizziness would need the patients' cooperation to limit the factors that lead to dizziness. These include being in standing position, feeling hungry or thirsty and being exposed to the sun.

5.4.3 Impairments in cardiovascular and respiratory system functions

Under cardiovascular and respiratory body function, fatigue was the most predominant problem in both groups of participants. Fatigue has been frequently reported as one of the most prevalent problems in various studies with similar population groups (Anandan, et al., 2006; Henderson, et al., 2005; Jong, et al., 2010; Newshan, et al., 2002; Phillips, Sowell, Rojas, & Tavakoli, 2004; Rusch, et al., 2004a). It has been observed that in numerous studies the prevalence of fatigue ranges from 37% to 88% (Jong, et al., 2010). Remarkably, in the survey, fatigue was the most highly rated and the most severe body function impairment reported (83%, moderate to extremely bad).

This finding supports that of Anandan et al. (2006), where fatigue was also the most highly rated impairment (84, 4%, mild to severe) in their study group. However, in our group the intensity (moderate to extremely bad) was greater. These two findings are far higher than those found in many other reviewed studies. In some previous studies, fatigue was reported as being more closely related to HIV infection and its associated conditions rather than to antiretroviral treatment (Henderson, et al., 2005; Phillips, et al., 2004; Siegel, et al., 2004). A longitudinal study conducted by Ferrando et al. (1998) demonstrated that there was no direct relationship between chronic fatigue among PLWH and their CD4 count or HIV viral load, but fatigue was found to be more severe in cases where the disease was advanced.

Interestingly, one observational study found that the use of antiretroviral treatment over a longer time period with the HIV infection predicted low fatigue rates among PLWH (Pence, et al., 2009). Common causative factors of fatigue among PLWH, described in the literature, include physiological factors such as anaemia, which is a common problem in people with HIV (Barroso, 1999; Phillips, et al., 2004) and abnormality of thyroid gland (Adinolfi, 2001). However, researchers have emphasised that mental/psychological factors such as

depression, anxiety, stress, emotional distress and sleep disturbance have been also identified as most significant causative factors (Adinolfi, 2001; Aouizerat, et al., 2012; Barroso, 1999; Henderson, et al., 2005; Jong, et al., 2010; Pence, et al., 2009; Phillips, et al., 2004).

Furthermore, certain studies have highlighted two socio-demographic factors, low income and being unemployed, as being strongly associated with the increased incidence of fatigue among PLWH (Jong, et al., 2010; Pence, et al., 2009; Siegel, et al., 2004). Some lifestyle behaviours, such as lack of rest or exercise, and inadequate diet and substance abuse, have also been identified as additional causal factors for increased fatigue among PLWH (Adinolfi, 2001). It was also reported by Ferrando et al. (1998) that fatigue was found to be an independent and strong contributor to physical limitations and disability among PLWH. In the present study, fatigue appeared to be independent of other significant impairments. We did not demonstrate any association between fatigue and the socio-demographic status of our population, or with emotional dysfunction.

However, consistent with what has been reported in previous studies regarding fatigue and its related factors, the high incidence of fatigue in our study group could explain the low income levels among most of our study group (less than US\$100 per month), and the high number of unemployed people in the sample.

This shows that, as a result of fatigue, even those who reported that they were involved in some form of self-employment may not have earned sufficient income to cover their needs, for instance their nutritional needs. It is also possible that their jobs are manual in nature and require the use of physical force, which contributes to feeling very tired. Furthermore, fatigue could have contributed to the limitations in mobility function and could interfere with the ability to participate in household activities. However, there is a need for further research to apply sound scientific insight to the above interpretation and, additionally, to highlight the relationships between mental/psychological factors, especially emotional impairment and sleep disturbance; these were found to be significant impairments in this study.

These findings need to be used to inform the health care providers involved in the management of PLWH in Rwanda that fatigue/lack of energy is a significant problem among PLWH and that regular assessment is required and that this has the potential to improve the

management of the disease. The evidence of the existing literature is that there is a need for a holistic approach to care that will include rehabilitation to deal with fatigue or lack of energy and this could involve physical rehabilitation, such as that provided by physiotherapy (O'Brien, et al., 2010), psychological and social rehabilitation; for example improved nutrition and the provision of food supplements.

Respiratory problems were the second most common impairment in this group, reported by 21% of the sample in the survey. A few of the FG participants that reported coughing and respiratory conditions were not very common in this group. The findings in our study are very similar to those in another study (22%) conducted in South Africa by Van As, et al. (2009). It should, however, be noted that in the study by Van As et al. the sample was small (45 people), and scores were documented using a scale from 'mild' to 'moderate'. Another study, also carried out in South Africa, (Myezwa, et al., 2009) demonstrated a prevalence of respiratory problems almost three to four times greater than in this study. This can be explained by the fact that, in our study people had been taking antiretroviral medications for a longer period, and as a result their general health status had improved and, consequently, there was a lower risk of acquiring respiratory infections such as TB (Hull, et al., 2008; Wagner & Chaisson, 2003). As is described in Chapter Two, various studies have demonstrated that respiratory problems among PLWH are related to the HIV infection itself and/or to its associated pathologies or opportunistic infections such as TB. These problems could also be a consequence of an autoimmune reaction to the antiretroviral medications.

Further research that involves objective assessment is needed to determine the causative factors for the respiratory symptoms reported in the survey. However, it should be noted that routine assessment of the associated impairments, such a shortness of breath and difficulty in breathing, should be done as well as the use of intervention strategies to minimise the impairment of functioning. Health care providers involved in the management of PLWH need to be made aware that physiotherapy, which uses exercise, can play a big role in the rehabilitation of those suffering from the effects of the cardiovascular and respiratory impairments mentioned above.

5.4.4 Impairments of the digestive and reproductive system functions

Digestive problems were present among both study populations, the most common of these being intolerance to food, reported by 35% of the survey respondents, followed by sensations of nausea (32%). Other studies have also reported digestive problems in similar population groups (Alexander, 2011; Myezwa, et al., 2009; Rusch, et al., 2004a). Together with other problems, these were found to affect the general functioning of the patients (Myezwa, et al., 2009). It is also possible that digestive problems present and prominent in the survey sample could have an influence on the general status of the study population and were likely to affect their physical and social well-being. Therefore, it is recommended that regular assessment and management intervention strategies for general function status include digestive functions.

5.4.5 Genito-urinary tract impairments

Among reproductive functions, discomfort with sexual intercourse was the function most affected in the survey group (33%). Many of the men in the FGDs reported that sexual activity was reduced due to decreased energy levels, whereas for women, it was decreased libido. Similarly, in studies conducted by Van As et al. (2009), and by Rusch et al. (2004a), among the reproductive impairments, sexual dysfunction was commonly reported by their sample; it was suggested that it was caused by reduced libido. Other studies have also demonstrated significant rates of sexual discomfort and/or sexual inactivity among PLWH. They suggest that sexual problems among PLWH could be a consequence of the physiological and, most importantly, the psychosocial effects of the HIV infection on the patient's body (Balaile, Laisser, Ransjö-Arvidson, & Höjer, 2007; Bell, et al., 2006; Scanavino & Abdo, 2010). Schrooten et al. (2001) discovered that antiretroviral treatment, especially PIs and most particularly Indinavir and Ritonavir, were associated with sexual problems and that the risk was increased among those who had lipodystrophy. Schrooten et al. (2001) postulated that the higher risk of sexual dysfunction in the group with lipodystrophy, apart from the possible influence of pathophysiological factors, could also be related to problems with body image.

The findings on reproductive function problems have shown that discomfort with sexual intercourse was common. This could have an impact on the general status of the survey study

population and was likely to affect their physical, psychological and social well-being. Discomfort with sexual intercourse needs to be regularly assessed among PLWH, and management strategies should incorporate psychological and social rehabilitation strategies; this would result in the provision of more comprehensive care.

5.4.6 Neuromuscular and skin impairments

The survey findings demonstrated that neuromuscular impairment and skin functions were frequent (50% and 46% in our sample). In contrast, the FG participants reported general “body weakness” rather than specific muscle weakness. Impairment of neuromuscular and movement functions received a higher rating (over 70%) in the Myezwa et al. (2009), a study that was conducted with a similar population group. One reason for this could be their use of objective assessment (dynamometry and goniometry); another reason could be the general health status of their participants, as their sample was conducted among those who were in the advanced stage of the disease. The majority of their participants were in stage 3 or 4 on the WHO HIV disease classification, and more than half had a CD4 count below 100. In contrast, in Van As et al. (2009), a sample of ambulatory PLWH reported low rate of problems with neuromuscular and movement functions compared to our findings, with approximately half (27% of the sample); however, only muscle power was assessed and, as with Myezwa and others, dynamometry was used. The low rate could be attributed to the small sample size (45 people) and to the use of one site for data collection. This could have led to an underestimation of the magnitude of the problem.

On the other hand, several previous studies reported pain as a significant and most important symptom for both the neuromuscular and the skin conditions that manifest in PLWH (Alexander, 2011; Cuellar & Espinoza, 2000; Gray & Berger, 2007; Mody, et al., 2003; Nicholas, et al., 2002; Patrice K Nicholas, et al., 2007c; Osborne, et al., 2003; Ownby & Dune, 2007; Sagar, et al., 2010; Singer, et al., 1993; Verma, 2001). Both neuromuscular and skin conditions in PLWH have been identified as consequences of the HIV infection itself or the antiretroviral treatment (Anwihar, et al., 2011; Kumarasamy, et al., 2008; Lopez, et al., 2004; Owczarek, et al., 2005; Peltier & Russell, 2006; Sangle, et al., 2010; Scruggs & Naylor, 2008; Tschachler, et al., 1996; Walker, et al., 2008). This could explain why our findings showed evidence of a strong positive correlation between pain and neuromuscular

functions (for both mobility and muscle power) and skin functions (for both skin function and skin sensation).

Pain was found to be very significant body function impairment in our sample: it was more likely to contribute to increased problems with regard to neuromuscular functions and movement and skin functions, as borne out by the highly significant correlation found between pain and muscle function and pain and joint mobility in the survey group. These findings suggest the need to pay attention to pain as a significant sensory impairment among PLWH and to its impact on neuromuscular and movement and skin functions. Health care providers involved in the daily care of PLWH should be aware that in clinical practice, routine assessment of pain is required, but problems with neuromuscular and movement and skin functions should also be detected and documented. They should also plan for more comprehensive management with the aim of reducing the impact of pain and of problems with neuromuscular and movement and skin functions on the daily functioning of PLWH. Physiotherapy is a rehabilitation discipline that deals with pain and the effects of pain on neuromuscular and skin functions (Hillier, et al., 2010; O'Brien & Nixon, 2010); therefore, it should be involved in any intervention program. Furthermore, there is need for further research that uses objective measurements in order to provide more reliable knowledge regarding the magnitude of pain, and problems with neuromuscular systems and movement, and with skin functions, and the influence of these problems on the daily functioning of PLWH.

5.5 Activity limitations and participation/social restriction

Participants in both, the FGDs and the survey in this study indicated that they experienced difficulty in performing various activities that were part of daily living and also that their participation in society was restricted. The ICF defines difficulty in executing a task as an activity limitation. Difficulties with involvement in life situations are defined as participation restrictions (Coster & Khetani, 2008; Vanleit, 2008). Participants in the FGDs described how activity limitations and participation restrictions were caused by various impairments. These findings support those of other studies with similar study populations, but many of these studies utilised quantitative methods (Myezwa, et al., 2009; O'Brien, et al., 2008; Rusch, et al., 2004a; Van As, et al., 2009).

Consistent with the findings of a qualitative study by O'Brien et al. (2008), reported in the literature (section 2.4), the limitations in functioning or disability were multidimensional in nature with a connection between the different dimensions. For example, findings of the FGDs indicate that lack of energy as an impairment was associated with limitations in work performance and in participation in social relationships. However, unlike the findings of O'Brien et al. (2008) which reported that participants experienced disability as episodic and as characterised by unpredictable periods of wellness and illness, the FG participants described disability or functional limitations as a permanent problem. They said; *“our problems are there for life”*, whereas O'Brien et al. reported that participants used the terms: *“nothing is constant with HIV”* and indicated how they often considered themselves healthier after overcoming an unhealthy episode.

5.5.1 Cognitive domain

Cognitive functions were commonly affected in both study groups. Similar studies have also demonstrated significant cognitive problems in their respective samples (Ciccarelli, et al., 2011; Salawu, et al., 2008; Simioni, et al., 2010). In the survey in this study, analysing and finding solutions to problems in day to day life was reported as most problematic (49%), followed by problems in learning new tasks. The domain that showed the least problems was concentration, with 20% people reporting moderate to extreme bad performance. In a study by Van As et al. (2009), participants also reported some cognitive problems, even where assistance was provided. These problems were mainly with learning, but also with applying knowledge. In contrast to the findings of this survey, difficulty with concentration was the only cognitive impairment reported by 75% of participants in a study by Anandan et al. (2006). Participants in a study by Simioni et al. (2010) reported that the most commonly experienced cognitive problems were memory loss (18%), followed by a slowing of mental function and a reduced attention span. Salawu et al. (2008) indicated that those in their sample also reported experiencing significant cognitive problems, the most common being problems with attention/concentration and calculation (30%), followed by memory loss (27%) and orientation to place (27%).

Most of the respondents in the survey had been receiving the antiretroviral treatment and had been living with the HIV infection for many years. It is possible that the changes that were

happening in their lives were due to the HIV infection and the adverse effects of antiretroviral medications, as well as to worry and uncertainty about what the future would hold. Many people in the survey sample were cognitively affected to the extent that they were unable to achieve self-efficacy and did not have the ability to resolve problems and learn new things. This could have a significant impact on their self-development. As was discussed earlier (in the literature review), various studies have shown a positive correlation between cognitive problems in PLWH and psychological distress. An intervention strategy that emphasizes mental health and psychological rehabilitation could assist to overcome the problem. However, there is need for further research to demonstrate the relationship between the emotional problems that were found to be prevalent among participants in this study, and the cognitive problems that were reported.

5.5.2 Mobility domain

The mobility function was severely affected in both study groups: in the survey problems with standing for long periods was the most prevalent, with 57% of people rating this as 'moderate', 'severe' and 'extremely bad'. The next most commonly affected function was 'getting out of home' (38%), while 'moving inside home' received the lowest score (15%). The mobility function was also found to be a problem in other studies. In Myezwa et al. (2009) this received an even higher rating than in our study, with 75% of participants experiencing difficulties without help, perhaps because of their general health status: these participants were in-patients and some had a CD4 count below 100; most required some assistance.

Van As et al. (2009) and Hughes et al. (2004) indicated that 40% and 30.9% respectively of their samples reported that their overall mobility was affected. The respondents in a study by Crystal et al. (2000) also reported mobility problems; however, unlike our subjects, they complained about the limitations in activities involving considerable energy expenditure, such as walking long distances, and other vigorous activities.

It was interesting that 'getting out of home' came second in the survey and was more highly rated in difficulty than other important functions in the mobility domain, such as 'walking long distances' and 'standing from sitting down'. Likewise, subjects in a study by Myezwa et al. (2009) revealed that they were reluctant to go out into the community. They gave

numerous reasons for this, among which they mentioned fear of stigma. It is also possible that fear of being stigmatised was the reason why many participants did not want to leave their homes.

The FGDs' participants said that mobility activities, such as walking, standing and climbing stairs, were usually limited on account of decreased energy, pain, breathlessness and paraesthesia. Similar studies have reported that mobility limitations were associated with decreased energy and pain, paraesthesia or breathlessness (Crystal, et al., 2000; Lorenz, et al., 2001; Ownby & Dune, 2007; Van As, et al., 2009). Mobility is very important for physical functioning, and limited mobility is likely to affect the physical and social functioning of an individual. This finding indicates the need for identification by routine screening followed by effective management of the identified impairments

The findings reveal that both physical and psychological factors could contribute to limited mobility. This implies that there is need for a coordinated intervention strategy that includes physical rehabilitation, such as physiotherapy and mental health/psychological rehabilitation, to improve mobility among PLWH. However, further research is needed to provide more insight into this problem, specifically regarding the influence of psychological factors on mobility.

5.5.3 Self-care domain

The functions in the self-care domain were among the functions least affected that were assessed in this survey. The respondents were able to care for their bodily hygiene and feed themselves. 'Staying by yourself a few days', scored highest in this domain, with 46% of the people reporting moderate, severe and extreme problems in this regard. This item received a ten times higher rating than other functions assessed in this domain and, as will be discussed in the validation of the WHODAS.02 Chapter **Error! Reference source not found.**, did not do well within the construct of self-care. For example, it was rated ten times higher in difficulty than 'washing your body' (4%), which was the second most affected function. This contributed to low internal consistency in the self-care domain thus there was an inability to measure the same construct as the others.

When discussing the function of ‘staying by yourself a few days’, many participants expressed a fear of being alone for some time, not because they were unable to care for themselves at that time, but because they were uncertain of what might happen to them, despite the positive effects of the antiretroviral treatment. Who would be able to assist if their situation deteriorated?

Rusch et al. (2004a), in their study conducted with a large sample of PLWH in British Columbia, Canada, showed a higher rating of difficulty given to personal care functions, such as showering (10%), dressing (9%) and eating (20%). However, staying by yourself for a few days was not one of the variables measured in their study. The differences with our study could arise from the data collection method: the use of self-administered anonymous surveys mailed through the post as a method of collecting data in the study by Rusch et al. could limit perceptions of the extent to which those activities were affected. In addition, there was no specification regarding the stage of the disease among those who experienced difficulties in self-care, and there was no specification as to whether all the PLWH involved in the study were on antiretroviral treatment. Our survey might have excluded those who were most severely affected as they might have been unable to leave the house, whereas as a postal survey could have included them.

Furthermore, in contrast to the present study, Gaidhane et al. (2008) reported that in their study conducted among PLWH at a rural tertiary care hospital in India; 65% of the sample reported that one or more self-care activity was affected. The following activities were assessed: washing ones whole body, caring for body parts, using the toilet, eating and drinking, and looking after one’s health. However, it is relevant to note that all respondents in their study were hospitalised and all had met the WHO stage criteria for the diagnosis of AIDS. Therefore, it is possible that they were more severely affected than our participants. This could explain the increased difficulty in completing those activities which were found not to be a problem in our study. It should also be noted that, in comparison to both the above described studies, scores in our study ranged from moderate, severe and extremely bad, and not from mild.

There is need for further research in order to explore in depth the reasons why a large number of respondents in the survey in this study expressed worry and fear about staying alone for

few days, while most reported they were able to care for themselves independently. In clinical practice, health care providers involved in the management of PLWH should be aware of the problem in order to put in place an appropriate management strategy that could include mental health/psychological rehabilitation and social rehabilitation. However, in conclusion, this finding suggests that staying by oneself should not be regarded as self-care as there are too many cultural and other variables, such as socio-economic factors, which could impact on this.

The FGDs' participants identified pain and paraesthesia in the legs as the major contributor to difficulty in performing self-care activities. Pain and sensory impairments have been reported in other studies as factors contributing to decreased physical functioning and difficulties with self-care activities (Myezwa, et al., 2009; Ownby & Dune, 2007). The pain combined with the paraesthesia experienced by our participants could be attributed to peripheral neuropathy. Ownby and Dune (2007) describe participants complaining not only about unbearable pain and other symptoms of peripheral neuropathy, such as numbness and pins and needles, but also about the difficulty having to depend on other people in order to be able to perform the activities of daily living.

5.5.4 Getting along with people function

The function most affected in 'getting along with people' was sexual activities, which scored 40%, whereas the least affected function was 'dealing with people you do not know', which scored 14%. As it is described above in Section 5.4.5, sexual dysfunction was also reported as a significant impairment of body function. The FGDs yielded interesting insights as to the factors contributing to dysfunction or a lack of interest in sexual activity as an independent function among PLWH. The decreased energy levels of male participants led to a reduced frequency of sexual intercourse. Additionally, participants believed that increasing the frequency of sexual intercourse would decrease a person's energy levels. It is important to mention that decreased energy levels as a leading factor of decreased frequency of sexual intercourse was only reported by men, in both urban and rural areas. Similarly, in a qualitative study, however conducted among women only, Balaile et al. (2007) found that women believed that more frequent sexual intercourse could lead to decreased energy levels; it could also strengthen the virus and lead to premature death. As with women in the FGDs,

women in Balaile's study did not indicate that a lack of energy caused decreased frequency of sexual intercourse.

This lack of energy which (it is believed) reduces the frequency of sexual intercourse combines with the belief that increased frequency of sexual intercourse contributes to a lack of energy, but this needs some teasing out. The first part involves physical and social functioning while the second part involves physical and psychological and social functioning. This demonstrates the need for a multi-disciplinary intervention strategy which will include physical, psychological and social functioning. This needs to target the impact of a lack of energy on sexual intercourse and the effect of an increased frequency of sexual intercourse on energy levels. However, due to the sensitivity of discussing sexual activity, individualised rather than collective intervention strategies are likely to be more acceptable.

In this study, women in both rural and urban areas reported that a reduction in sexual desire affected participation in sexual intercourse. Other studies have reported similar findings. Balaile et al. (2007) reported decreased frequency of sexual intercourse due to reduced sexual desire. As with some of the women in our study, their participants feared getting involved in relationship where it would be impossible to abstain; they tried to avoid any involvement in sexual activity. They continued to have feelings of guilt and lived with the perception that sexual intercourse was the source of HIV. Bell et al. (2006) also found a lack of desire, leading to decreased sexual intercourse, and highlighted the fear of transmission of HIV and the fear of disclosure of their HIV status to a partner; this would involve negotiation over condoms and fertility issues.

There could be many reasons for the reported lack of desire for sexual intercourse among our female participants. Like participants of a study by Balaile et al. (2007), it is possible that our participants have been traumatised by HIV and experienced feelings of remorse and believed that sex was the source of HIV. With careful consideration an effective intervention program that includes psychological functioning could have an impact on levels of sexual activity.

These findings reinforce the need for mental health/ psychological rehabilitation intervention strategy to overcome the problem.

The second function most affected in this domain was 'making new friends' (36%). A similar group of people in Van As et al. (2009) also reported problems with relationships. However, these were mostly limited to creating relationships with strangers, which is similar to dealing with people you do not know; here problems were also found in forming social relationships, and also with family and intimate or sexual relationships. Unfortunately, there was no information on the rating of these functions. It would be interesting to determine the relationship between lack of interest in sexual activity and making new friends who could be new partners, especially among women, as in the present study most of the participants were widowers.

5.5.5 Life activities

Household and work or school activities were the two activities assessed in life activities and problems in both of these areas were prevalent. However, FGDs findings demonstrated that except for one man in rural area, it appeared that household activities were frequently performed by women. 'Getting the activity done as quickly as needed' was the function most affected in both cases. Least affected in household activities was 'taking care of household responsibilities' (28%) and 'day to day work/school activities' (20%) in work or school activities. Moreover, activities were interfered with for almost five days in every month, and there were approximately three days in which the participants were completely unable to work because of their health condition. Consequently, 44% of the participants declared that they worked at a low level because of their health condition and, as a result, 45% reported that they earned less money. In support of the present study, over half of the subjects in a study by Crystal et al. (2000) demonstrated difficulties in carrying out housework and work or school activities at least some of the time. In a study by Van As et al. (2009), subjects experienced problems with school and work activities, but mostly with remunerative work and as with our subjects, they could not earn sufficient money. Consequently, they reported that they were unable to sustain themselves and their families financially.

The quantitative data are supported by the comments of the FGDs participants, who additionally identified the reasons for decreased productivity and the effect on livelihood. Due to a lack of energy, participants' involvement in work and household activities was reduced. Anandan et al. (2006) also report that participants experienced difficulty performing

routine physical activities related either to work or to household tasks. As in our study, they suggested this was due to significant levels of fatigue. Our participants, both women and men believed that work that demanded a lot of energy could exacerbate their condition. Siegel et al. (2004) indicated that working too hard could contribute to decreased levels of energy. Crystal et al. (2000) also described the difficulties experienced in executing physical tasks, particularly those demanding more energy.

Careful assessment of the pattern of lack of energy, including the factors contributing to its exacerbation (such as vigorous activities), and an evaluation of its influence on the performance of PLWH is necessary. This finding suggests that to improve the work performance of PLWH, interventions need to first target problems with lack of energy. Therefore, both physical and social functioning should be considered.

Work and household activities were reduced because of pain. Crystal et al. (2000) found that significant levels of pain were associated with physical limitations and with difficulty in carrying out physical activities such as work and school activities and household activities. Our finding points to the need for special interventions regarding pain management among PLWH with the broader goal of improving physical activities and facilitating work and household activities.

Loss of memory affected work and household activities. There is a dearth of published studies that demonstrate the impact of memory loss on the performance of work and household activities. Several researchers have reported on the effect of memory loss on adherence to antiretroviral treatment (Becker, et al., 2011; Harzke, et al., 2004). Our findings demonstrate that memory loss not only interferes with participants' work and household activity performance, but also impacts on their social roles in the home and the workplace. Improving work and household activity performance will need an intervention that is aimed at overcoming memory difficulties among PLWH. Routine screening for the presence of memory loss is required. However, a change in performance in the home or at work will necessitate an intervention using expertise related to both psychological and social functioning.

As it is mentioned above, participants in FGDs indicated that these limitations in the performance of activities affected their productivity overtime, and this could have a negative impact on the livelihood. This implies that the impairments were so severe that they affected the participants' physical ability to work effectively. Although the participants did not report on their income, the decrease in productivity was likely to affect their income. Thus the impairments also affected their socio-economic functioning, and any intervention intended to overcome physical and psychological functional limitations should also target the social and economic functioning of the patient.

Activity limitations in carrying out housework activities were also reported to be prevalent in studies by Rusch et al. (2004b) and Rusch et al. (2004a), in which they also found associations with social role restriction. In contrast, participants in Myezwa et al.' study (2009) reflected a different picture with regard to general activity performance, as their limitations were more with the basic activities of daily living, rather than with social role activities, as in our study. An explanation for this could be that most of the respondents in their study were at an advanced stage of the disease, some with a CD4 count below 100, and there was no certainty regarding the patients' adherence to antiretroviral treatment. This could have contributed to their inability to perform even the simple activities of daily living without help.

These findings substantiated the discrepancy found between the survey respondents and the sample from the Rwanda national demographic survey regarding levels of education and employment status, especially paid work. In the survey there was a very small percentage of respondents who were in paid work particularly among female respondents, who were in the majority. Not only was the performance of the activity affected, but most importantly, their productivity and livelihood, and this had a substantial negative impact on the participants' socio-economic status. This could explain why the majority of the participants declared that they earned less than US\$100 per month. The findings suggest the need for social rehabilitation and social workers involved in the management of PLWH to be made aware of this. This would assist them to plan for intervention strategies that target the development of income generating projects that have the potential to improve the socio-economic status of PLWH in Rwanda.

5.5.6 Participation/social role restriction

As it is stated above, functions in the participation/social restriction domain were the most significantly affected of all the functions assessed in this study. The FGDs' participants shared that their social activities and ability to take part in leisure activities were severely curtailed. Similarly, respondents in a study by Rusch et al. (2004a) experienced a more problems with regard to overall social role functioning (93.2%). In this present study, in the survey, 'participation in relaxation or pleasure activity' was the most function most affected, with a score of 84%, followed by 'problems the family have due to the health condition of the patient' (75%). The least affected area was 'problems because of barriers in the world around you', with 21% of the people in the sample reporting moderate, severe and extreme problems. It was very interesting that many of our participants declared that they had significant problems with involvement in relaxation/pleasure activities: which apparently most of them thought was similar to involvement in sexual intercourse; this in fact referred to other activities, such as playing games or getting together with others and playing music. Mental health/ psychological rehabilitation, social rehabilitation and education intervention strategies could be effective in dealing with restrictions relating to participation in relaxation/pleasure activities.

Further research is also recommended to explore why our respondents could not think about other relaxation activities. Perhaps this reflects a lack of knowledge and/or a lack of those activities or barriers to those activities in their community. Additionally, it would be interesting to explore the relationship between involvement in relaxation/pleasure activities and involvement in sexual intercourse. The second most affected function under participation was 'problems that the patient's family encountered due to his or her health condition'. One interpretation of this finding could be that patients' families did not accept the patients' status, or they might have experienced problems in their community resulting from issues with regard to discrimination and the stigmatization of the HIV infection. This could result in a lack of family and/or social support and this could increase problems with emotional functions. These were found to be significant problems in our study group and came third, with 72% of the participants rating this as moderate, or severe and extremely bad. Problems included financial problems the family was experiencing because of patient's health

condition, problems with ensuring the patient was able to live with dignity, and problems in joining community activities; 50% or more of participants reported problems in these areas.

Participants' family financial problems were not unexpected as the socio-demographic findings show that our study group consisted of adults, the majority of whom were either married or widowed, which meant that it was likely they had children to care for. However, the evidence showed that their socio-economic status, especially of women, might be poor compared to that of the general Rwandan population. For example; the recent national demographic survey found that 11% of women were not working at the time of data collection (National Institute of Statistics Rwanda, et al., 2012), whereas our findings showed that 15.4% of the women in our study were unemployed.

Similarly, participants in studies by Van As et al. (2009), and Anandan et al. (2006), complained about financial problems and how to manage finances. These problems interfered with their role as parents and their responsibilities towards their immediate families. Another study, also conducted in Rwanda by Uwimana & Struthers (2008), found out that financial problems were the most prevalent (77%) among a group of PLWH who participated in their study. However, as was mentioned earlier, their study focused on palliative needs. This finding reflects on the way functional limitations among our study group were multifaceted and not simply determined by the impairment of body functions. Problems the patient experienced in living with dignity and problems in joining community activities could be consequences of social discrimination and stigmatization; these problems suggest a lack of social support and this could also affect the psychological functioning and well-being of the patient.

Restrictions to participation in social life were also influenced by impairments, particularly by a lack of energy. As was also found in a study by Basavaraj, Navya and Rashmi (2010), In both rural and urban areas, our participants were generally unable to socialise with others in the community because of a lack of energy. They experienced difficulty with some important socialising activities: they failed to participate in leisure activities, and their spiritual practices decreased due their lack of energy. It appeared as if this lack of energy had isolated the participants from their social worlds. This may not only have affected their social functioning but also their psychological functioning. On the other hand, it is possible that psychological

factors such as a lack of motivation, coupled with lack of energy, could have worsened these difficulties with social participation.

As was found in a study by O'Brien et al. (2009), few participants in our study recognised the way their limited financial means restricted participation in leisure activities. As stated by Anandan et al. (2006), many PLWH have significant financial difficulties as well as physical or psychological functional limitations, and this results in an inability to participate in productive work.

This finding points to the need for effective multiple intervention strategies to deal with lack of energy as a physical factor and to improve socialisation and participation in leisure and spiritual activities. It is also important also to consider a person's psychological functioning and social-economic status. A multidisciplinary rehabilitation intervention programme that involves the community would be beneficial.

Our findings with regard to participation/social restriction revealed a multidimensional picture and suggest that the society plays a considerable role in the everyday functioning of a PLWH. This implies that in clinical practice, health care providers involved in the management of PLWH should put greater emphasis on rehabilitation intervention strategies; these should involve the family and the community of PLWH and this will help to ensure a comprehensive and holistic approach to care.

5.6 Predictors of activity limitations and participation/social restriction

Multivariate analysis has demonstrated to what extent various impairments predicted patients' activity performance limitations and restrictions on their participation in society.

Associations between impairment, activity limitation and participation/social restriction were also demonstrated in other studies with similar study groups (Myezwa, et al., 2009; Rusch, et al., 2004a; Van As, et al., 2009).

5.6.1 Understanding and communication/cognitive

Several body function impairments, as described in results section of the survey, were likely to increase problems with understanding and communication/cognitive functions. Among these, memory and energy and drive were found to be the best predictors. Despite being the

least scored function in mental impairments, it was not surprising that memory was also a strong predictor for cognitive functions; memory is part of the cognitive domain and increased scores by 21%. Poor memory was also reported as interfering with work and household activities by FGDs' participants.

However, it was not so clear how energy and drive could worsen the cognitive domain and added a further score of 9% to the problems experienced. A possible explanation for this is that PLWH in our study were so demoralised that they had lost trust in themselves. This was probably a result of the changes that were happening in their lives because of the HIV infection and the compound adverse effects of antiretroviral medications. Consequently some participants become demotivated and were unable to think clearly, or to find solutions for their problems and or to take the initiative in learning new tasks (these were the two most serious problems in the cognitive domain). Surprisingly, and contrary to the findings of our study, an unusual finding from a study conducted by Van As et al. (2009) revealed that neuromuscular impairment was a strong predictor of cognitive function, particularly with regard to learning and applying knowledge.

A likely interpretation of this finding could be that those who were most affected by the HIV, experienced the most problems across all domains. In other words, those who were the most ill experienced problems in both the cognitive and energy and drive domains. However, further investigation is required to determine the effect of patients' motivation on the cognitive functions, such as understanding, learning new tasks, analysing and finding solutions, concentration etc. Notably few of these items emerged as problems during the FGDs.

5.6.2 Getting around/mobility

The getting around/mobility function was adversely affected by various impairments to body function that were identified among our subjects. The greatest adverse affect was due to problems experienced in the mobility body function (this was assessed together with muscle power under neuromuscular movement impairment) and the blood pressure function, with both having the same contribution rate of 11%. In two similar studies conducted by Van As et al. (2009) and Myezwa et al. (2009), getting around/mobility was also affected by impairment of neuro-musculoskeletal movement, particularly relating to muscle power, but also to pain.

In our study, pain was also identified as a predictor for the mobility/getting around function, but it was not as strong a factor as mobility and blood pressure.

It was not unexpected that the mobility impairment should predict getting around/mobility, but in the case of blood pressure; this was an unusual finding, especially as it rated equal to mobility. Blood pressure was among the least common impairments in the cardiovascular and respiratory domain. However, its observed influence on the mobility function could be a result of its known symptoms, such as dizziness and headache, which might impact on the ability to stand for long periods or to leave the home; both of which were identified as the most affected abilities in mobility function. Fatigue, which was found to be the most prevalent impairment of body function in this study, and which could also be a symptom of blood pressure, could also play the role of mediator between blood pressure and getting around/mobility.

It is difficult to draw conclusions from the assumptions we have made above as we did not perform a thorough subjective examination. However, the analysis of the FGDs supported the results of the regression analysis with many participants reporting that their mobility was affected by pain, breathlessness and lack of energy. The survey did not include paraesthesia which was an omission as this was identified by the FGDs' participants as also affecting their mobility function.

More importantly, a clinical/ objective examination is needed to confirm clinically what was reported by the participants. Further research that involves a comprehensive clinical examination is required to confirm evidence regarding the association between blood pressure and mobility, and the mediation of its symptoms, especially fatigue, is required.

5.6.3 Life activities domain

Heart problems were the first most significant predictor for life activities and increased the score for life activities by 16% (i.e. made them worse). This was followed by mobility, which added a further 10%. As in Myezwa et al. (2009), it was understandable and to be expected that mobility impairment will predict problems in life activities functions that include household and work activities. However, in this present study, it was somewhat unclear and rather unexpected that this would be true for heart problems. Interestingly, the influence of

this factor was more significant and increased the problem six times more than mobility. As was demonstrated earlier, the greatest limitation with regard to life activities was how quickly the activities were done. The speed and intensity involved in performing activities could have been worsened by heart disease problems.

The FGDs supported the negative impact of poor energy and drive, poor memory, weakness and pain as contributors to problems in the life activities domain. As was the case with blood pressure, the finding on heart problems was obtained from the self-reported views of our respondents. There was no clinical examination to confirm the evidence regarding the severity of the disease or its impact on life activities. This finding underlines the need to investigate the problems of heart disease and their influence on the life activities of PLWH.

5.6.4 Participation/social restrictions domain

Emotional problems, which increased the scores by 10%, were followed by the sexual discomfort function, which added a further 7% to the score; these were the most significant predictors for participation/social restriction. Decreased sexual desire, linking sexual activity to the contracting of HIV and a fear that sexual activity would result in a decreased amount of energy were all discussed in the groups. It may be that the impairment, sexual discomfort, in fact relates to a wider range of problems and was not interpreted simply as physically experienced pain. The other significant predictors were similar to those reported by the FGDs' participants, with decreased energy emerging as the greatest limitation to participation.

Respondents in a study by Rusch et al. (2004a) also demonstrated that mental problems and sexual activities influenced their participation in society, whereas Benedict, Mezhir, Walsh, & Hewitt (2000) discovered that mental impairment contributes to incapacity to perform work and consequently leads to an increased rate of unemployment among PLWH. The predictive function of sexual intercourse confirmed the earlier discussion concerning patients' view that sexual intercourse was the most important activity for relaxation/pleasure. It is possible that the greater rate of limitations in the participation in the relaxation/pleasure activity that dominated all other functions assessed in this study could have been mediated by problems in sexual intercourse.

Further research is required to understand how emotional problems experienced by our respondents and sexual discomfort are the most significant impairments that adversely affect their participation in the society. It will also be interesting to find evidence regarding the factors that could mediate between participation/social restriction and emotional problems and sexual discomfort, for example, stigma, discrimination and lack of support.

5.6.5 Conclusion regarding interrelationship between factors

It appears that decreased energy combined with muscle weakness (described as bodily weakness) and decreased exercise tolerance are the primary impairments which are perceived to impact on function. These impairments are amenable to physiotherapy treatment in many cases and by increasing endurance and building up exercise tolerance the functioning of PLWH might be improved. Neuropathic pain and paraesthesia are additional impairments which are difficult to treat but certain physiotherapy interventions, such as joint mobilisation and vibration have been reported to be effective (Benjamin & Jelsma, 2014)

5.7 Influence of environmental factors on functioning

As discussed in the literature review, in the ICF model environmental factors are described as factors that are external to an individual and include aspects of the physical, social and attitudinal factors in the context in which people live and conduct their lives. These may have a positive or negative impact on a person's functioning (Schneidert, et al., 2003).

Environmental factors were examined exclusively through the use of the FGDs as there were no items relating to environmental factors included in the survey.

5.7.1 Influence of family and community social relationships on functioning

Factors in the social relationship environments that acted as facilitators or barriers to performance of activities and to social participation were described by the participants. In both rural and urban areas, women and men shared their positive and negative feelings and experiences about their relationship with their family and community after contracting HIV.

Some participants recognised that their family members had accepted their HIV status and given them support. This finding corresponds with the findings of other studies (Edwards, 2006; Majumdar, 2004; Serovich, Kimberly, Mosack, & Lewis, 2001). As Gaskins (2006) has also reported, one participant in our study stated that at times her family showed too

much support; this verged on overprotection. It is possible that the family considered the PLWH to be vulnerable and regarded her as a dependant. However, it is important to recognise how PLWH understand and view their abilities and situation.

On the other hand, some participants related how they experienced non-acceptance, negative attitudes, rejection and stigmatization from their family members. This is in accordance with the findings of other similar studies (Brashers, Neidig, & Goldsmith, 2004; Emlet, 2007; Nichols, Tchounwou, Mena, & Sarpong, 2009; Zukoski & Thorburn, 2009).

The findings regarding family support for the PLWH point to the need for a comprehensive intervention programme beyond the hospital environment that involves the families of PLWH in their usual caring roles. The intervention could include training families and bringing them together to educate one another about how to deal with the needs of PLWH. The intervention could also target PLWH and educate them about the benefits of and the ways of strengthening family relationships.

As in other studies (Brashers, et al., 2004; Majumdar, 2004; Serovich, et al., 2001), certain participants said that there were people in their community, such as friends, who accepted their HIV status and demonstrated positive attitudes and support. Some participants acknowledged the support from the community, encouraged socialization, and indicated that it improved psychological well-being overtime. Their positive attitude could assist the implementation of community programmes to foster the involvement of the community in the holistic care of PLWH.

However, our findings are similar to those which indicate that PLWH continue experiencing negative attitudes, discrimination and stigmatization from their community members, including from their close friends (Emlet, 2007; Majumdar, 2004; Zukoski & Thorburn, 2009). A 64 year old man in Emlet (2007, p. 746) revealed; "...I could drop dead in my house and no one might know about it for three weeks". Given this finding, there is a need for further exploration of the community situation in order to understand more fully the awareness of, perceptions of and attitudes towards HIV. The aim would be to inform the community regarding the need for awareness and behaviour change towards PLHW; this could have long term QoL benefits.

5.7.2 Influence of the hospital environment on service provision and utilisation

The findings of this study described the factors within the hospital environment that acted as barriers or facilitators to the functioning of participants. The participants felt that they belonged in the ARV clinic, trusted the health care providers from the ARV clinic, and had a good relationship with them. They appreciated the service provided by the ARV clinic more than the other services provided within the hospital. Similar studies have found that PLWH had a good relationship with their health care providers and appreciated the services provided (Bakken et al., 2000; O'Brien, et al., 2009).

O'Brien et al. (2009) reported in their article that patients felt secure and had confidence in their health care providers because of their knowledge and skills and because of the support they provided. Bakken et al. (2000) indicated that any improvement in the relationship between health care providers and patients was important as it influenced patients' adherence to antiretroviral treatment. Our participants' sense of belonging in an ARV clinic, their trust in and appreciation of the health care providers were founded on the value they attributed to the antiretroviral treatment and its health benefits.

However, despite their appreciation of and trust in the health care providers, participants also described a number of problems that led to a failure to effectively provide the necessary holistic care. Lack of assistance from the ARV clinic concerning the treatment of participants' functional limitations or problems was emphasized. The ARV clinic did not provide adequate treatment for their functional limitations. Although they often complained about these problems and sometimes had their antiretroviral treatment changed, most of time they did not receive help. Occasionally, they were told to be patient and, with time, the problems would pass.

There are many explanations for what participants described as ineffective care of their functional limitations. It is possible that their functional limitations were difficult to treat, or that the health care providers at the ARV clinic were not concerned with their functional limitations: they did not always do a comprehensive assessment and they did not think about providing a holistic treatment. It is possible that what mattered to them was to provide the antiretroviral treatment while ignoring its possible side effects or other complications associated with the HIV infection. It is also possible that health care providers at the ARV

clinic lacked knowledge about the effectiveness of the rehabilitation services, such as physiotherapy and the psychological management of functional problems.

There are no published studies in Rwanda that determine the knowledge of health care providers with respect to rehabilitation services such as physiotherapy and psychology; functional limitations require treatment by skilled rehabilitation professionals. Future research could explore the extent of understanding and knowledge on the part of health care providers at ARV clinics with regard to rehabilitation services for PLWH.

Furthermore, it is also recommended that the hospital organisation should develop a training plan for health care providers at the ARV clinic in order to ensure appropriate screening and referral. Rehabilitation specialists, including physiotherapists and psychologists, could be instrumental in creating awareness among ARV clinic health care providers of the services they provide. They could teach basic assessment skills to detect impairment and identify functional problems among PLWH. This would result in a more holistic assessment of PLWH and would be an important step towards holistic management.

Participants were particularly appreciative of the initiative that health care providers from the ARV clinic had taken regarding the involvement of their families and their communities in their care. Following the profile of their functional limitations, described previously in the sections on impairment, activity limitations and participation restrictions, this finding needs to be understood in the context of the need for holistic care that goes beyond the hospital setting. It implies that apart from the usual clinical care, based on the provision of antiretroviral treatment, health care providers from the ARV clinic need to consider including the patients' family members in their efforts to care for PLWH.

The involvement of the community could result in the development of community-based health care programmes. This might assist in removal of barriers in the family and community that lead to discrimination and that stigmatise PLWH. Parker and Aggleton (2003) also suggest that interventions targeting stigma and discrimination could require community involvement. Such interventions might result in improved psychological and social functioning and improved quality of life for PLWH.

Similar studies have also found that, despite the manifestation of multiple impairments requiring rehabilitation services among PLWH, there are very few referrals to rehabilitation services such as physiotherapy or psychology (Freeman, et al., 2007; Myezwa, et al., 2007). Our findings have revealed that not only were there few referrals to rehabilitation services or to any other service within the hospital from ARV clinic, but there were also weaknesses and inconsistencies in the referral procedure. Normally, according to the referral procedure at the hospitals where the study took place, referrals should be made by the ARV clinic directly to the outpatient service, and from there, if necessary, to the specialized services. However at times, participants were referred from the ARV clinic directly to specialized services without passing through the out-patient service. At other times, when there was no referral: participants who felt they needed treatment for functional limitations would take the initiative to seek further care, even if they did not know of the existence of these specialized rehabilitation services. This created difficulties as it led to there being multiple files for one patient within one hospital. Moreover, using their own initiative without guidance could result in PLWH looking for inappropriate care.

There were no policies in place at either hospital regarding the referral procedure within the hospital. At times patients from ARV clinic would decide to visit other services on their own initiative. It is possible that the health care providers at the ARV clinic considered their clinic to be a special service and separate from other services within the hospital; they may have found it difficult to fully integrate their health care services within the hospital structure. Some NGOs have been described as having more interest and investment in HIV health care delivery than in other health services (Parker, 2002). The ARV clinic health care providers in Rwanda may also have the impression that they are independent of other services provided by the same hospital organisation, hence the temptation to make their own rules and plans about health care delivery with the support of NGOs.

To ensure that appropriate treatment is given for functional limitations, there is a need for the development of guidelines or a protocol that would guide referral procedures within the hospital, in particular with regard to the ARV clinic and the provision of rehabilitation services. Future research should consider looking at policies and procedures regarding referral systems within the hospital setting and their impact on other services; in particular,

they should consider the use of one combined medical file. A procedure needs to be laid down for referral from the ARV clinic to other services, particularly rehabilitation services.

Participants strongly recommended collaboration among all health care providers at the hospital; they wished the ARV clinic health care providers would improve their referral procedure and they advocated the use of one file per patient for all hospital services. Interestingly, they believed that collaboration would improve the referral procedure and significantly improve the management of their functional problems, and that the use of one medical file would improve collaboration, enhance the referral procedure, and benefit the patient-health care provider relationship, and also assist with patient follow-up.

It is interesting and encouraging that participants thought of strategies to improve the referral procedure, which they believed would contribute to better management of their functional limitations. Importantly, their recommendations go beyond the issue of referral procedure and suggest the need for changing the systems in place in hospitals: these are responsible for encouraging team spirit and team work and are important in a patient-centred approach to care. The ultimate goal was improve the management of the functional limitations of PLWH in holistic way. Apparently, planning for changes in the referral procedure could involve several health care providers within the hospital setting, particularly those from rehabilitation services. However, ARV clinic health care providers should play a big role in driving these changes.

Our study added to the existing evidence that prolonged waiting times and the unavailability of doctors would lead to difficulties in accessing care and have an effect on patients' appreciation of health care delivery (Kennedy, Rhodes, Walls, & Asplin, 2004; Wouters, Heunis, van Rensburg, & Meulemans, 2008). The majority of participants who visited other services following referral from the ARV clinic explained that they always had to wait too long to receive care and that sometimes doctors were not available, so they were not attended to. The most important reasons for this (also mentioned in other studies) are the shortage of health care providers, particularly doctors, and the great number of patients (Hoot & Aronsky, 2008; Wouters, et al., 2008).

5.7.3 Participant recommendations regarding hospital services

Our participants also recognised that there was of shortage of health care providers and made the following recommendations:

- (1) They suggested that the ARV clinic health care providers should advocate at the hospital level for more medical doctors in the ARV clinic. This would improve the assessment and treatment of their problems, reduce the number of cases for referral, and improve the referral procedure, particularly by ensuring referral to competent specialists for their functional limitations.
- (2) Participants suggested that the ARV clinic health care providers should advocate for an increase in the other types of health care provider for the entire hospital. This implies that PLWH recognised the need for other health care providers to contribute to the improvement of their care. Hospital managers should be aware of this need in order to ensure the augmentation of their staff; this would have a positive impact on the care provided for PLWH.
- (3) A special recommendation was that the ARV clinic health care providers should advocate at the hospital level for rehabilitation specialists to be more available, as this would assist with the treatment of functional limitations. Participants proposed that rehabilitation specialists could either be integrated in ARV clinic team or provide their own services, to which the PLWH could be referred. This recommendation applies to the health care providers at the ARV clinic, but the hospital authorities should also recognise the need for rehabilitation services for PLWH. Perhaps a reorganization of the ARV services is required, with the aim of integrating the rehabilitation services. However the health care providers at the ARV clinic should remain the key people in providing a continuum of care.
- (4) Finally, participants recommended that the ARV clinic should advocate for their own identified team of health care providers. This could be provided at their usual clinic in the hospital or at the ARV clinic. They believed “their own” health care providers would give them greater consideration, reduce waiting times and improve care. This suggests that there is need for stronger education and intervention strategies that

would assist PLWH to understand that improvement of the hospital services as a whole would also benefit them.

It should be noted that Rwanda lost a large number of health care providers during the genocide (Logie, et al., 2008; Rusa, et al., 2009). Additionally, despite the efforts made by the government through the Ministry of Health to retain health care providers in public hospitals (by providing incentives through performance-based financing) (Logie, et al., 2008; Price, et al., 2009), there has been an internal migration of health care providers, particularly doctors, from the public service to international NGOs and donor agencies which pay better salaries (Logie, et al., 2008).

Our findings testify to the growing problem of staff shortages in public (government) hospitals in Rwanda. Ways must be found of encouraging staff retention, beyond the performance-based financial incentives. Government health sector managers need to assist the government to look into the issue and propose strategies which would reduce long waiting times and reduce the unavailability of health care providers. The finding invites further research to explore the problem from the perspective of health care providers, whose opinions and experiences need to be understood.

Another important finding was that PLWH need special consideration. The participants believed that they were different and had special needs as a result of the severity and the chronic nature of their illness. Similarly, participants in another qualitative study by Hughes, Davies, and Gudmundsdottir (2008) also expressed the need for special consideration, but they used the term “dignity”; they explained that being treated with dignity meant being treated with respect, which included having their medical needs met in timely manner, and not being ignored. Noticeably, our participants also complained that they were lost in those services to which they were referred, because they did not have someone in particular to look after them, as in the ARV clinic, and they did not know the health care provider responsible for assisting with their functional limitations.

Apparently participants considered themselves to be very vulnerable and wanted to be protected and be considered as patients with special needs, due to the permanent nature of their health condition. Male participants could not accept being mixed in with other patients.

It is also possible that participants did not easily fit into the organisation of the hospital as a whole. They considered themselves to belong at the ARV clinic, and not to the hospital as a whole. They were not like any other patient. Therefore, participants recommended that ARV health care providers should advocate for greater consideration for PLWH, for recognition of their special needs and for respect for their privacy. Participants also wished that their health care providers would respect their time at while on duty and avoid mixing work and socialising.

Health care providers at the ARV clinics need to play a role in educating PLWH about the hospital's organisation, structures and procedures, and in assisting them to integrate into the hospital system like any other patient seeking care (and not primarily as a PLWH). If this were to be achieved, it might reduce the levels of social discrimination and stigmatization. The finding suggests further research is needed to clarify and explore the meaning of the need for 'special consideration' from the perspective of both PLWH and the health care providers. Participants' recommendations with regard to time management apply to the health care providers engaged in caring for PLWH and perhaps a behaviour change intervention strategy at the hospital would be beneficial.

Another finding related to poor communication by those services situated outside the ARV clinics. A study by Ownby and Dune (2007) found similar complaints about communication by health care providers. Interestingly, a review of the relevant literature by Stewart (1995) has found that good communication between health care provider and PLWH could improve the patients' general health status. In our study, participants wished that they were listened to and emphasized the need for good communication. They said this would improve self-acceptance. This was also suggested by Stevenson, Cox, Britten, and Dundar (2004), who said that effective communication with health care providers was needed if patients were to understand their health condition and to be involved in decision-making regarding their care; this would also lead to greater understanding of their treatment. Participants in our study wanted improved communication to empower them, rebuild trust and contribute to self-acceptance. Interventions were needed to provide communication skills training programmes for health care providers. However, it could also be valuable to develop the communication

skills of PLWH, as this would enable them to express their problems with clarity and confidence.

Our findings confirm the generally accepted evidence that PLWH experience stigmatization and discrimination from their health care providers (Emlet, 2007; Zukoski & Thorburn, 2009). Our participants explained that health care providers at the referred services demonstrated negative attitudes once they discovered their HIV serostatus. Participants in studies by Zukoski and Thorburn (2009) and by Emlet (2007) highlighted the discriminatory attitudes and behaviour of health care providers, who feared contamination.

It is possible that participants' expressed wishes for special consideration and better communication that would assist them with self- acceptance and contribute to their empowerment might be hindered by the negative attitudes of health care providers. There is a need for an intervention programme to develop strategies to combat stigma and discrimination on the part of health care providers within the hospital setting. It is possible that health care providers from the ARV clinics could assist with advocacy, since they had accepted PLWH and shown positive attitudes. They could serve as resources for the development of strategies to combat stigma and discrimination towards PLWH from colleagues working in other hospital services

Another important finding in our study was that those services to which PLWH were referred by the ARV clinic were not able to treat their functional limitations adequately. The health care providers did not have enough time for them because of the number of patients and they only prescribed medicines for their functional limitations. These medicines were not always effective and often failed to bring healing. This finding reinforces the evidence from previous studies that doctors generally only provide drugs and do not attend to the functional limitations experienced by PLWH, especially pain (Larue, et al., 1997; Nair, et al., 2009; Ownby & Dune, 2007).

This finding suggests that participants' needs and expectations were not met by the services to which they were referred. Although participants knew that antiretroviral treatment caused some of their functional limitations, they appreciated the care received from the ARV clinic because antiretroviral treatment is recognised and had assisted with the major problem.

Apparently they thought that the services to which they were referred outside ARV clinic were specialised in the management of their functional limitations or problems and they expected to be assisted with the problems which could not be solved by the ARV clinic.

This finding suggests that doctors and other health care providers working in different services within the hospital to which PLWH are referred might require further training to improve their knowledge of the functional limitations or problems experienced by PLWH. This training could be linked to the development of guidelines and appropriate assessment tools in order to enable a thorough assessment and to plan for effective management. The training would need to focus on an awareness of the rehabilitation services' ability to deal with functional limitations or problems. It could stimulate doctors to recognise their boundaries and refer patients when needed.

A few participants indicated that the rehabilitation services, particularly physiotherapy and psychology or mental health, had been successful in the management of functional limitations. After the other participants heard about these rehabilitation services, they indicated that they needed to visit them. Additionally, they recommended that a counselling program be established at their clinic as they believed this would support behaviour change, adherence to ARV medication, and improve psychological well-being and the quality of life.

These findings add to the limited evidence regarding the effectiveness of rehabilitation services in treating the functional limitations experienced by PLWH (Fillipas, et al., 2010; Freeman, et al., 2007; Mutimura, et al., 2008; Ownby, 2006). There is little published research conducted in Rwanda that has attempted to describe the utilisation of rehabilitation services such as physiotherapy by PLWH. Future research should therefore explore the use of the various rehabilitation services by PLWH; this will assist with planning interventions to improve the utilisation of these services by PLWH. Rehabilitation health care providers need to make other health care providers and PLWH aware of the benefits of their services for reducing functional limitations among PLWH. This might result in increased referrals to rehabilitation services and motivate PLWH to seek rehabilitation. PLWH who have experienced an improvement in functioning as a result of rehabilitation could assist with a peer education strategy during the awareness-raising intervention program.

Failure to get help for their functional problems led some participants to seek treatment elsewhere, including at a private clinic and even at a doctor's home, and this was more reported and encouraged by men in both rural and urban areas. Although they seemed uncomfortable that their visit to the private clinic might be "discovered", the majority of those who visited private clinics appreciated the care they received. However, participants indicated that it was too expensive, compared to the service provided by a public hospital. They indicated that only those who had a higher quality health insurance such as "RAMA" would be able to afford private care.

It appears that participants who went to private clinics felt strongly about the ineffective care they were receiving for their functional limitations and the poor referral procedure. They felt they did not have any other choice. If they had received better care for their functional limitations at the hospital (similar to the effective treatment of HIV through antiretroviral treatment) they would not have considered seeking care outside the hospital. This finding suggests that there is great need to strengthen the public health care system as a basis for providing effective and comprehensive care for PLWH. However, this finding also suggests that it might be advisable to engage with the private sector in broader health care planning, particularly with regard to the management of the functional limitations experienced by PLWH.

The majority of participants used the Rwanda National Insurance medical cover; *Mutuelle de Santé* (see section 1.1.1). They appreciated its benefits, particularly because it covered all the treatment costs in almost all the services they made use of. However, as indicated by Logie et al. (2008), it only provides basic services and does not cover all the necessary care. It does not cover all of the costs of special care, and sometimes participants had to pay the extra costs from their own pockets.

Participants wished they could be provided with services beyond those covered by *Mutuelle de Santé* or get a more comprehensive medical cover. Participants' income status was not determined but their employment status (see section 5.2.4) suggests that they might not be able to afford more expensive medical insurance or to contribute towards the extra costs of such cover. There may be a need for a special grant to assist them with the extra costs, instead of relying on special insurance medical cover; this might be difficult to obtain as it would

require changing government policy. Perhaps there is also a need for NGOs that have HIV care on their agenda to be informed of this problem.

This study supports the findings of other studies that recognise the benefits of nutrition support and the effect of good nutrition on the health of PLWH (Ivers et al., 2009; Serrano et al., 2010). Participants expressed the need for food programme support to be provided to all PLWH without exception. Community based intervention projects that aim to empower PLWH and improve their income, were also needed. Community social workers and nutritionists could assist in planning effective interventions. It is possible that the advocacy for a food program should go beyond the hospitals and involve other sectors, such as PLWH associations, NGOs and the Ministry of Health. It might also require changes in government policy

5.8 My reflections on perceptions of how the hospital services address the functional limitations of PLWH with associated disabilities

I am a physiotherapist by profession, and an educator and a trained counsellor. Initially, I was prompted to look in-depth into PLWH, in particular the associated disabilities and functional limitations of PLWH, and to explore to what extent the hospital services were able to respond to their functional limitations. This emerged, firstly, because of the issues raised during the survey (see Chapter Three). In addition, what motivated me to conduct the study was my experience with regard to the management of physiotherapy provided to PLWH for treatment of their disabilities. From my observations in Rwanda, when a PLWH with an associated functional limitation (such as low back pain) comes for treatment to a physiotherapy department, the main focus of the physiotherapist during treatment is the functional limitation which brought the patient to seek help; the original problem, which is HIV, is ignored, even though this could be the underlying cause of the functional limitation. In addition, the patient could have other problems which might need assistance from other services existing within the hospital and these were not investigated.

5.9 Limitations

These studies have limitations that must be acknowledged.

5.9.1 Limitations of the Quantitative study

It is possible that the use of a cross-sectional design could have resulted in a failure to capture the entire picture of disability among our participants, particularly because the nature of the reported functional limitations varies across time. Cross-sectional design could have contributed also to an inability to draw some causal inferences from the findings. Additionally, our findings relied on self-reported diagnoses rather than on clinical examination; its findings have not been confirmed clinically. During data collection, participants retrospectively recalled their difficulties with functioning. It is possible that they could have experienced difficulty in remembering details of their past experience; this applies especially to those with memory problems. In this present study we did not determine the relationship between socio-demographic factors, such as age, education and employment, and the functions assessed, and this has limited the ability to make findings regarding causal relationships and the variation of impairment and other functional variables across socio-demographic and economic variables.

However, despite these limitations, the present study, in a form of a survey, is one of the few studies that describe the profile of disability among PLWH, using a standardized and reliable instrument. The study used also a large sample obtained from numerous settings, and this enabled its findings to be generalised.

5.9.2 Limitations - Qualitative study

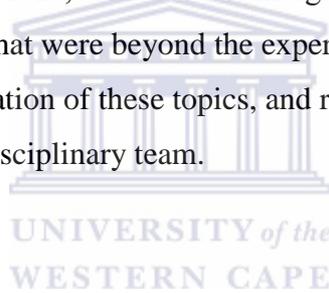
Although this part of the study has provided rich information for understanding the experiences of PLWH, particularly with regard to their functional limitations (and how contextual factors influence their functioning) there are some limitations.

The data was obtained from only two focus group discussions, with each group consisting of eight people. The study was conducted in only two purposively selected hospitals out of a total of 45 hospitals in the country. Future research should consider conducting more group discussions and involving more hospitals so as to achieve a broader understanding of the problem. The hospitals were in an urban and a semi-rural setting. However PLWH from a rural area might provide a different perspective because of the influence of demographic, socio-economic and cultural factors. They would be influenced by a culture which is more traditional than that found in the urban areas.

Data was collected at the ARV clinic, the place where the participants received daily care. This might be considered as a limitation as participants might have left out some information for fear of offending their health care providers. But this may also be a potential strength because of the selection of a familiar and safe environment for the participants.

Another possible limitation of the study has to do with the nature of the focus group discussion. Due to the sensitivity of certain topics, such as sexual activity behaviour and stigma, it is possible that participants were reluctant to freely express their feelings and opinions about these issues. It is possible that individual interviews would have led to a different understanding. It is recommended that if further research is conducted that aims to explore the influence of sensitive problems on the functioning of PLWH, individual interviews should also be used.

Despite the strength of the discussions, which provided thick and rich information, and exceeded the researcher's expectations, some issues emerged, such as spirituality, stigma, sexual behaviour and disclosure that were beyond the expertise of the moderator. We recognise the limits to our exploration of these topics, and recommend that further research should be conducted by an interdisciplinary team.



6 CHAPTER SIX: VALIDATION OF INSTRUMENTS

6.1 Background

Rehabilitation professionals need a valid and reliable tool to measure disability amongst people seeking rehabilitation services, such as physiotherapy and psychotherapy. Disability tools or instruments are used to determine functional limitations among people who encounter problems with health conditions that can affect their functional status. Various studies have shown that PLWH encounter numerous functional limitations that affect their health-related quality of life (Gale, 2003; Rusch, et al., 2004a). There is no instrument in Kinyarwanda that assesses functional limitations, particularly among PLWH. The WHODAS 2.0 was identified as a suitable instrument.

WHODAS 2.0 was developed based on the ICF which utilises a bio-psychosocial model. It was chosen because of its multidimensional character, as it assesses several important areas of functional status, including physical, mental/psychological and social status. In addition, it can be used for any disease or health condition. It has been developed for use in a number of countries with their own languages and has been shown to be appropriate across cultures (Üstün et al., 2010b). Three versions of WHODAS 2.0 were developed: a 36-item, a 12-item and a 12+24 item version. Of the three, the 36-item version of WHODAS 2.0, which is interviewer-administered, was selected by the researcher because it is the most detailed and it allows users to generate scores for the six domains of functioning (cognition, mobility, self-care, getting along, life activities and participation) (Üstün, et al., 2010a).

WHODAS 2.0 has been translated into 27 languages (Üstün, et al., 2010b), following WHO translation guidelines. There are only a few African language translations: these include Yoruba, one of the Nigerian languages (Üstün, et al., 2010b), and isiXhosa (personal communication, Maart, University of Cape Town, 2012). The reliability and validity of WHODAS 2.0 as a tool to measure the functional limitations of various population groups and health conditions has been established. The internal consistency of the WHODAS 2.0 domains has been found to be satisfactory. In addition, the tool has displayed consistency in repeated measurements. WHODAS 2.0 also displays concurrent validity: its results correlate

highly with the results of other disability tools that measure the same problems (Üstün, et al., 2010b).

It remains an on-going challenge to translate different instruments from the source language to local languages and a common process entails the use of both forward and backward translation. The translation approach followed in this study is similar to those used in several other studies that have also described the procedure followed for the translation of various clinical and research tools across cultures. For effective translation, the whole process typically goes through many stages. These include forward translation, a first consensus meeting, backward translation, a second consensus meeting, a third consensus meeting, proofreading and, finally, a fourth consensus meeting, after a debriefing interview (Cha, Kim, & Erlen, 2007). This process can result in the development of an instrument which is clear, concise and valid.

It was demonstrated that the translation process of “the European Quality of Life 5-dimensions (EQ-5D)” from English to the Shona language (spoken in Zimbabwe by more than half the population) started with forward translation, carried out independently by two native Shona speakers, and followed by a consensus meeting. Thereafter, the Shona version was backward translated independently by two translators, and this was also followed by a consensus meeting and, finally, by the testing of the instrument (Jelsma, Chivaura, De Cock, & De Weerd, 2000). Furthermore, it was reported that the ICF checklist was translated into the isiXhosa language, one of the South African languages, and went through the following procedure: forward translation by two independent translators; then a consensus meeting to compare the two versions; thereafter backward translation to produce an English version; followed by a consensus meeting to compare with the original version (Toni, 2007).

Various scientific papers have also examined instrument translation experiences in Asian countries and shown how they follow translation procedures similar to those used in the present study. For example, a Korean version of the “hip disability and osteoarthritis outcome score (HOOS)”, was produced. The process entailed forward translation; a first consensus meeting involving translators and three orthopaedic surgeons; backward translation; followed by a second consensus meeting that included the backward translators, the three orthopaedic surgeons and, in addition, one medical professional whose first

language was English, a native speaker of Korean English with a speciality in education psychology and, finally, a research assistant specialist in orthopaedic scoring systems (Lee et al., 2011).

In another research paper, also produced in Korea, it was reported that “a Korean version of the disability of arms, shoulder, and hand outcome questionnaire (K-DASH)” was developed through cross-cultural adaptation using the following methodology: forward translation by two translators whose first language was Korean, one of whom had a medical background; this was followed by a review and a synthesis of the translation, and then by consensus. The second step was backward translation into English followed by a consensus meeting that involved health professionals, linguistic professionals and the translators. Finally the instrument was tested on a group of patients with upper extremity problems to produce a final “K-DASH” Korean version (Lee, Lim, Oh, & Ko, 2008).

In China, development of a Chinese version of the “Diabetes Management Self-efficacy Scale (DMSES)” went through the following stages: forward translation by two bilingual professional translators, followed by the first consensus meeting, which involved the two forward translators, two bilingual Chinese researchers and a diabetes educator who did the checking before the instrument moved to the next stage. Then a focus group discussion was conducted, involving two diabetes educators, a bilingual Chinese researcher and three patients considered experts on providing opinions on the cultural equivalence. Thereafter, a backward translation was carried out; this included two native English-speaking translators with experience in biomedical Sciences and nursing. They were blind to the DMSES original version. Backward translation was followed by a consensus meeting consisting of two native English-speaking researchers and a bilingual Chinese researcher. Their role was to compare the backward-translated instrument with the original in order to check for differences in meaning (Wu et al., 2008).

WHODAS 2.0, like any other instrument, has limitations and, more importantly, it excludes the impairment domain. For this reason, an ICF condition regarding a set of impairments of body functions was included in the study. The study aimed at identifying impairment among PLWH, across two countries: Brasilia and South Africa (Myezwa, Buchalla, Jelsma, & Stewart, 2011)

The English versions of the two instruments were translated into the Kinyarwanda language, following the translation guidelines in the WHODAS 2.0 manual and the WHO guidelines for translation. The WHO has developed a method for translating an English instrument into any other targeted language, producing a conceptual meaning equivalent to that of the original version rather than a literal or word-for-word meaning (World Health Organisation (WHO), 2012). Therefore the integration of both the linguistic or semantic meanings of the words in the instrument and the conceptual meaning were considered in order to ensure a cultural understanding of certain concepts.

The aim of the translation was to produce Kinyarwanda versions of these two instruments which were linguistically and culturally valid, and which were able to test associated body function limitations among PLWH and receiving Antiretroviral Treatment. Cultural equivalence can help to determine how people from different linguistic and cultural groups interpret and give meaning to the questions under study (Pena, 2007). The translation included the WHODAS 2.0 section on background and demographic information, questions in WHODAS 2.0 assessing activity limitations and participation restrictions, and an ICF core set of impairment questions.

It is hoped that the translated Kinyarwanda version can be used in clinical practice to assess the functional needs in the Rwandese population and that it will help rehabilitation professionals to plan and monitor holistic intervention programs. It is possible that it could also serve as a cultural instrument model for other countries in the same region: Burundi has a similar culture and language to Rwanda, and in East Congo (DRC) there is a group of people with a culture similar to that of Rwanda and whose mother tongue is also Kinyarwanda.

However an instrument may be valid within one context but inappropriate for use in another. It was therefore necessary to establish the cultural appropriateness and validity of the Kinyarwanda version of the WHODAS 2.0 and the impairment questionnaire. Validity incorporates face, content and construct validity. In addition, reliability needs to be proven.

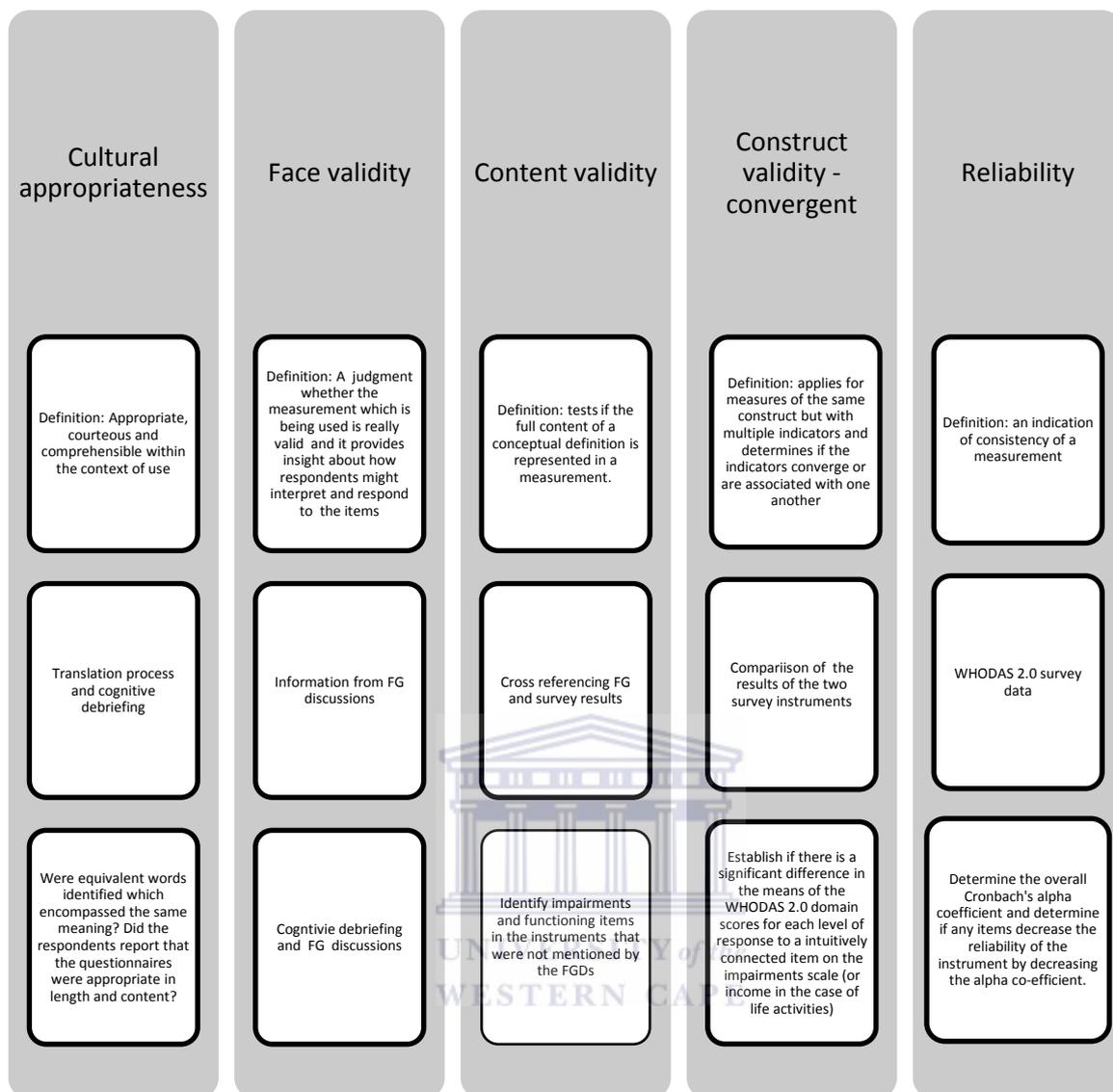


Figure 24: Conceptual framework for validation of the instruments

Definition of cultural appropriateness is taken from Beaton, Bombardier, Guillemin, and Ferraz, (2000) and Wild et al. (2005).

Definition of face validity is from DeVon et al. (2007) and Neuman (2003).

Definition of content validity is from Neuman (2003) and Punch (2005).

Definition of construct validity-convergent is from Neuman (2003) and Punch (2005).

Definition of reliability is from DeVon et al. (2007) and Neuman (2003).

6.2 Aims and Objectives

6.2.1 Aim

The aim of this chapter is to establish whether the translated Kinyawanda versions of the WHODAS 2.0 and the ICF core set of questions were valid instruments with which to document the presence of impairments and functional limitations. This entailed interrogating the face and content validity, as well as the reliability and construct validity.

6.2.2 Objectives

1. To explore the cultural appropriateness, linguistic equivalence and face validity of the translated questions by describing the process of forward translation (from English to Kinyarwanda) and backward translation (from Kinyarwanda to English) of the ICF core set of questions regarding impairment of body functions and the WHODAS 2.0 outcome instrument and to document and report difficulties encountered during consensus meetings or analysis due to linguistic differences or cultural influence.
2. To establish the content validity by comparing the items included in the instruments with the impairments and activity limitations and participation restrictions that emerged during the focus group discussions.
3. To establish the construct (convergent) validity of the WHODAS 2.0 by establishing whether there was a significant difference in the means of each domain for each level of response to an intuitively associated impairment or income level. (Cognition domain and level of memory problems, Mobility domain with mobility impairment levels, Self-Care domain with muscle power impairments, Getting Along with people with Emotional impairments, Life Activities with Income category and Participation with impairment level in Energy and Drive).
4. To determine the reliability of the impairments questionnaire and the WHODAS 2.0 through determining the internal consistency of the instrument and the component domains.

6.3 Methodology

This chapter includes a description of the translation process and the difficulties encountered in reaching a consensus as to culturally appropriate translation of certain concepts and items.

The further validation of the instrument was done post hoc and the data gathered in the FGDs and during the survey of functional limitations and participation restrictions was utilised for this purpose.

6.3.1 Participants

6.3.1.1 Participants in the forward and backward translations

Participants in the forward and backward translation, the consensus meetings and the proof reading were drawn from different backgrounds, thus increasing the validity of the instrument. The translation process and consensus meetings included the following disciplines: linguistics, physiotherapy, psychology and medicine. The first language of all participants was Kinyarwanda, and they were all fluent in English and had experience of translation. Four individuals were selected, two physiotherapists and two professionals in linguistics, as well as two translators per translation, one being a professional in linguistics and the other a physiotherapist. The professional linguist in forward translation was a Kinyarwanda secondary school teacher who had been involved in translation consultancies before, and was very experienced in the field of translation. The professional linguist in backward translation was working in the Department of Language Studies at KHI and was employed to teach English. The linguistically trained translators had no knowledge of medical terminology, thereby ensuring that the translation was appropriate for lay people. Both were qualified to translate, and were well placed to understand and retain concepts while integrating them within the local cultural context. The physiotherapist translators held masters degrees and were both lecturers in the Physiotherapy Department at KHI. Consequently they were highly qualified in the field of disability, were knowledgeable with regard to medical terminology, and had experience in HIV research. As Rwandese, these professionals were also equipped with cultural insight and were able to link this to certain concepts used in the instrument.

6.3.1.2 Participants in consensus meetings and debriefing cognitive interview

Four consensus meetings were held. **The first consensus meeting** was held following the forward translation. Participants in this meeting were: the researcher, whose role was to moderate and occasionally take notes during discussion; the two forward translators; two lecturers in the physiotherapy department at KHI; and one physiotherapist working in the

Hospital. All the participants were familiar with either HIV or with disability studies. One of the research assistants was a newly qualified physiotherapist. Apart from the researcher, the participants in the first consensus meeting did not participate in the second meeting, thus ensuring that the first discussion did not influence the backward translation.

The second consensus meeting was held following the backward translation. Participants in this meeting included: the researcher, the two backward translators, one lecturer in the Physiotherapy Department at KHI, and one of the research assistants, who was also a newly qualified physiotherapist. **The third consensus meeting** included all participants from the first and the second consensus meetings.

The **cognitive debriefing interview** took place at Muhima Hospital. It was conducted by the researcher, the physiotherapy lecturer who participated in the forward translation, and the two selected researcher assistants. The interview involved 24 participants, all PLWH and on antiretroviral treatment.

The last consensus meeting took place after the cognitive debriefing interview and it included the researcher, the two research assistants, the physiotherapist translator who participated in forward translation, and the professional linguistic translator who participated in the backward translation. The selection of the last two participants was based on their availability. The rest of the participants were involved in proof reading before the finalization of the first draft; this draft was used for the cognitive debriefing interview. The people who participated in the final proof reading were: a medical doctor working in the Ministry of Health/HIV division, two psychologists (both lecturers in the Mental Health department at KHI), and two qualified physiotherapists working in the hospital setting.

6.3.1.3 Participants in the validation studies

The responses of participants of the prevalence survey (described in Chapter Three) and in the focus group discussions (described in Chapter Four) were used to determine the validity of the study.

6.3.2 Instrumentation

The original WHODAS 2.0, 36-item version, interview administered, was downloaded in PDF format as it was received from the WHO. However, the characters were not very legible,

so the researcher decided to retype the instrument, with all the instructions, without changing any words. Questions measuring impairment among PLWH were also typed in words but, to allow for a smooth flow during the interview, these were added to the questionnaire after the Demographic and Background Information section. Certain background information specific to PLWH (clinical variables such as time since diagnosis, CD4 cell count, etc.) was also included at the suggestion of participants in CNLS to whom the project was presented. Some of these questions were taken from The World Health Organisation Quality of Life (WHOQOL-HIV BREF).

The instrument for translation (See Appendix XI) consisted of two parts, divided into four sections:

Section 1: entitled face sheet, which covered interviewer and interviewee identification (ID) information, such as interviewer and respondent ID numbers, and the interviewee's living situation.

Section 2: questions in this section covered demographic and background information, such as sex, age, and marital status, taken from WHODAS 2.0. In the first paragraph, instructions were provided explaining the purpose of developing the interview questionnaire as well as instructions concerning ethical considerations.

Section 3: included questions assessing impairment in PLWH using the HIV code set identified by Myezwa et al. (2011). Two paragraphs on the first page contained information explaining impairment, the nature of the health condition, the time since onset, and the severity.

Section 4: was about activity limitations and participation restrictions. This section started with three paragraphs of instructions. The first paragraph dealt with information regarding ethical considerations, while the second paragraph covered the meaning of health conditions, the difficulties experienced in doing an activity, the time since onset and the severity. Following these instructions, the WHODAS 2.0 domains which were to be assessed were described: these were cognition, mobility, self-care, getting along with people, daily activities (comprising household activities and work or school activities) and participation. Instructions were repeated before each domain.

6.3.3 Procedure of translation – Cultural appropriateness

The two forward translators were given the English version to translate into Kinyarwanda. Each translator developed a spread sheet in Kinyarwanda. Thereafter, the two backward translators were given the Kinyarwanda version developed after the first consensus meeting which took place after the forward translation. The backward translators developed a spread-sheet in English, but had no sight of the original transcripts.

The process was lengthy and was delayed due to various factors. Permission for the translation was obtained from the WHO, the CNLS (the national institution supervising and coordinating all activities regarding HIV in Rwanda), the KHI IRB, which represented the National Ethical Research Committee, and from the hospital selected for the cognitive debriefing interview. This took a considerable amount of time. In addition, the availability of translators was a limiting factor, particularly for consensus meetings, where the time allocated to translation had to be extended. (For example instead of the envisaged 10 days, each group spent 14 days doing translation, as a result of the translators' other obligations).

Immediately after approval, all participants in the translation were approached to give their consent.

6.3.3.1 Forward translation

After the selection of the two forward translators by the researcher, they were invited to a meeting clarifying the required translation procedure. It was explained that they should each produce one translation aimed at addressing a multi-audience group. The translations should not simply be linguistic or semantic translations, which could result in literal translation, but should take the Kinyarwanda cultural context into account. They were also instructed to highlight and report terms and phrases which caused problems so that these could be discussed during consensus meetings; the date for the consensus meeting was also decided upon. In addition, each translator was instructed to work independently, and to produce an individual transcript. After two weeks, the consensus group then met to analyse and compare the two Kinyarwanda versions in order to produce one final forward translation.

6.3.3.2 Backward translation

After the Kinyarwanda version was developed in the first consensus meeting, the two selected backward translators were given the Kinyarwanda transcript to translate into English. They were asked to each do one translation and they were requested to take cultural issues into account. Translators at this point had not seen the original English version and were instructed to produce individual work. It took them two weeks to complete the translation.

6.3.3.3 Cognitive debriefing interview

The purpose of the cognitive debriefing interview was to get feedback with regard to the length of the interview from a group similar to the final participants. Were the questions easy to understand and answer? Was there clarity with regard to both the linguistic and cultural meanings? The debriefing took place at a randomly selected ARV clinic at Muhima hospital, in Nyarungege District, Kigali City. Prior to the interview, all interviewers were asked to keep notes on ambiguous words or concepts and to note any alternative suggestions regarding wording. Face-to-face interviews were conducted. All PLWHs on antiretroviral treatment who attended the ARV clinic on the day of the debriefing interview were invited to participate in the interview. The study was explained to the participants using the Participant Information sheet. It was emphasised that participation was voluntary, and that confidentiality and anonymity would be maintained. Participants were also requested to give permission to access their medical records. The interview lasted for three hours.

6.3.4 Ethical considerations

Ethical approval was obtained from UWC and from the KHI IRB and CNLS, and permission for the cognitive debriefing interview was obtained from the WHO, CNLS and Muhima hospital.

6.4 Data management /analysis

6.4.1 Cultural appropriateness, linguistic equivalence and face validity

Analysis started during **the first consensus meeting** held after the forward translation. During analysis the WHODAS 2.0 manual was occasionally consulted, particularly when the consensus team failed to clearly understand the meaning of an English word or phrase. The meeting took place at KHI, and was held over one day, five hours in the morning and three

hours in the afternoon, with a one hour break in between. Before discussion commenced, team members were briefed and the procedure for the analysis was agreed upon. Team members were requested to focus on both the linguistic meaning and on cultural nuances during the discussion.

The analysis was based on the translated transcripts submitted by the two translators in the target language, Kinyarwanda, with reference to the source version in English. The consensus group analysed all the sections mentioned above, sentence by sentence, and discussed the nuances of the words or phrases in order to arrive at the linguistic meaning. Appropriateness with regard to Rwandan culture was also considered. Firstly, every translator had to read the sentence, before meeting with the other consensus team to discuss the linguistic meaning of the concept. Discussion and analysis was done phrase by phrase, while comparing the two Kinyarwanda versions and also referring to the source, the English version. Consensus teams attempted to identify ambiguous or difficult words, or those which were translated differently by the translators, and to determine whether they could propose more appropriate alternatives to the words chosen. Deliberation continued until all team members were satisfied and in agreement about the correct option. Difficult phrases or words, where consensus could not be reached, were highlighted for the attention of the backward translators, and a decision was taken after backward translation.



The discussion was recorded. The researcher had to moderate the discussion and notes were taken by one physiotherapy lecturer team member. The professional translator assisted in transcription of the recorded information and, before producing the final forward version, the team member who was taking notes, the transcriber and the researcher met to discuss whether all comments had been considered and integrated into the transcript developed during the consensus meeting; thereafter, the final forward version was completed.

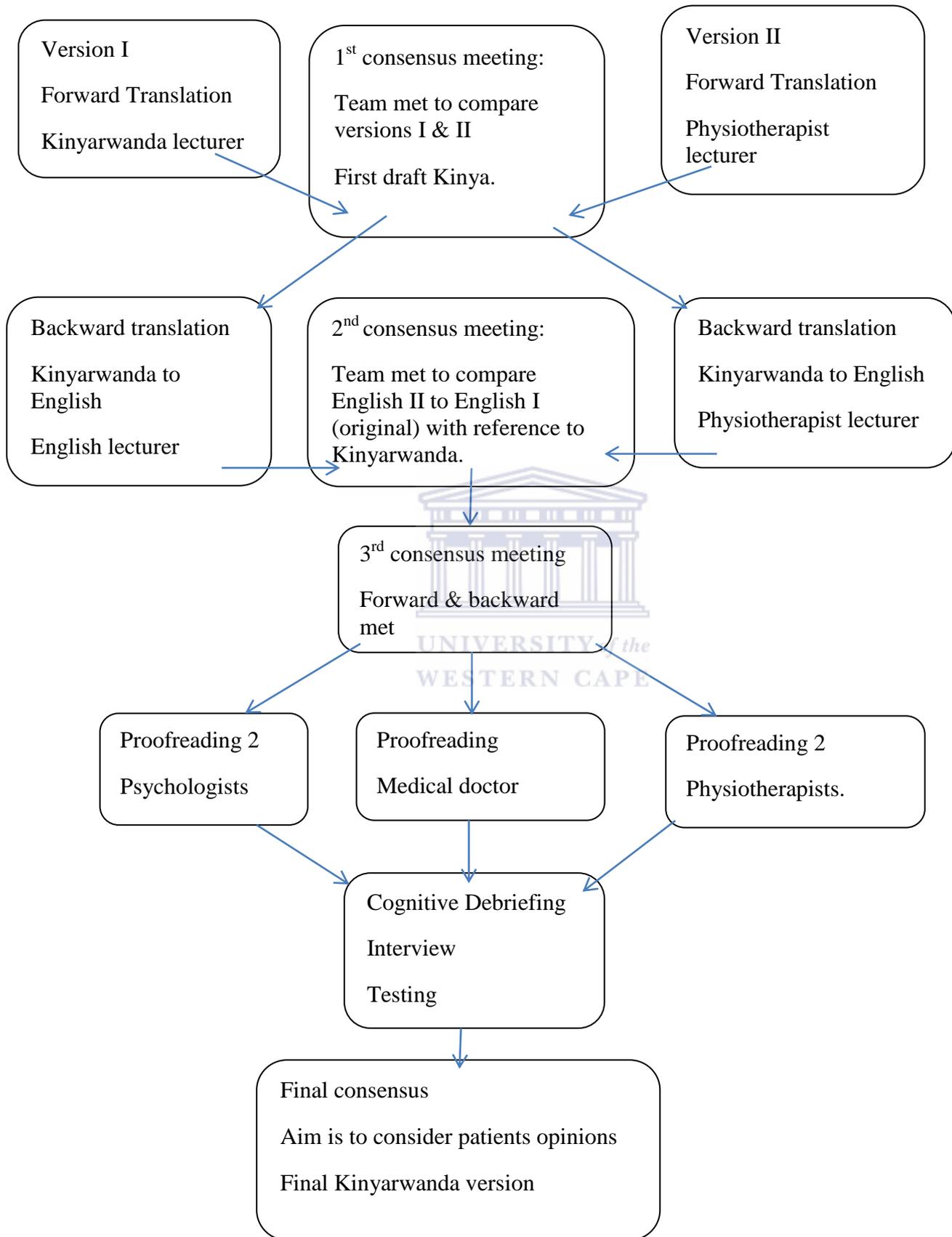
The second stage of the analysis was conducted in the **second consensus meeting**, held after backward translation. It went through the same procedure as the first meeting. The consensus group met at KHI and consisted of five team members. The meeting lasted for two half days, for three hours each day. Once again, analysis took place, by reading one translation after the other, sentence by sentence and then analysing phrase by phrase. At this stage, however, a comparison was made of the concepts in the two English transcripts produced by the two

backward translators and those in the Kinyarwanda version, with reference to the source in English. Emphasis was placed on the Kinyarwanda version, with the aim of improving its validity and reliability. Highlighted and difficult words that the previous consensus meeting had identified with were given much consideration. Contentious issues identified in the first consensus meeting were raised, and there were a few phrases where consensus could not be reached. All these cases were highlighted and kept for analysis and discussion in the third consensus meeting.

The third stage of the analysis was conducted **in the third consensus meeting**, which took place at KHI and lasted for two hours. The meeting involved twelve team members and brought together members of the first consensus meeting and those involved in the second meeting. The debate focused on the cases highlighted in the second consensus meeting, that is, on ambiguous words or phrases where consensus could not be reached. At this stage, the first draft of the Kinyarwanda version was completed.

However, there were few words which remained ambiguous and did not have a definitive equivalent in Kinyarwanda. The fourth step of the analysis was performed by a **multidisciplinary group of health professionals**, selected to participate in **proof reading** the text. The transcript was then given to two psychologists, one medical doctor and two physiotherapists working in hospital. Ambiguous words were identified words for which we had failed to find an agreed interpretation in the three consensus meetings. The problematic words/phrases were clarified and, at this stage, definitive Kinyarwanda terms were agreed upon and the transcript was ready for the cognitive debriefing interview. The last step followed the cognitive debriefing interview. The researcher, the two researcher assistants, the physiotherapy lecturer who participated in forward translation and the cognitive debriefing interview, and the professional linguist who participated in forward translation finally met to discuss and analyse the outcome of the interview. All problems raised were resolved and a final translation was produced (Appendix XII).

Figure 25: Diagram representing translation procedure and data management



6.4.2 Content validity

The thematic analysis of the Focus Group Discussions was used to identify the impairments and functional limitations and the participations restrictions that the participants had identified. These were then tabulated against the corresponding items of the WHODAS 2.0 and the Impairments Questionnaire.

6.4.3 Construct validity

The one-way ANOVA was used to establish convergent validity of the WHODAS 2.0. It was not possible to do this with the Impairments Questionnaire.

6.4.4 Reliability

Cronbach's Alpha was calculated to test for internal consistency of the Impairments questionnaire and the WHODAS 2.0. This was calculated for the entire scale and for the subsections of the scale. In addition the contribution of each item to the overall correlation was examined by calculating the alpha with each item included. If the correlation increased once the item was excluded, it implied that the item did not fit well with the construct of the domain.

6.5 Results – Cultural appropriateness and Face validity

6.5.1 Cultural appropriateness, language equivalence and face validity

The following section discusses the results of the analysis. As explained above in the analysis section, definitive terms were chosen at various stages after consensus had been reached. The main aim of the analysis was to capture conceptual equivalents of the English version, but there were certain concepts for which, at various stages, consensus could not be reached. This was due to changes in the meaning of words between the two languages, and the cross-cultural challenges that arose. Provincial variations of the Kinyarwanda language were also considered, and the choice of one of several possible words (with the same English meaning) was sometimes based on the whether the word was commonly used in most of the provinces. For example, people in the Northern Province not only share certain specific concepts, but their pronunciation also differs. This was taken into consideration during the training of the research assistants for the survey (see Chapter Three).

6.5.1.1 Face sheet section

It was noticed that “complete” and “filling” are translated by one word in Kinyarwanda, “*uzuzza*”.

“F1”: The respondent identification number (ID), produced discussion and disagreement during the forward consensus meeting. Some consensus team members proposed recording the respondent identity number (ID), while another group suggested recording the hospital code number of the respondent. This was because the use of the ID as the identification number would not facilitate easy tracing and identification of the respondent in the hospital. It was also indicated in the manual that the respondent’s or subject’s identification number should simply be recorded. It was decided that F1 (respondent ID) was to be translated using the ARV clinic /hospital code number of the respondent, “*Nomero iranga ubazwa*”. During the cognitive debriefing interview, it was observed that every respondent had an identification card with an ARV clinic identification number. It was decided to add a code for each hospital after the cognitive debriefing interview during the fourth consensus meeting.

For “F2”: interviewer identification number, it was decided that every interviewer should be provided with a code number used for identification, particularly during data checking. It was translated as, “*numero iranga ubaza*”.

“F3”: the assessment time point, was a source of confusion, and there was no detailed explanation in the WHODAS 2.0 manual. After great deal of discussion, it was decided that it would be translated as how many times the interview is conducted, “*inshuro ibazwa rikoreshejwe*”. It was decided that the interview date would start the page, so automatically “F5” replaced “F4”.

The term “community” was difficult to translate as there is no exact concept in Kinyarwanda that describes community as it is understood in English. The Kinyarwanda word does not have the sense of belonging, as in English; it usually simply denotes a group of people. It was translated as “*muryango*” which means a group of people who share same activities.

“*Muryango*” can also mean a family.

6.5.1.2 Demographic and background information

Difficulties found in the demographic and background sections arose more from differences across culture than from linguistic differences. This section began with instructions. The term “health condition”, which is repeated several times in the instructions, was translated in each section as “*ndwara/ uburwayi*”, which, in a literal sense in Kinyarwanda, means “illness” or “disease”. There is no precise word for the broader concept of “health condition”. The two terms (“*ndwara*” and “*uburwayi*”) mean the same and were used interchangeably, depending on the context. “*Ndwara*” is more precise and specific to the kind of the disease, whereas “*uburwayi*” is a more general term used to signify illness or disease.

There are two words in Kinyarwanda expressing “being married”, “*warashatse*” and “*urubaste*”, and they both have the same meaning. The forward team consensus opted for “*urubaste*”, while the backward team consensus chose “*warashatse*”, but, when the two teams met, they agreed on “*warashatse*”, which is more commonly and widely used. However, being married in the Kinyarwanda culture does not only mean ‘officially married’, or “*warasezeranye imbere y’amategeko*”, it can also mean “traditionally married”, particularly in rural areas, where this entails the involvement of the two families and sometimes bride price payment. There are certain cases (similar to cohabiting) in both rural areas and urban areas, where people decide to live together and may have children without necessarily having the involvement of their families; with time, eventually these relationships become recognised by their specific community. Although the law doesn’t recognise these relationships as it does an official marriage, the couple may subsequently decide to make their relationship official.

“Cohabiting” could be expressed in the following phrases in Kinyarwanda: “*kubana nk’inshuti, kubana n’undi bitemewe n’ amategeko*” or “*kubana n’undi mutarasezeranye*”. It is, however, inappropriate and unacceptable in Kinyarwanda culture. It would be considered inappropriate and embarrassing to ask anyone if he or she were cohabiting, and he or she would feel very uncomfortable about admitting this. As explained above, cases of cohabitation do exist, but most of the time they are recognised as being equivalent to marriage. In order to avoid offence, “cohabiting” was translated with the following phrase, “*Mubana n’undi by’igihe gito*”, which means “living with someone for a short time”. Guided

by the WHODAS 2.0 manual, it was recommended by the team consensus that, during the interview, when it came to the marital status question, the interviewer should simply inquire about the marital status of the respondent, without reading out the choices in advance, and then, based on the response, the interviewer would choose and tick among the options.

“Work” (A4) was first translated as “*Akazi*” in Kinyarwanda. However, “work” has two possible linguistic meanings in Kinyarwanda, “*Akazi*” and “*Imirimo*”. Depending on the context in which the concept is used, a distinction can be made between “*Akazi*”, which generally involves a specific payment, and “*Imirimo*”, which is broader and includes “*Akazi*” as well as other types of activity (paid or unpaid). As the following phrases included broad activities, for “self- employed such as owning your own business or farming”, and for “keeping house/homemaker”, “*Imirimo*” was used. After the cognitive debriefing interview, it was agreed to include “income” in the questionnaire because it was observed that respondents were more concerned with what they earn than with the work they did. Monthly income was included, because in Rwanda, in both public and private institutions, a salary is normally a monthly package.

The question “How many years in all did you spend studying in school, college or university?” resulted in an interesting debate in the forward consensus meeting. Discussion was focused on whether to retain only “in school” and leave out “college or university”, or to keep the phrase as it is but inform the interviewer that, in order to avoid offence, during the interview it would not be necessary to read out “college or university”. In Rwanda, the level of education, particularly in rural areas and among women, is still low, and there are many older people who did not go to school, or who dropped out at a primary level. Consequently, the question was translated as, “*wamaze imyaka ingahe mu buzima bwi'ishuli?*” which means “How many years did you spend at school?”. It was proposed that options regarding the level of education should be added before the years spent studying in school, allowing respondents to remember the level, and then use that to indicate the years. Options ranging from “never went to school” to “tertiary education” were proposed, as these would enable respondents to respond appropriately.

The term “tertiary education” has two meanings in Kinyarwanda, “*Amashuri makuru*”, and “*Kaminuza*”. “*Amashuri makuru*” is the accurate idiomatic equivalent of tertiary education

in Kinyarwanda. It was first suggested in the forward consensus meeting, but following discussion in the third consensus meeting it was rejected, and “*kaminuza*” was chosen as it was regarded as the more commonly used and more familiar term to an audience from different provinces. “*Kaminuza*” is possibly preferred by many people because it suggests speciality and mastery, which helps to differentiate between secondary and tertiary level education.

It was suggested during the interview that in the interests of sensitivity, it was preferable to avoid repeating the term “HIV/AIDS”, and “*uburwayi*” was recommended instead, which means “health condition”.

6.5.1.3 Impairments of body functions

The section on impairments presented several problems as the respondents were less familiar with medical terms. Translation of the phrase “impairments of body functions” brought confusion and stirred a debate in both the forward and backward consensus meetings. There is no word or concept which means “impairment” in Kinyarwanda. In forward translation, the professional linguistic translator claimed that “impairments” translates as “*Kumerwa nabi*” or “*Kumerwa nabi m’ umubiri*” (the latter if it refers to impairments of body functions; it literally means to “feel bad”/“feel bad in the body”, and can mean “disease”).

On the other hand, the second translator, a physiotherapy lecturer, claimed the correct translation was “*kononekara kw’ibice n’imikorere by’umubiri*”, which means “problems in anatomical and physiological function”. The debate in the forward consensus meeting was on finding a tangible concept in Kinyarwanda which positioned “impairment” between “disease” and “disability” but which was not overly scientific or medical, and would be clear to the audience. One member of the consensus team group was of the opinion that “impairment” in Kinyarwanda means “disability”, which can be translated as “*ubumuga*”; he indicated that there is no difference between “disability” and “impairment” in Kinyarwanda. Other group members disagreed, and suggested that “impairment” was synonymous with “disease” (“*uburwayi*”). This view was based on different questions under the impairments section, which were consequences of the disease rather than of disability.

The aim was to find a word or phrase that meant neither “disease” nor “disability”, but which would include both concepts and be simple enough for respondents to understand. It was difficult in Kinyarwanda to find such a word. The following Kinyarwanda phrase, which is simple and short, “*Ibibazo by’umubiri*”, and which literally means “problems of the body”, was agreed upon by the forward consensus meeting, but this was later rejected by the backward consensus meeting, which opted for “*ibibazo by’uburwayi*” which means “disease problems”. Finally, in the third consensus meeting, after discussion, the two consensus teams agreed on “*ibibazo by’umubiri*”, but proposed to highlight the phrase and the two proposed meanings for the medical doctor’s assessment during proofreading. The doctor subsequently agreed with the consensus teams on the meaning of “*ibibazo by’umubiri*” and agreed that it would be understandable for the audience.

The paragraph of instructions, which is repeated on each page, was more applicable for activity and participation, rather than for impairment, so some changes were necessary to adjust it for the impairment section. For instance, “problems or changes in body structure or body function” was replaced by “difficulties doing activity”. It was observed that “health conditions”, “disease” or “illness” were repeated in the instruction but that they all meant the same in Kinyarwanda, “*uburwayi/indwara*”; where “disease” and “illness” were found together; one word could be used for both concepts. The phrase “mental or emotional problems” produced discussion in both consensus meetings. It was translated in the same way by both translators in forward translation, “*Ibibazo by’ihungabana*”, which literally means psychological “trauma problems”. After much debate it was supported by team consensus in both the forward and backward consensus meetings. The debate in both meetings was about the fact that psychological trauma was a stronger concept than simply emotional problems. It was concluded that in Kinyarwanda, “*ihungabana*” is appropriate when emotional issues are linked to health problems. It was also suggested in the third consensus meeting that the phrase and its meaning in Kinyarwanda should be highlighted for the psychologist’s input during proof reading. This was supported and accepted by the psychologist, although, he explained that “emotional” could have another meaning: it did not necessarily mean “health problems”. For example “emotional feelings” that could refer to either positive emotional feelings or negative emotional feelings, literally translated as “*Amaranga mutima*” in Kinyarwanda, which also means “sentiment”. Finally “*ibibazo by’ ihungabana*” was used.

The word “effort” was also found in the instructions, and was translated as “*imbaraga*” in Kinyarwanda, which also means “energy” or “force/power”.

There was a difference between the translators when it came to translating the scales described in the instructions that are used for each question: “none, mild, moderate, severe and extreme or cannot do”. The first translator suggested the following: “none”: “*ntabyo*”; “mild”: “*biroroheje*”; “moderate”: “*biringaniye*”; “severe”: “*birakomeye*”; “extreme or cannot do”: “*birenze urugero*” or “*byarananiranye*”. However, the second translator translated as follows: “none”: “*Nta na rimwe*”; “mild”: “*buhoro*”; “moderate”: “*biringaniye*”; “severe”: “*cyane*”; “extreme or cannot do”: “*bikabije*”. The consensus team in the first and in the second meetings indicated that both sets of words were similar and suggested different levels of difficulty. However, the second version was accepted as the suggestions of the first translator were very literal and might not be familiar to people in certain provinces.

Different impairments were described and divided into domains and each domain was identified by a particular impairment. The word “domain” was translated as “*ishami*” in Kinyarwanda.

Domain 1 (D1), which applies to “mental functions” was translated by the phrase, “*imikorere yo mu mutwe*”, “*imikorere*” being “function” and “*mu mutwe*” being “mental”. However, “*mutwe*” also means “head”. The phrase, “energy and drive function” was the first impairment listed for mental functions. There was a debate on “energy and drive” in both the forward and the backward consensus meetings. The major problem was to consider only mental factors, and exclude physical factors, and to find a word or expression that would be clear and easy for the audience to understand. The phrase “*Ingufu n’imikoranire y’ibice by’umubiri*” was agreed upon in the forward consensus meeting, and literally means, “energy and body parts functioning”. The consensus team based their agreement on the idea of brain functioning being like that of an engine which makes the body parts move and function. However, they realised that the phrase was ambiguous, and they decided to refer it to the backward translators for their opinion. The backward consensus meeting preferred “*Imbaraga n’imikoranire y’ibice by’umubiri*”, where “*Imbaraga*” is used for “energy”, instead of “*Ingufu*”; as it was thought that *Ingufu* was jargon and a rather abstract word. The consensus team was still not fully satisfied with this expression, as they felt it was

linguistically and conceptually imprecise. A final, more acceptable and simpler phrase was found by the psychologists. It was agreed that “*Imbaraga nu mwete*” would be appropriate, as it means the “energy and courage and the will to do something”.

Another word/phrase in this domain which brought about confusion was “emotional functions”. The problem was due to the contrast between what was understood as the meaning of “emotional problems” in the instructions paragraph, and what both translators produced as a translation of “emotional functions”, namely “*Kwakira ibikubayeho*”, which literally means “how someone deals with or manages what affects him or her”. In fact, the difference arose because the previous phrase consisted of the words “emotional and problems”, while the second instead included “emotional and functions”. This last phrase has a more general meaning, while “emotional problems” means simply when “something goes wrong with the emotional function”. The two words, “problem” and “function”, influenced the choice of the translation.

After discussion, the team in the forward consensus meeting agreed and supported the translators. They understood that emotional functions are general in nature, involving all the emotional issues, and how one manages or deals with feelings in general can have a large impact on one’s life.

“Haematological system functions” was translated as “*ibigize amaraso*” with the support of the medical doctor during proofreading; it literally means “blood compositions”. During the cognitive debriefing interview, the concept seemed to be a bit complicated. It was understood by the majority of respondents to refer to “anaemia”, which translates as “*kugira amaraso make*”, whereas “blood pressure”, translated literally as “*umuvuduko w’amaraso*”, was very familiar to the respondents. “Immunological system functions” translated as “*ubudahangarwa bw’umburi*”, meaning “body protectors”; this was quickly understood during the cognitive debriefing interview to refer to a “CD4 count”; the respondents were very concerned with changes to CD4 and how these could affect their health.

“Digestive functions” was translated as “*igogorwa ry’ibiryo*”. During the cognitive interview, it was observed that respondents would explain only the digestive process in the stomach and the intestine, and would forget that the digestive process begins in the mouth. Instead,

problems relating to the mouth were mentioned in relation to “tolerance to food”. For instance, some respondents complained about an inability to chew and swallow food due to wounds in the mouth. Another difficult word found while describing impairments of the digestive function was “tolerance to food”, translated by the first translator as “*kubasha ibiryo*”, meaning “managing food”, and by the second translator as “*kuyobokwa ibiryo*”, meaning to “tolerate food”. After discussion, the consensus team decided to keep both concepts, “*kubasha*” and “*kuyobokwa*”, in addition to *ibiryo* which means “food”. The implication was that “tolerance to food” means that one is able to manage food, so that, for instance, one has an appetite and at the same time one tolerates food and does not have any adverse reaction to food. Finally, “*kubasha no kuyobokwa n’ibiryo*” was the phrase chosen.

“Regularity of menstrual cycle” was translated in Kinyarwanda as “*ukudahinduka kw’ibihe by’imihango*”, which means “no changes in menstrual periods or cycle”, and this was agreed upon in the forward consensus meeting. However, there were objections in the backward consensus meeting, and “*ukudahinduka kw’iminsi y’imihango*”, meaning “no changes in menstrual days”, was agreed upon by both teams during the third consensus meeting. This was supported by the medical doctor during proofreading, who indicated that it is the most widely used phrase.

“Muscle power” was translated similarly by the two first translators as “*Imbaraga z’imitsi/z’imikaya*”. The two terms mean exactly the same thing but “*imitsi*” is more frequently used in many provinces. Both consensus team groups (forward and backward) supported the translators but were concerned with the concept “*imitsi*”, which can also mean “well nerves and vessels”. This could produce confusion during the subjective physiotherapy assessment.

The following terms, “system”, “function” and “sensation”, were frequently used with other concepts in this impairment section. A general comment regarding those words was that, when aiming at a conceptual and concrete meaning of the word/phrase in Kinyarwanda, these words were found to be very broad and abstract, and were sometimes excluded to avoid changing the meaning or confusing the audience. “System” and “function” were only used in domains and were generally excluded when describing impairments in each domain.

“System” was translated as “*urwungano*” and “function” as “*imikorere*”, which also means

“activities”. In the forward consensus meeting, “*imikorere*” was excluded in certain domains such as “sensory functions and pain”, and “functions of cardiovascular and respiratory systems”. However, the backward consensus team recommended that it be included simply to have a complete phrase and not for the sake of any additional linguistic meaning.

There is no single general meaning for the word “sensation” in Kinyarwanda. Its meaning depends on the context in which it is used and sometimes it is excluded. “*Imyumvire*”, which means “sensation” in one context, might mean “understanding” in another context. The only situation in which it is commonly used and has a concrete meaning, is in the sense of touching or physical feeling, and it was included here. “Sensation related to the skin”, “*imyumvire idasanzwe y’uruhu*”, literally means “unusual sensation of the skin”. However, for other impairments the word “sensation” was excluded. For example, “sensation of nausea” was translated as “*kugira sesemi*”, which literally means “*to have nausea*” and “sensation associated with the digestive system” was translated as “*kugubwa nabi mu nda*”, meaning “feeling an upset stomach/stomach full of gas”.

During the debriefing interview, it was realised that there were certain questions on reproductive functions which were not appropriate for men, such as “menstruation function”, translated as “*kujya mu mihango*”, so a decision was made during the last consensus meeting to add “not applicable” (NA) to the scale.

6.5.1.4 Activity limitations and participation restrictions

As mentioned previously, the researcher decided to give the title of “activity limitations and participation restrictions” to the second part of the instrument, which includes the WHODAS 2.0 domains. The first translator in forward translation translated “activity limitations and participation restrictions” as “*aho ibikorwa n’ubwitabire bigarukira*”, literally meaning “where activities and participation are limited”, whereas the second translator translated it as “*Ingorane mu mikorere no m’ubwitabire*”, which literally means, “difficulties/problems or limitations in activities and participation”.

The consensus team was concerned with the appropriateness of the two meanings, and realised that the phrase would sound better if reference were made to a person having difficulties in performing certain actions in his or her everyday life. The phrase in

Kinyarwanda was therefore changed to “*Ingorane mu mikorere yawe n’ubwitabire mu bikorwa mu buzima busanzwe*”, which literally means, “difficulties/problems or limitations in your activities and participation in daily life”. This was also supported by the backward consensus team.

“Activities and participations” was divided into domains. The term “cognition” (domain 1), was translated by the first translator in forward translation as “*ibijyana n’ubwenge*”, which literally means “regarding intelligence”, while the second translator translated it as “*ubwenge*”, which means “intelligence”. The consensus team recommended that the phrase “*ubwenge n’ubumenyi*”, meaning “intelligence and knowledge”, be used, based on what is described in the WHODAS 2.0 manual: “*the domain asks questions about communication and thinking activities*”. It was concluded that in Kinyarwanda the word “*ubwenge*” alone did not adequately reflect the meaning of “cognition”. In addition, culturally, a person is recognised as intelligent when he is able to express and to defend his intelligence and this requires knowledge. The phrase “*ubwenge n’ubumenyi*” was chosen by team consensus in the second meeting.

There was an interesting debate regarding the phrase “understanding and communicating” in the first consensus meeting. The first translator’s translation was “*gusobanukirwa no kuvugana n’abandi*”, where “*gusobanukirwa*” means “comprehension”, and “*kuvugana n’abandi*” means “communicating with others”. However, in some contexts, the word “*gusobanukirwa*” can also be used to mean “understanding” or even “conception”. The second translator suggested “*bijyanye n’imyumvire n’imivuganire*”, “*bijyanye n’imyumvire*” means “regarding understanding”, and “*n’imivuganire*” means “communication”. The concern was that in Kinyarwanda, if you have understood in the context of cognition, then you know and you are able to explain what you have understood. After a long discussion, assessment of the items listed under “understanding and communication” and based on the description in the manual: “communication and thinking activities”, the following phrase was chosen by the consensus team, “*gusobanukirwa, gusobanura, kumvikana n’abandi*”. This literally means “comprehension or understanding, explanation and understanding/communication between people for effective communication”. The consensus team in the backward consensus meeting was satisfied with this.

“Concentrating on doing something for ten minutes” was translated by the first translator as “*gushira ingufu mu gukora ikintu mu minota icumi*”, meaning “put effort in doing an activity in ten minutes”, and by the second translator as “*kumara iminota cumi ukora*”, which means “spend ten minutes doing something”.. The consensus team in the forward consensus meeting criticised both meanings as they were more oriented towards physical-functions while this section was focused on mental functions, and the word “concentration” was seen as the most important. After discussion, they produced the following translation, “*kumara iminota cumi ukora ushishikaye*”, which means, “spend ten minutes doing something while you concentrate”.

There was a disparity between the forward and the backward consensus meetings regarding the word “finding” in the phrase “analysing and finding solutions to problems in day to day life”. This was first translated as “*kuvumbura*”, which means “to discover”. The backward consensus recommended a more literal translation of “finding”, which is “*kubona*”. This is more concise and convenient, and was adopted in the third consensus meeting.

The phrase “learning a new task, for example learning how to get to a new place” was translated literally as “*kwiga igikorwa gisha*”, meaning “to learn a new task”, and “*uregero kwiga ukuntu wagera ahantu utari uzi*”, meaning “for example learning how to get to a new place”. This produced confusion during the debriefing interview, particularly with regard to the example, “learning to get to a new place”. The respondents found the example rather inappropriate as they regarded themselves as being mentally normal and as being able to learn how to get to a new place. Instead, they were more concerned with learning a new task/activity, such as a new job. It was decided during the consensus meeting, after the debriefing interview, to not use the example and to only inquire about difficulties experienced in learning a new task.

The term “mobility” (domain 2) produced an interesting debate in the forward consensus meeting. The first translator’s translation was, “*kwinyagambura/kunyeganyega*”, which means “moving the body”, while the second translator’s translation was, “*kugendagenda*”, meaning; “moving around or walking around”. There was no consensus in the first meeting as to which translation to adopt, and the consensus team highlighted the two concepts for the backward translators’ input. During the backward consensus meeting, following analysis of

the items in the mobility domain and their description in the manual, it was decided to keep both “*kunyeganyega*” and “*kugendagenda*”, and an observation was made by the two physiotherapists, in the proofreading process, that there was no specific word which means “mobility” in Kinyarwanda.

It was decided after the debriefing interview to include examples for the phrase “moving around inside your home”, meaning in Kinyarwanda, “*kugendagenda mu rugo*”, such as “moving from your bedroom to the bathroom”, and “from bedroom to the toilet”, because, without examples, respondents did not grasp the tangible meaning and the context in which the action is done.

The word “eating” in the “self-care activities” section has no single meaning in Kinyarwanda. It translates as, “*kurya*”, “*gufungura*”, “*kwigaburira*” and “*kwitamika*”, and the meaning sometimes depends on the context and the province in which the word is used. “*Kurya*” is normally the direct and literal translation of “eating”. “*Gufungura*” means the same as “*kurya*”, but it is more polite. It is common in Rwanda’s culture to have words that show more respect than others while conveying the same meaning. “*Kwigaburira*” and “*kwitamika*” both indicate somebody’s “ability of doing the action of eating”. However “*kwigaburira*” could also mean “being able to provide food for yourself”, so it might involve socio-economic status.

The first forward translator chose “*gufungura/kurya*”, whereas the second translator preferred “*kwigaburira*”. In the first consensus meeting, it was agreed to keep “*kwigaburira/kwitamika*” with regard to the ability of performing the eating activity in self-care activities. However, in the second consensus meeting, “*kwigaburira*” was rejected on the grounds that it was very broad, and it was proposed to keep only “*kwitamika*”, which specifies the “action of being able to put food into the mouth”. In the third consensus, which brought the two consensus groups together, after consulting the explanation in the manual, it was agreed to keep the two concepts, “*kwigaburira*” and “*kwitamika*”, for both generalisation and specificity. This was also supported and recommended by the two physiotherapists during proofreading.

The phrase “dealing with people you do not know” in the “getting along with people domain”, was given the translation “*kubana n’abantu utazi*” in the first consensus meeting, which literally means “living with people who don’t know”. This was not accepted in the backward consensus meeting. Based on the description given in the manual, “*kumvikana/gusabana n’abantu utazi*”, it was suggested, meant “getting along and interacting with people you don’t know”. This was then adopted, as it was explicit and concise.

The term “household”, translated as “*mu rugo*”, has other meanings in Kinyarwanda. It can also mean “at home” and “family”. In forward translation, the phrase “doing your most important household tasks well” was translated by both translators as “*gukora neza imirimo ushinzwe*”, which literally means “doing activities/tasks which are under your responsibility well”, and this was accepted by the consensus team. However, the backward consensus meeting was concerned that “most important” and “household” were not included in the phrase. The team suggested the following translation: “*gukora neza imirimo yawe y’ingenzi yo mu rugo*”, which means “doing your important household activities/tasks well”, and this was adopted in the third consensus meeting.

With regard to the phrase, “getting all the household work done that you needed to do”, the forward translators as well the consensus team agreed that the translation should be “*kurangiza imirimo yo murugo yose n’kuko byakagombye*”, which literally means “getting your household work done as it is needed”. However, the backward consensus team found that there was a problem with “*n’kuko byakagombye*”, which literally means “as it is needed” or “supposed to be”, and not exactly “as you needed to do” or “as you would like it to be”, which translates as “*n’kuko wabyifuzaga*” and involves the self-appreciation of the person who is doing the activities. The phrase was then adapted to “*kurangiza imirimo yo murogo yose n’kuko wabyifuzaga*” and this was adopted in the third consensus meeting. The expression “getting your household work done as quickly as needed”, was translated literally in the forward translation and the consensus team agreed upon “*kurangiza imirimo yo murogo vuba n’kuko byakagombye*”. The backward consensus team recommended “*n’kuko bikwiye*” instead of “*n’kuko byakagombe*”, and indicated that both meant “as needed”, but that “*n’kuko bikwiye*” was more courteous and appropriate.

The word “school” literally means “*ishuli*” in Kinyarwanda when it indicates a school as a place of studying. It changes its meaning when it involves school activities and one of the following terms is used: either “*imirimo yo ku ishuli*” or “*amasomo*”, but “*amasomo*” can also mean “courses”, “modules” or “subjects”. For school activities, both “*imirimo yo ku ishuli*” and “*amasomo*” were used.

6.5.2 Content validity

The cross tabulation of the items in the two questionnaires that were specifically mentioned in the focus group discussion indicate that the majority were represented in both the questionnaires and the FG discussions.

Table 30: Items in the Impairments questionnaire that were referred to during the Focus Group Discussions

| Questionnaire | Focus Group | |
|------------------|-------------|---|
| Energy and drive | X | They used the words lack of energy (<i>kubura imbaraga</i>) |
| Sleep | | |
| Memory | X | <i>I can tell you how the medicines have caused much memory loss!</i> |
| Emotional | X | <i>I had an idea of committing suicide because of unhappiness</i> |
| Body Image | X | <i>After some time, my legs, arms and buttocks got thinner, the face and the belly swelled.</i> |
| Pain | X | <i>Ah I feel much pain.</i> |
| Heart | X | <i>The heart pumps fast.</i> |
| Blood Pressure | | |
| Haematological | | |
| Immune system | X | HIV status |
| Respiratory | X | Cough, breathlessness, |
| Fatigue | X | They used the words..... tiredness or fatigue (<i>umunaniro</i>), |

| | | |
|--|---|--|
| Digestive | X | <i>I always suffer from abdominal pain.</i> |
| Tolerance to food | X | Complained of altered tolerance to food |
| Defecation | | |
| Weight maintenance | X | <i>I am getting thinner</i> |
| Sensations associated with digestive tract | | |
| Sensation of nausea | X | : Even for..nausea,, they prescribe us medicines but we are not cured |
| Metabolic functions | | |
| Fat metabolism | | |
| Endocrine | | |
| Sexual | X | <i>Don't mention about sexual relationship! The desire is not there, I am not motivated and my husband is always weak.</i> |
| Menstruation | | |
| Regularity of the menstrual cycle | | |
| Genital and reproductive functions | X | <i>My husband always wishes he had a child, but it may cause me problems</i> |
| Discomfort with sexual intercourse | X | <i>After being infected with HIV, I was about to vomit just after looking at any man</i> |
| Muscle power | X | <i>In general, I feel [I am] getting weaker and weaker.</i> |
| Joint mobility | | |
| Skin functions | X | skin hardening |

| | | |
|-----------------|---|--|
| Skin sensation | X | <i>I feel paraesthesia in the legs with pins and needles in the hips</i> |
| Missing items | | |
| Dizziness | | <i>I very often feel dizzy when I am standing.</i> |
| Visual problems | | <i>Now it has left me with eye problems [and] they have decided to give me a transfer to the ophthalmology service</i> |

Nineteen of the thirty items (63%) were referred to, either obliquely or directly. Dizziness and visual problems were the two impairments which were mentioned by the participants but which were not included in the questionnaire.

Table 31: Items in the WHODAS 2.0 that were referred to during the Focus Group Discussions

| WHODAS 2.0 | Focus Group | |
|---------------------------|-------------|--|
| Concentration | X | <i>I think the... lack of concentration I am experiencing are caused by those medicines</i> |
| Remembering | X | <i>I can tell you how the medicines have caused much memory loss!</i> |
| Analysing | | |
| Learning | | |
| Understanding | | |
| Conversation | | |
| Standing for long periods | X | <i>I have difficulties with standing for a long time</i> |
| Sitting to standing | | |
| Moving around the home | X | <i>Sometimes I am unable to walk.</i> |
| Getting out of the home | X | |
| Walking a long distance | X | <i>: I have difficulties with standing for a long time as well as to walk a long distance,</i> |

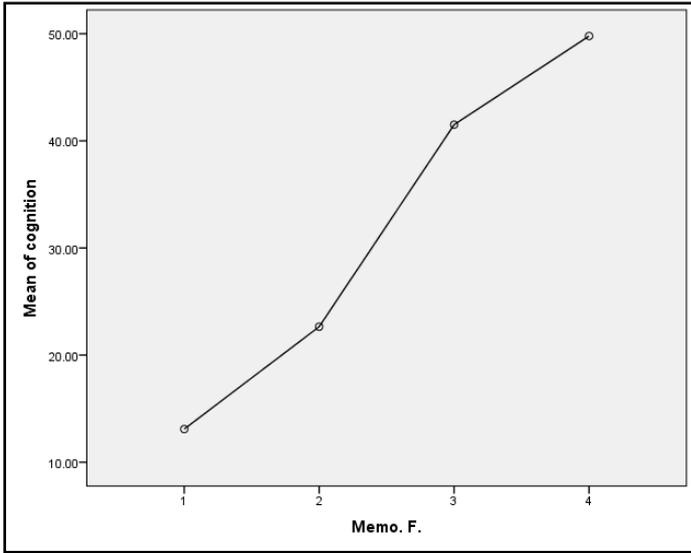
| | | |
|--|---|--|
| Washing | | |
| Dressing | X | <i>even wearing shoes has become difficult for me.</i> |
| Eating | | |
| Staying alone | | |
| Dealing with unknown people | | |
| Maintaining a friendship | X | <i>Because of the body weakness, we are not able to visit friends</i> |
| Getting along with people close to you | X | <i>In my family, they really pay much attention, very much</i> |
| New friends | | |
| Sexual activities | X | <i>Since I have known that I am HIV-positive, sexual relations with my wife have become difficult.</i> |
| Household responsibilities | X | <i>I could fetch water, but I cannot any longer</i> |
| Household tasks well | X | <i>This has caused shortcomings at my work.</i> |
| Completing household tasks | X | <i>My daily productivity has significantly reduced!</i> |
| Housework done quickly | | |
| Day to day work | X | <i>The household activities, farming, and even carrying heavy luggage, are all difficult for me because I always feel weak</i> |
| Work well | X | <i>I am saying this because I was a very good assistant builder! And for sure my performance has been reduced!</i> |
| Work completed | X | <i>I only work before noon.</i> |
| Work tasks quickly | X | <i>None can work as before because the strength is reduced.</i> |
| Joining community activities | X | <i>Because of that, I do not visit people any longer</i> |
| Barriers in world around | X | <i>We don't disclose because we are afraid of being stigmatized!</i> |

| | | |
|--------------------------------------|---|---|
| Living with dignity | X | <i>They really showed negative attitude towards my status, they were even unable to come near me</i> |
| Time spent on health condition | X | <i>but again there is a time, the transfer is to go through normal channel, which is from outpatient service then to specialists; this last option takes time!”</i> |
| Emotional effect of health condition | | <i>I had an idea of committing suicide because of unhappiness</i> |
| Drain on financial resources | X | <i>After getting better, I had no capital</i> |
| Problem to the family | X | <i>Can you imagine, even my father used to tell me that I am a dead person</i> |
| Relaxation/pleasure | X | <i>I was a football player...Now, I gave up playing.</i> |
| Missing | | |
| Stair climbing | | <i>I hardly breathe when climbing up stairs</i> |
| Spiritual activity | | <i>When I feel like having strength, I manage to go to church and the preaching makes me stronger and motivated</i> |

Comments relating to 24 out of the 31 items could be mapped to a corresponding item (77.5%). Stair climbing and spiritual activity were mentioned by several respondents but were not represented in the transcripts.

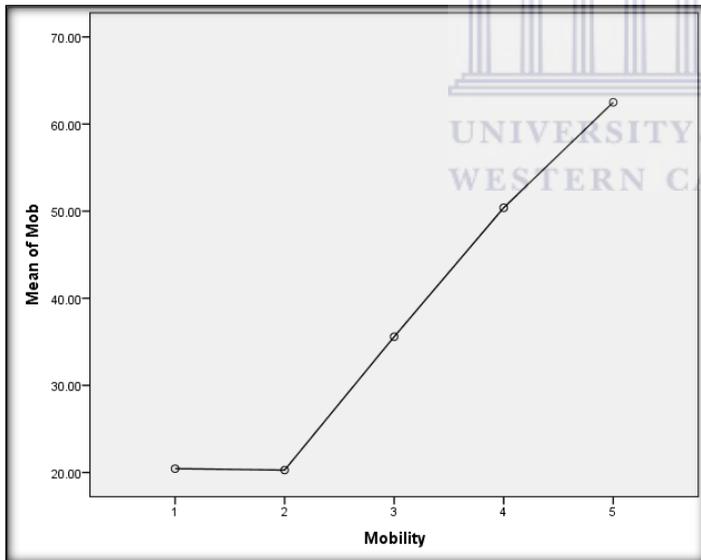
6.5.3 Construct validity – Convergent validity

The following graphs indicate that there was a significant difference between the means of the relevant domain of respondents scoring different levels of the impairment scales. In every case the ANOVA indicated that there was a significant difference between the means and as the plots indicate, the scores were higher (indicating poorer functioning) as the impairment level increased. In the case of the Life Activities, the categories indicate increasing levels of income and the score thus decreased as the categories increased.



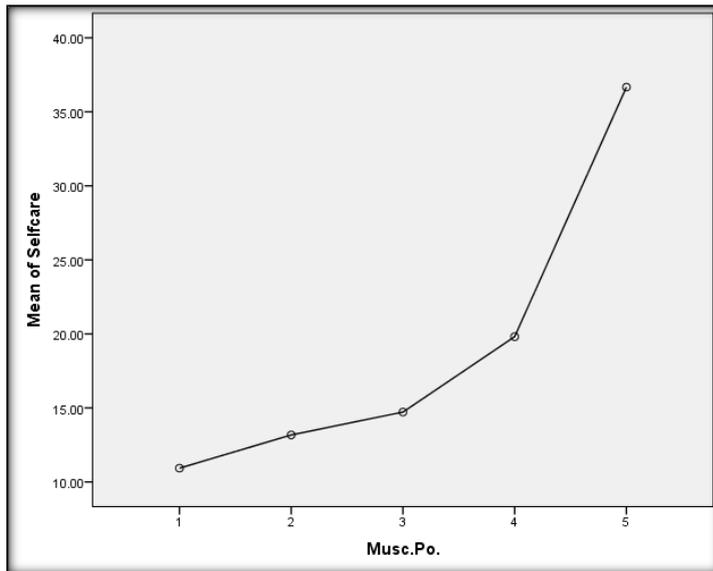
F=87.4, p<.001

Figure 26: The mean scores of the Cognition domain for each level of the memory impairment.



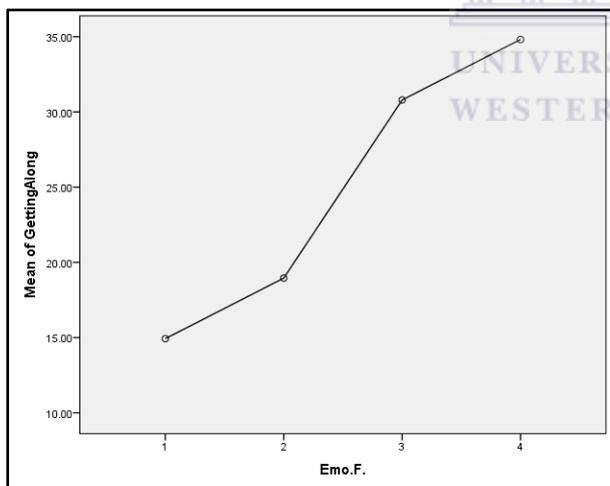
F= 51.1, p<.001

Figure 27: The mean scores of the Mobility domain for each level of the mobility impairment



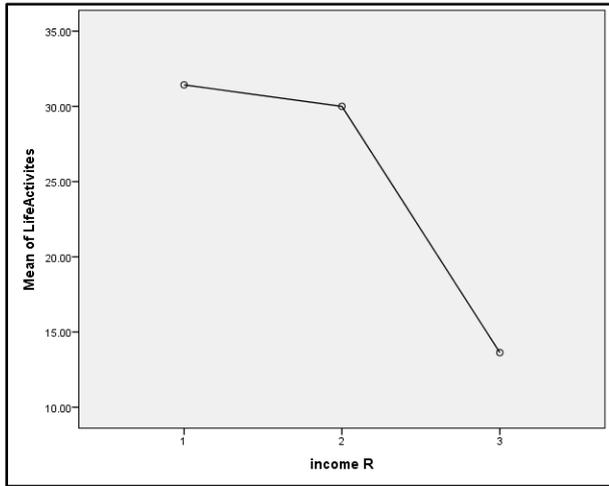
$F= 14.9, p<.001$

Figure 28: The mean scores of the Self care domain for each level of the Muscle Power impairment item



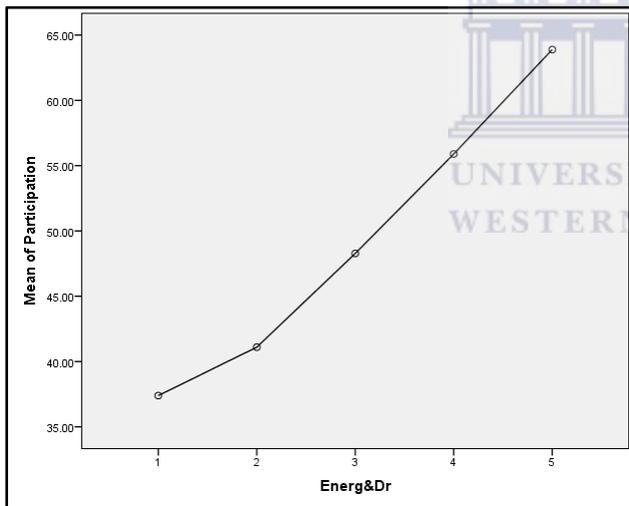
$F= 12.1, p<.001$ (Note that there were only two respondents with a 5 and these were excluded)

Figure 29: The mean scores of the Getting Along with people domain for each level of the Emotional functioning impairment item



$F= 1.2, p=.151$ (Note that there were only two respondents with a 4 and these were excluded). Higher domain scores denote more limitation and higher Income categories indicate better income).

Figure 30: The mean scores of the Life Activities domain for each level of Income.



$F=25.2, p<.001$

(Note that there were only two respondents with a 4 and these were excluded)

Figure 31: The mean scores of the Participation domain for each level of the Energy and Drive impairment item

6.5.4 Reliability

6.5.4.1 Testing internal consistency

The Impairments Questionnaire yielded a Cronbach's Alpha score of .85, with no item pulling the scale down. This falls within the good category of reliability, as did the WHODAS domains of Understanding and Communication (.872, six items); Moving around (.840, five items); Life activities (.947, seven items) and Participation (.829, eight items). As the value fell below acceptable levels in the domains of Self-care (.204, four items), and Getting along with people (.543 five items), these domains were subjected to further analysis.

6.5.4.2 Self-care

Table 16 shows that in Self-care, the item 'staying alone' was the least correlated and, if deleted, the Cronbach's Alpha increased considerably.

Table 32: Internal consistency of the self-care section of the WHODAS 2.0 (n=502)

| | Scale mean if item deleted | Scale variance if item deleted | Corrected item- Total correlation | Cronbach's Alpha if item deleted |
|---------------------------------------|-------------------------------|--------------------------------------|--------------------------------------|--|
| Washing whole body | 6.39 | 2.793 | 0.236 | 0.071 |
| Getting dressed | 6.46 | 3.031 | 0.305 | 0.103 |
| Eating | 6.50 | 3.300 | 0.234 | 0.185 |
| Staying by yourself for a few days | 3.17 | 0.668 | 0.085 | 0.688 |

6.5.4.3 Getting along

Table 17 shows that no single item was identified in the 'Getting along with people' domain that threatened the internal consistency of this domain. However, as noted above, Cronbach's Alpha was low.

Table 33: The internal consistency of the getting along with people section of the WHODAS 2.0 (n=502)

| | Scale mean if item deleted | Scale variance if item deleted | Corrected Item- Total correlation | Cronbach's Alpha if item deleted |
|---|----------------------------------|-----------------------------------|--------------------------------------|-------------------------------------|
| Dealing with people you do not know | 9.02 | 13.802 | .356 | .478 |
| Maintaining a friendship | 8.70 | 11.873 | .481 | .396 |
| Getting along with people who are close to you | 8.83 | 13.281 | .331 | .480 |
| Making new friends | 8.31 | 10.825 | .435 | .401 |
| Sexual activities | 7.13 | 12.032 | .106 | .674 |

The Cronbach's Alpha value for the whole scale was 0.933 (35 items) which is regarded as representing excellent internal consistency.

Table 34: The internal consistency of the impairments questionnaire and WHODAS 2.0 (n=502)

| Cronbach's Alpha | Internal consistency |
|-------------------------|----------------------|
| $\alpha \geq 0.9$ | Excellent |
| $0.8 \leq \alpha < 0.9$ | Good |
| $0.7 \leq \alpha < 0.8$ | Acceptable |

| | |
|-------------------------|--------------|
| $0.6 \leq \alpha < 0.7$ | Questionable |
| $0.5 \leq \alpha < 0.6$ | Poor |
| $\alpha < 0.5$ | Unacceptable |

(Wikipedia, 2013)

6.6 Discussion

The WHODAS 2.0 and the impairments of body functions questionnaire were translated by a group of people whose mother tongue was Kinyarwanda, and who were all fluent in English, with an aim of developing an instrument in the target language (Kinyarwanda) which would be linguistically and conceptually equivalent to the source language version (English). The requirement was that it would be used to collect valid data across cultures and countries regarding impairments, activity limitations and participation restrictions among PLWH. The final instrument appeared to meet these requirements. The process highlighted problems with cross-cultural translation, specifically with requirements related to cultural sensitivity, contextual factors and linguistic issues (such as a lack of equivalent words in the target language), in some cases several words had the same meaning as the words or phrases used in the source language. This brief discussion will consider the process and the problematic concepts identified during the translation.

6.6.1 Translation process

All the translators were Rwandese in origin and were fluent in English, but they came from different educational backgrounds. Thus, they were familiar with both the culture and the languages of Rwanda. Bringing together translators with similar linguistic backgrounds and with experience in translation, and including others with rehabilitation/disability backgrounds and with experience in disability and HIV research, provided for a rich diversity of experiences and skills, and produced interesting and constructive debate during consensus meetings and analysis. The input of the rehabilitation multi-disciplinary team in proofreading also proved very valuable and assisted in attaining a clear understanding of some more abstract and difficult concepts or words. The testing of the questions on the target population

provided for the inclusion of lay people's opinions with regard to clarity, effectiveness and the definitive meaning of the items.

6.6.2 Tension between literal translations and cultural contexts

The issue of culture applicability in the Kinyarwanda language is complex and could affect conceptual equivalence. An example of this is the difficulty of finding a translation for "cohabitation" (discussed above). Cohabitation as a practice actually exists in the country, but because it is not accepted by the Rwandese culture, it was impossible to find an appropriate or equivalent term. Similarly, in isiXhosa, one of the indigenous languages in South Africa, cohabitation was found to be difficult to translate appropriately for similar reasons: it is not acceptable in Xhosa culture for a man and a woman to live together while they are not recognised as being traditionally married. Marriage involves mutual understanding between two families and payment of the dowry (Toni, 2007).

In another African country, Tanzania, the SF-36 health survey was translated from English to the Kiswahili language, which is regarded as the indigenous language for the whole Tanzanian population. It was observed that most of the concepts related to physical functioning, for example, "pushing a vacuum cleaner, playing golf", had to be changed to expressions such as "drawing water", "washing clothes" and "carrying a baby", activities that were familiar to the target population, in order to make sense within the Tanzanian culture. The activity of climbing a "flight of stairs" resulted in debate simply because many Tanzanians traditionally do not climb stairs. Translators had to think carefully and search for another word to translate the activity of climbing and to produce a phrase that could convey the meaning of "climbing a flight of stairs". Finally they decided to use a word "*Mulima*", which literally means "hills". Apart from issues related to physical functioning, other concerns arose, such as the appropriate time frame considered for judging a person's health status. In the SF-36 source instrument, it was to recommend that one should think back "for the past four weeks". However, translators preferred to use the word "*Mwezi*", which literally means "a month", but can also signify "the moon". The reason why the term "*Mwezi*" was chosen was because translators believed people in Tanzania routinely think in terms of a month for the purposes of forward planning (Wagner et al., 1999). It is possible that other

African countries might encounter similar problems with cultural influence when translating research instruments into their indigenous languages.

In some Asian countries as well, cultural influence was found to be a factor in the translation of other health measurement instruments. For example, The World Health Organisation Quality of Life (WHOQoL-BREF) was translated from English to Malayalam, one of the Indian languages, and it was shown that conceptual equivalence of certain words or phrases was difficult to achieve due to cultural influence. For instance, it was difficult to retain the expression, “Are you able to accept your bodily appearance?” simply because Indian culture does not consider place much importance on the physical appearance. Translation of the item, “Sex life”, was also problematic. Translators thought that it might be insensitive to ask people who had lost their recognised partners, or people who were advanced in age, if they had been involved in sexual activity (Menon, Cherkil, Aswathy, Unnikrishnan, & Rajani, 2012).

In Korea when translating an instrument developed to assess disability of the upper extremities, “Disabilities of arm, shoulder and hand (DASH)”, various items lacked corresponding words/concepts in the Korean language because they were not recognised in the Korean culture. For example, a “jar” could literally be translated into the Korean language as “*dan-ji*”, but because the “*dan-ji*” in the traditional Korean culture has a different shape from a jar, it was difficult and it took time to explain that a jar could mean “*dan-ji*” (Lee, 2008). In the same group, cultural sensitivity was associated with gender roles in the traditional society. For example, the term, “prepare a meal”, was not appropriate for a group of older males because in Korea, traditionally, cooking is the responsibility of women and not men (Lee, 2008).

6.6.3 Problems with translation of some specific concepts

English is a rich and very explicit language, and allows for generalisation while at the same time ensuring specificity and precision. Kinyarwanda is also rich, but very complex in that you may find that one word in English may have two, three or more different meanings in Kinyarwanda, depending on the population’s characteristics and background, the context in which the word is used, and the region in which the word is used. Sometimes the exact word to express the equivalent meaning is lacking. Several problems were encountered while trying to achieve linguistic and conceptual equivalence.

For instance, it was difficult to find an exact word in Kinyarwanda that means “community”, a word that conveys a sense of belonging (in English). The Kinyarwanda word literally signifies a group of people. Community was translated as “*Muryango*”, which means “a group people who share the same activities”. But “*Muryango*” can also mean “a family”. Similarly the word “work” was found to have two linguistic meanings in Kinyarwanda and both meanings are commonly used. Firstly, “*Akazi*” is used where a specific payment is made; secondly, “*Imirimo*”, includes all types of activities (paid and unpaid) in which one may be involved. “*Imirimo*” was used and found to be appropriate because of its broader connotations. In contrast, during translation of an ICF checklist into isiXhosa, for the term “work”, translators preferred to use the word “*phangela*” which means “paid work” instead of “*uyasenbeza*” which is more general and involves other types of activity which are not necessarily paid (Toni, 2007).

Translation of the phrase “impairments of body functions” was problematic, primarily because of the translators’ consideration of the background of the target population or audience. Secondly, there was a debate about whether to classify “impairment” as a disease or a disability. After much discussion, it was agreed that a simple word or concept which included both meanings, should be found, provided that it was not a specialised medical term. Finally, “*Ibibazo by’umubiri*”, which literally means “problems of the body”, was agreed upon. In his study, Toni (2007) indicated that in isiXhosa, one cannot differentiate impairment from disability. He declared that it was difficult to find words or concepts that mean “disability” in isiXhosa; during translation of the ICF checklist, the translators agreed to use “*ukhubazeko*”, a Nguni word commonly used in isiZulu. The word “disability” in Kinyarwanda is linguistically specific and precise: “*ubumuga*”.

There was a major problem in finding a specific equivalent of the phrase “emotional problems” in Kinyarwanda. After a lengthy debate and much disagreement, it was agreed to use the expression “*Ibibazo by’ihungabana*” as a translation; this literally means “psychological trauma problems”. However, it was observed that the meaning of the word “emotional” always depends on the context in which the word is used. For example, it was found that the word “emotional”, when it is not related to a health problem, could have another meaning. The concept of “emotional problems” also provoked discussion during

translation of the SF-36 Health survey from English to Kiswahili. Translators could not find an exact equivalent for “emotional problems” in Kiswahili. They decided to use “*mawazo mengi*”, which literally translates the English concept “many thoughts” (Wagner, et al., 1999).

It was found that there was no one specific linguistic or conceptual equivalent for the term “mobility” in Kinyarwanda, as the whole activity of moving. After several discussions and after consulting of the WHODAS 2.0 manual, it was decided to use two terms, “*kunyeganyega*”, which literally means “moving the body”, and “*kugendagenda*”, which means “moving around or walking around”. This was important to ensure that the full meaning of the term “mobility”, as it is described in the manual, was retained. Similarly, when translating the ICF checklist to isiXhosa, translators chose the concept “*Intshukumo nemo yokuhamba*”, because it literally means “moving the entire body” and not only the limbs (Toni, 2007). Surprisingly, during the translation of the EQ-5D from English to isiXhosa, after discussing many options, the translators decided to use the term “*ukuhamba*”, which literally means “to walk”, but also could also mean “moving from one place to another”(Mkoka, Vaughan, Wylie, Yelland, & Jelsma, 2008).

It was indicated that during translation of WHOQoL-BREF from English to Malayalam, it was difficult to find the equivalents of certain expressions, such as “blue mood”, “How safe do you feel in your daily life” and the activity of “getting around”, which is part of what is meant by “mobility”. Translators had to find concepts which expressed more or-less the same meaning (Menon, et al., 2012).

Other important words in this study which were difficult to translate were “sensation” and “eating”. It was difficult to find a single equivalent for the word “sensation” in Kinyarwanda. Its meaning depends on the context in which it is used. It has a clear and concrete meaning only when it is related to physical feeling, for instance, when touching the skin. The word “eating” also has no single meaning in Kinyarwanda. Its meaning depends on the context and in which province the word is used.

6.6.4 Content validity

The mapping of the comments of the respondents to the different items in the two instruments indicated that most of the domains were relevant to this group of PLWH. The items related to homeostatis such as metabolism and blood pressure were not mentioned by this group, and neither were functions related to menstruation. The WHODAS 2.0 performed better with more than three quarters of the items represented in the responses. It appears that the more severe items, specifically to do with eating and self-care are not a problem in this group. This is likely to be as a result of the ARV medication preventing the development of full blown AIDS with the corresponding severe functional loss. It is suggested that the WHODAS 2.0 demonstrates acceptable content validity but that items relating to stair climbing and spirituality be included (albeit that spirituality can be regarded as a personal factor within the ICF, it was clearly of great importance to the respondents).

6.6.5 Construct validity

The WHODAS 2.0 demonstrated good construct validity in that in almost every case the domain scores increased with each level of impairment. Although it was not possible to assess divergent validity as there was a strong relationship between the items and those who were more affected scored worse in both instruments, it was clear that those domains which were more directly associated with the impairment chosen had higher F values (such as Cognition domain and Memory impairment, $F=87.4$, Mobility domain and Mobility impairment $F=51.1$) compared to those with a less strong intuitive link (such as the Getting Along with People domain and Emotional impairment, $F=12.1$). The lack of significance in the means of the different income categories is likely to be due to the small number of respondents who reported anything other than a 2 level (18 compared to 410 in category 2). It would appear that the convergent construct validity of the WHODAS 2.0 was acceptable.

6.6.6 Internal consistency and reliability of the WHODAS 2.0

Internal consistency and reliability of the responses for the questions related to activity limitations and the participation/social restriction domains assessed under WHODAS 2.0 scale and for the whole scale were obtained. The Cronbach's Alpha for the Impairments Questionnaire was good and it can be concluded that the internal consistency and reliability are acceptable within this context. The Alpha of the whole WHODAS 2.0 scale was very

high with a score of 0.933, which represents excellent internal consistency. With regard to the respective domains, Cronbach's Alpha for four domains was very good. These were the domains of understanding and communication, moving around/mobility, life activities and participation/social restriction, but Cronbach's Alpha fell below acceptable levels for the domains of self-care and getting along with people. Subsequently, these two domains were not subjected to further analysis. In self-care, the item 'staying alone for some time' correlated least with the other items assessed under this domain; if this was removed, the Cronbach's Alpha increased. On the other hand, for 'getting along with other people', the overall Cronbach's Alpha score was low, and there was no single item that threatened the internal consistency of this domain.

As it is described early in this present study, the development of the WHODAS 2.0 has been found to have high internal consistency (Cronbach's Alpha: 0.86), and good concurrent validity was obtained when compared with other recognised disability measurements (T. B. Üstün, et al., 2010). As was the case with our study group, the WHODAS 2.0 has also demonstrated good to excellent internal consistency for its applicability to assessments of disability in other health conditions. For example, Schlote et al. (2009) indicated that the internal consistency of the WHODAS 2.0 was found to be good to excellent, with Cronbach's Alpha of 0.81-0.99 among stroke patients (this was obtained from both patients and their relatives' opinions). Also, in a study conducted with a large group of schizophrenia patients, Guilera et al. (2012) found that the internal consistency of the WHODAS 2.0 was also very high, with Cronbach's Alpha of 0.94. It was also reported in a very recent article that the internal consistency of the WHODAS 2.0 was tested among patients from a large sample of people with breast cancer in China, and this showed satisfactory internal consistency (0.72-0.92) (Zhao et al., 2013).

As supported by other studies that used the WHODAS 2.0 in other health conditions, our findings confirmed that the WHODAS 2.0 is a very reliable instrument to measure functional limitations/disability across health conditions, countries and cultures but it is less reliable as a measure for the self-care and getting along with people domains.

6.7 Conclusion

To conclude, the whole process of translation was challenging but proved fruitful. Debate in consensus meetings would continue until consensus was reached and the consensus team was satisfied with the meaning. In difficult situations, the word or phrase was highlighted and was referred to the next stage for further discussion. The rigorous translation process made it possible to come up with a WHODAS 2.0 tool in Kinyarwanda, which has appropriate linguistic and cultural meanings, and uses clear and understandable expressions.

The difficulty of finding appropriate words and phrases relating to impairment and disability concepts highlights the role of language in defining how people conceptualise issues relating to disability. By identifying appropriate words, the translation process can introduce new concepts into a language, as indeed the ICF did by redefining disability in terms of impairment and activities and participation and environmental and personal factors.

Unfortunately there was no “gold standard” instrument that has been validated in Rwanda with which to test the concurrent validity. Similarly, there were no appropriate markers to explore divergent construct validity.

The resulting translated instruments demonstrated reasonable content validity; good construct validity and good reliability. It is suggested that both instruments yielded valid data and that the results of this study demonstrate good internal validity. The translated instruments could be used with confidence in similar studies in Rwanda with participants who speak Kinyarwanda.

7 CHAPTER SEVEN: CONCLUSION

This chapter includes the summary of the thesis, conclusion, limitations and the significance and recommendations of the study.

7.1 Summary

In Rwanda the health system uses the bio-medical approach to health care and many PLWH are on antiretroviral treatment (Ministry of Health (MoH) Rwanda, 2012b) and, as a result HIV has become a chronic disabling disease which requires rehabilitative intervention. Using the ICF as the conceptual framework, this thesis explored the experience of living with HIV in Rwanda through the lens of the bio-psychosocial model of health care. This model could be used to plan and manage the health related support given to PLWH including rehabilitative interventions. In this model the personal factors and the health condition are considered central to the experience the person living with HIV. There is recognition of the interaction between the personal factors, health condition, impairments, functional limitations, participation restrictions and the hospital and external environments. Disability is defined in the ICF as “impairments, activity limitations and participation restrictions” (Vanleit, 2008; World Health Organisation (WHO), 2001). The ICF is considered an appropriate framework for identifying impairments, activity limitations and participation restrictions among PLWH (Hanass-Hancock & Nixon, 2009a; Myezwa, et al., 2009). These can be identified using the ICF checklist and WHODAS 2.0.

The aim of the study was therefore to explore the need for and nature of care that PLWH living in Rwanda receive from their health care providers using a bio-psychosocial framework. A further aim was to determine if the Kinyawanda version of the WHODAS 2.0, which was used to gather the functional data, was valid within the Rwandan context. A mixed methods approach was used.

7.1.1 Research question 1

In answer to the first research question: Who is receiving ARVs? In other words what are the personal factors, e.g., gender, educational factors of PLWH who are receiving ARVS?

On the days of data collection at the ARV clinics for the survey 35.7% of all patients attending the clinics were males and 56.6% females. The survey sample shows an over-

representation of women, as 75% of the respondents were female. This indicates that more women than men came to seek care on the days of data collection, and more volunteered to participate in the study. Likewise in the FGDs more women than men volunteered to participate; the proportion was 3 male participants: 5 female participants. Other men declined to participate.

The mean age of the sample in the survey was 39.7 years. In the FGDs the mean age was 41.8 years for FGD A and 36.8 years for FGD B. In the survey, the most common marital status among males was 'married' (65%) while 'widowed' was most common among females (41%). In the FGDs the commonest marital status among males was 'married' (40%), there was no widowed, the rest was either single or separated. Among females, the commonest marital status was as well married (60%), followed by widowed (30%). In the survey findings, there were more females unemployed compared to males, and males were found to be more educated than females.

The FGDs participants described factors within themselves which built resilience that contributed to their well-being and assisted them to deal with the HIV infection, but also factors that limit their functioning.

Personal factors that facilitated functioning included: spiritual beliefs; faith in God; and positive thinking about disclosure as a strategy to improve psychological well-being, to overcome internalised stigma and to create awareness about HIV. Coping strategies that participants developed were also described. Personal factors that limited functioning included internalized stigmatisation, expressed by feelings of being hurt, and feelings of regret and shame, and of guilt and remorse about HIV. PLWH had negative thoughts about being stigmatized, being chased away, being judged or being dismissed from work. Age was identified as personal factor that could influence the ability to function.

In both urban and rural areas, the discussion in the FG about whether or not to disclose, and the positive and negative effects of disclosure as well issues around stigma, were reported more frequently by women compared to men. The only man who spoke of disclosure, indicated that it would lead to stigmatization and it was not clear that he had disclosed his

status to anyone beyond the ARV clinic. Other factors were spoken about by both men and women, in rural and urban areas.

7.1.2 Research question 2

In answer to the second research question: How effective is the ARV treatment received in terms of diminishing symptoms and improving the functioning of PLWH? Is there any need for further intervention and support? If it is effective, it is suggested that there will be few functional limitations present, the functional limitations will be less as the CD4 count increases and the longer that the PLWH receive ARVs, the better their functioning will be.

The findings of the survey show that among the participants there was no significant difference in the CD4 count (above and below 500) between those who declared that they were symptomatic and those who were not. However, this study showed that the longer the participants had been on antiretroviral treatment, the more likely they were to be symptomatic. This finding was supported by several of the FGDs participants, women and men, in both urban and rural areas and who attributed their functional limitations to the medication rather than the underlying pathology and indicated that symptoms occurred overtime. However, despite the side effects of antiretroviral treatment, in the survey, those who had been on antiretroviral treatment for a long period showed a higher CD4 count. The survey findings have confirmed that the manifestation of symptoms of impairment among PLWH is not related to the CD4 count, but it is likely to be associated with the longer duration of antiretroviral treatment and this was confirmed by the participants in both FGDs as they had spoken about symptoms changes that occurred overtime.

7.1.3 Research question 3

In answer to the third research question: What are the perceptions of PLWH with associated disabilities of the health services that address their functional limitations, in a hospital setting, in Rwanda? Are they satisfied that the care that they receive addresses all or a majority of their health related problems?

Two FGDs were carried out in two hospitals; the first hospital was located in urban area and the second one in rural area. Each FGD involved a final sample of eight (five females and three males) PLWH on ARVs with associated disabilities.

The study included the influence of the hospital environment and services on the functioning of PLWH; this included the ARV clinic and hospital services outside the ARV clinic environment. Environmental factors in the ARV clinic that facilitated functioning included the service provided by the ARV clinic, trust in the health care providers, the provision of antiretroviral treatment, a sense of belonging at the ARV clinic and the referral procedure from the ARV clinic to other services within the hospital.

Environmental factors in the ARV clinic that acted as limitations to functioning included a lack of assistance concerning functional limitations, health care providers also discriminated between patients due to misunderstanding of their functional limitations, and participants' lacked knowledge about specialist services that could help to manage these functional limitations. Other factors were the inconsistent referral procedure and the use of multiple medical files for one patient within the same hospital.

Environmental factors related to hospital services beyond the ARV clinic that facilitated functioning included assistance from the rehabilitation services, the involvement of the community in caring for PLWH, and aspects of *Mutuelle de Santé*. Environmental factors related to hospital services outside the ARV clinic that limited functioning included overcrowding, long waiting times, the absence of any special consideration for PLWH, the participants' lack of knowledge of health care providers who might assist with functional limitations, the health care providers' inability to assist with functional limitations, a concern about whether the private health care service was better than the public service, and this was more spoken about by male participants, poor communication, negative attitudes on the part of health care providers, the unavailability of doctors and the inability of *Mutuelle de Santé* to respond to all the health care needs of PLWH.

Participants made recommendations that could improve services at the hospital. These included: recognition of the vulnerability of PLWH, the establishment of counselling programmes, an increase in the number of health care providers, strengthened collaboration and an improved referral system within the hospital, a single medical file, improved quality of service by *Mutuelle de Santé*, a food programme, a dedicated youth HIV clinic, education support for PLWH orphans, health care providers' ability to respect time management, and

consideration for privacy at ARV clinics. Only male participants spoke about the need for consideration for privacy.

7.1.4 Research question 4

In answer to the fourth research question: What are the profile and the prevalence of impairment and functional limitations among PLWH in Rwanda? Is functional limitation common? If it is prevalent, then it is possible that the medical model of care does not result in complete recovery of functioning.

The aim of this part of the study was to determine the profile and the prevalence of disability among PLWH, by measuring impairment, activity limitation and participation restriction amongst PLWH who are also on antiretroviral treatment. In addition the relationship between functioning and medication is explored.

To determine the profile and the prevalence of disability among PLWH, a cross-sectional study was conducted. Fifteen hospitals were randomly selected in the five provinces in the country, and these hospitals were visited. Using an outcome instrument, 520 PLWH who were on antiretroviral treatment were approached to participate in face-to-face interviews. The Kinyarwanda version of the ICF core set of questions measured PLWH impairments and WHODAS 2.0 questions in Kinyarwanda were used to document impairments, activity limitations, and participation restrictions were identified among PLWH. These findings were then supplemented with the results of the focus group discussions.

Problems with pain (69%) and fatigue (83%) were more prevalent than problems found in other domains measured under impairment. Among the activity limitations, problems with mobility functions were most frequently reported (57%). The domain in which the highest number of people reported problems was the participation domain and in this domain, problems with participation in relaxation or pleasure activities (83%) were the most prevalent. The mean scores of the different domains were significantly different with participation scoring the highest (46%, with 100% the worst score rate). It was also found that participants experienced problems on approximately half of the days every month, and that there were three days in a month in which the participants were unable to work because of their health condition. Various impairments of body function predicted functional

limitations with regard to activities and the participation/social restriction domains. Energy and drive and memory functions were predictive of the means scores of all the domains.

Male and female participants in both urban and rural hospitals experience impairments and they indicated that these impairments were caused either by the HIV infection or the antiretroviral treatment and the severity might change overtime. The most frequently mentioned impairments were: lack of energy, pain, paraesthesia, dizziness, lipodystrophy, poor body image and memory loss and lack of concentration. The participants' body impairments, especially lack of energy, pain, paraesthesia, breathlessness and loss of memory, affected the performance of their daily activities and their participation in social life. The activities most affected were mobility, self-care and life activities, which included household and work activities. All activities, except households, were reported by men and women equally. Reduced activity performance contributed to decreased productivity, which affected livelihood. Body impairments, particularly lack of energy, restricted participation in social life, including in leisure activities, social relationships, spiritual practices and sexual relations. Male participants spoke about lack of energy as a leading factor of reduced frequency of sexual intercourse, whereas female participants complained about lack of desire as a cause of decreased involvement in sexual intercourse rather than lack of energy.

7.1.5 Research question 5

In answer to the fifth research question: it is necessary to validate the primary data collection tools to ensure that the data collected during the survey of impairments and functional limitations were a true reflection of the functional abilities and health of PLWH within the context of the study.

The aim was to establish whether the translated Kinyarwanda versions of the WHODAS 2.0 and the ICF core set of questions were valid instruments with which to document the presence of impairments and functional limitations. This entailed interrogating the face and content validity, as well as the reliability and construct validity.

It was necessary to produce a valid and understandable Kinyarwanda version of the ICF core set of questions and the WHODAS 2.0 in order to understand the impact of HIV on functioning. Chapter six documented the process of translating into Kinyarwanda the original

English version of the ICF core set of questions regarding the impairment of body functions identified among PLWH (Myezwa, et al., 2011) and of the WHODAS 2.0 outcome instrument and highlighted any problems that were encountered, whether related to linguistic meaning or to cultural influence.

Forward and backward translations were conducted with a consensus meeting after each translation; and a third consensus meeting was held that brought together the two previous meetings. Proofreading by a team of multidisciplinary health care providers comprising a medical doctor, two physiotherapists and two psychologists was completed before a cognitive debriefing interview that aimed to test the clarity of the outcome instrument. After this interview, a final consensus meeting was held; this involved participants in the previous consensus, and was conducted to come up with the final Kinyarwanda version, which was expected to yield valid data with regard to disability among PLWH. An ICF core set of questions regarding the impairment of body functions and a WHODAS 2.0 questionnaire in Kinyarwanda, which has appropriate linguistic and cultural meanings, and uses clear and understandable expression, was produced.

This process demonstrated that ensuring cultural applicability in the Kinyarwanda language is complex and could affect conceptual equivalence. It was also found that English is a rich and very explicit language that allows for generalisation while at the same time ensuring specificity and precision. Kinyarwanda is also rich and very complex. For example, one word in English may be translated by using two, three or more words in Kinyarwanda, depending on the population's characteristics and background, the context in which the word is used, and the region in which the word is used.

Sometimes it was not possible to find exact words to express the equivalent meaning. Thus, several problems were encountered while trying to achieve linguistic and conceptual equivalence. The difficulty of finding appropriate words and phrases relating to impairment and disability highlights the role of language in defining how people conceptualise issues relating to disability. By identifying appropriate words, the translation process can introduce new concepts into a language, as indeed the ICF did by redefining disability in terms of impairment and by taking into account activities and participation and environmental and personal factors.

The thematic analysis of the FGDs was used to identify the impairments, functional limitations and participation restrictions that the participants had identified, for content validity. These were then tabulated against the corresponding items of the Impairment Questionnaire and the WHODAS 2.0.

For the impairments questionnaire, nineteen of the thirty items (63%) were referred to, either obliquely or directly. Dizziness and visual problems were the two impairments which were mentioned by the participants but which were not included in the questionnaire. For the WHODAS 2.0, comments relating to 24 out of the 31 items could be mapped to a corresponding item (77.5%). Stair climbing and spiritual activity were mentioned by several respondents but were not represented in the transcripts.

The one-way ANOVA was used to establish convergent validity of the WHODAS 2.0. It was not possible to do this with the Impairments Questionnaire. There was a significant difference between the means of the relevant domain of respondents scoring different levels of the impairment scales. In every case the ANOVA indicated that there was a significant difference between the means, the scores were higher (indicating poorer functioning) as the impairment level increased. In the case of the Life Activities, the categories indicate increasing levels of income and the score thus decreased as the categories increased.

Cronbach's Alpha was calculated to test for internal consistency of the Impairments Questionnaire and the WHODAS 2.0. This was calculated for the entire scale and for the subsections (domains) of the scale. In addition the contribution of each item to the overall correlation was examined by calculating the alpha with each item included. If the correlation increased once the item was excluded, it implied that the item did not fit well with the construct of the domain. The Impairment Questionnaire yielded a Cronbach's Alpha score of 0.85, with no item pulling the scale down. This falls within the good category of reliability. The Cronbach's Alpha value for the whole WHODAS 2.0 scale was 0.933 (35 items) which is regarded as representing excellent internal consistency. For the subsections of the WHODAS 2.0 scale, domains of Understanding and Communication (.872, six items); Moving around (.840, five items); Life activities (.947, seven items) and Participation (.829, eight items). As the value fell below acceptable levels in the domains of Self-care (.204, four items), and Getting along with people (.543 five items), these domains were subjected to

further analysis. It was found out that in Self-care, the item 'staying alone' was the least correlated and, if deleted, the Cronbach's Alpha increased considerably. For getting along with people, no single item was identified in the domain that threatened the internal consistency of this domain; however, Cronbach's Alpha was low.

7.2 Conclusions

The study findings of both the survey and the FGDs confirm the interrelationship among the components of disability supporting the assumption of the ICF model that there is interaction and connection between all the disability components, and that there is mutual influence. It implies that intervention programmes to overcome disability among PLWH need to be comprehensive to address the three components including impairments, activity limitations and participation restrictions, and that interventions should also consider the influence of contextual factors including both personal and environmental factors that are found to exacerbate or alleviate disability. For example, energy and drive and memory functioning were found to affect all aspects of functioning and attempts to only improve the function (e.g. household activity) without addressing the underlying impairment would be futile.

The study supports that the bio-psychosocial model would result in a better approach to intervention in Rwanda. It could be used to plan and manage health related support given to PLWH.

The ICF framework is also useful in understanding how health service delivery within the hospital setting assists PLWH to overcome the multidimensional disabilities they encounter in everyday life. Findings from FGDs suggest that PLWH had a strong sense of belonging in the ARV clinic environment and preferred the care provided there to that provided by other hospital services. Their appreciation was primarily based on the provision of antiretroviral treatment in these clinics. However, health care providers from ARV clinic were unable to manage functional limitations adequately, and they did not refer patients to other experts in the hospital for management of those limitations. Of all the hospital services utilised by PLWH, including the ARV clinic, only the rehabilitation services (though in a very limited way) were recognised as being able to assist with their functional limitations.

It is evident that antiretroviral treatment should continue to be provided by the ARV clinic, but further regard to functional limitations is needed; it is evident that the use of rehabilitation services within or outside the hospital needs to be encouraged. This could be done using a vertical services approach, with the integration of rehabilitation services into ongoing HIV programmes offered in ARV clinic. Alternatively, it could also be done by strengthening the existing horizontal services approach. This would require referral of PLWH from ARV clinic to rehabilitation services, as happens with other chronic health conditions. This second option appears to be the more appropriate strategy as it would only require the reinforcement of existing capacities and policies. In contrast, the vertical services approach would require the restructuring and transformation of existing structures and policies.

The horizontal services approach would be more successful if it adopted the recommendations suggested by the PLWH in this study, especially with regard to collaboration among health care providers, including those in rehabilitation services. This would include the recommendations about the restructuring of referral systems within the hospital and the use of one medical file. If well planned, this approach to rehabilitation would help to reduce the stigma that was identified as a big problem by PLWH; it would help them to consider themselves as belonging to the hospital as a whole and not just to the ARV clinic.

Based on the findings on service provision and on the profile of disability, many health care providers from different disciplines need to be involved in the rehabilitation care of PLWH. Those include medical doctors, nurses, nutritionists, mental health professionals/psychologists, physiotherapists, occupation therapists and social workers. The ICF model has the potential to bring people together who have a common approach to health problems, while recognizing one another's expertise (Shaw & MacKinnon, 2004). This could serve as a model to encourage collaboration among all these health care providers. The finding concerning the inability of health care providers in ARV clinics to accomplish a thorough assessment of functional limitations and their inability to make referrals to the appropriate rehabilitation services when necessary, suggests a need for training programmes that deal with knowledge about disability and PLWH and that the ability of rehabilitation services to manage functional limitations or disability. An education program on disability and HIV and

the need and benefit of rehabilitation services, targeting PLWH, is also essential as this could create awareness and help PLWH to take full advantage of the hospital services throughout their continuum of care.

It was possible to translate the majority of the concepts of the WHODAS 2.0 into Kinyarwanda; however, the concept of disability is not well represented in the Kinyarwanda language. Disability cannot be addressed if it is not understood and the correct words are not used. The rigorous translation process allowed for the collection of valid data through the use of appropriate instruments. Additionally, the translated instruments demonstrated good content and construct validity and good reliability. It is suggested that both instruments yielded valid data and that the results of this study demonstrate good internal validity. It is concluded that the translated instruments could be used with confidence in similar studies in Rwanda with participants who speak Kinyarwanda.

7.3 Outcomes and significance of the study

1. The study has produced a validated ICF core set of impairment questions and a WHODAS 2.0 questionnaire in Kinyarwanda, with the aim of assessing functional limitations among PLWH in Rwanda.
2. Using the ICF framework, the study has identified and documented a profile of the disabilities or functional limitations present and the relationship between them among PLWH in Rwanda.
3. The study has documented the experience of functional limitations among PLWH in Rwanda
4. The study has explored the extent to which the hospital services have addressed the functional limitations of PLWH in Rwanda.
5. The study has contributed to an awareness amongst PLWH of the rehabilitation care available in Rwanda.
6. The study has found that PLWH recognise the need for interdisciplinary collaboration among health care providers in the hospital setting, as this would improve the quality of care.
7. The study has contributed to identifying the need for further research in the area of disability among PLWH in Rwanda including the role of rehabilitation interventions.

The significance of the study lies in the confirmation that disability is a very common problem in PLWH in Rwanda and that although medical treatment is well managed and effective, the functional needs of these people are not being met. The complex interrelationship between impairments and functional limitations demands an interdisciplinary approach to management. This is not currently being provided as the bio-medical approach is used. This could be addressed by using the bio-psychosocial approach suggested through the use of the ICF.

7.4 Recommendations

The use of the ICF framework has demonstrated that PLWH on antiretroviral treatment in Rwanda experience multiple disabilities or functional limitations as a result of the infection itself and/or the antiretroviral treatment. In Rwanda the majority of PLWH who are eligible have access to antiretroviral treatment. It is possible that in the coming years, there might be even more PLWH with disabilities. The health system delivery for PLWH in Rwanda needs to be able to address the chronic nature of the disease.

Exploration of the perceptions of PLWH with associated disabilities about hospital services that seek to address their functional limitations has indicated that rehabilitation services based on the ICF, using a horizontal approach, could be the appropriate way to overcome disability among PLWH in Rwanda.

The following recommendations arose from this study. (Note⁴⁷)

7.4.1 Recommendations for clinical practice

1. Change in practice: Outcome measures based on the bio-psychosocial model using the ICF should be used by health care providers to assess disability among PLWH on antiretroviral treatment in Rwanda.
2. Strategies should be put into place to reinforce interdisciplinary collaboration among health care providers; including those in rehabilitation services, within the hospital setting.

⁴⁷ For other specific recommendations, see chapter 5

3. A referral protocol should be developed to guide the referral of PLWH from the ARV clinic to rehabilitation services and from one rehabilitation service to another and back to the ARV clinic.
4. The use of a referral card for PLWH would assist with the following up of patients from one service to another.
5. The development of a screening tool based on the ICF core set of questions on impairments and the WHODAS 2.0 would help to identify functional problems among PLWH and should be used in each service, starting with the ARV clinic.

7.4.2 Recommendations for education

1. The development of a training programme for health care providers (particularly those in ARV clinic) with regard to the ICF would help them to plan for the management of PLWH with functional limitations or disabilities, using a holistic approach.
2. An integrated bio-psychosocial model, utilising the ICF, should be used as a framework for understanding disability and outcome measures for the pre-service and in-service curriculum for health care providers; including doctors and nurses.
3. An education program based on bio-psychosocial model, utilising the ICF, should be developed for PLWH, this would help to create awareness about disability and the potential role of rehabilitation services in the management of disability.

7.4.3 Recommendations for research

1. Research is needed to test the effectiveness of training students, medical professionals and PLWH with regard to the ICF.
2. Research is needed to develop and test the effectiveness of a referral protocol.
3. Research is needed to conduct a longitudinal study to assess when functional limitations manifest in the course of the disease.
4. Research is needed to test the effectiveness of specific rehabilitation techniques such as an exercise programme, or a counselling programme in the management of functional limitations.
5. Research is needed to test for the reliability and internal consistency of WHODAS 2.0 after excluding the item “staying alone” in the self- care domain and the getting along with people domain.

Although much has been done in Rwanda to manage the scourge of HIV and improve the life expectancy of those who have this disease, there is still much to be done. It is not enough to simply prevent death, what is now important is to ensure that the life that is saved is worth living. This can be done through increasing our understanding of the impact of HIV on the functioning of patients and by using this information to mobilise health professionals from different disciplines to come together to provide an integrated effective service. It is hoped that the findings of this research will contribute to improving the lives of all the brave men and women with HIV who struggle daily with their disease.



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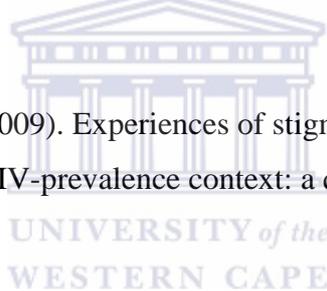
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9 APPENDICES

9.1 Appendix I: Letters of permission from UWC and from the National Aids Control Commission, Rwanda

FACULTY OF COMMUNITY
AND HEALTH SCIENCES

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HIGHER DEGREES COMMITTEE

17th September 2009

Director General
Rwandan Student Financial Aid
Kigali
Rwanda

TO WHOM IT MAY CONCERN

Dear Sir/Madam

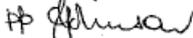
Research Project of Jeanne N Kagwiza (Student Number: 2239624)

This letter confirms that is a registered student in the Faculty of Community and Health Sciences at the University of the Western Cape.

Her research proposal entitled "*A Rwandan rehabilitation model for people living with HIV/AIDS with associated physical disability on antiretroviral therapy*" submitted in fulfillment of the requirements for the Doctorate in Physiotherapy has been examined by the Higher Degrees Committee and found to be of high scientific value, methodologically sound and ethical.

We fully support the research and kindly request that you allow her/him access to your organization.

Sincerely



DR GAVIN REAGON

Chairperson: Higher Degrees Committee



UNIVERSITY of the
WESTERN CAPE

26 APR 2010



B.P 7162 KIGALI

Ref: 0948.../CNLS/2010/S.E.

Mrs. KAGWIZA N. Jeanne
University of the Western Cape
Faculty of Community and Health Sciences

RE: Approval of Research Protocol

Dear Sir,

The HIV National Research Committee has agreed that you have provided adequate study design and safeguards; CNLS is therefore officially notifying you the approval of your study entitled "**Rehabilitation for People living with HIV/AIDS with associated disability on Antiretroviral Therapy, in Rwanda**".

We wish to remind you that the principal investigator is responsible for keeping this committee informed of any changes involved with the procedures or methodology in this study. Upon completion, we kindly request you to share the results with CNLS.

We support this study and will provide any assistance, if necessary, for its successful implementation.

Sincerely,

Dr Anita ASTIMWE
Executive Secretary



Cc:

- Hon. Minister of Health
- President of National Ethics Committee

9.2 Appendix II: Permission letter to conduct research in hospitals, in Rwanda



UNIVERSITY OF THE WESTERN CAPE
Private Bag X17, Bellville 7535, South Africa
Tel: +2721-959, Fax: 27 21-959
DEPARTMENT OF PHYSIOTHERAPY

The Director of Hospital

Rwanda

28th April 2010

Dear Sir/Madam,

Re: Permission to conduct research in hospitals, in Rwanda

I am a Rwandan PhD student at the University of the Western Cape in Cape Town, South Africa. I am expected to undertake a research project for the requirements of a Doctorate degree in Physiotherapy. The study is entitled “ Rehabilitation for people living with HIV with associated disability on antiretroviral treatment”. Permission to conduct the study has been obtained from the Higher Degrees Committee of the University of the Western Cape.

The aim of the research project is to determine “the profile and the prevalence of disability among PLWH, by measuring impairment, activity limitation and participation restriction amongst PLWH who are also on antiretroviral treatment”.

The information will be gathered by way of interview questionnaire. It is hoped that the results of this study would contribute to the knowledge of the extent of disability among people living with HIV and who are on antiretroviral treatment.

I hereby wish to request permission from your hospital to carry out the above-mentioned project. Ethical issues will be taken into consideration, participation in the study will be anonymous and voluntary and the information gathered will be treated with respect and confidentiality. The results will be made available to you as soon as they have been analysed. The co-operation from both the Health care providers and patients will be much appreciated.

Looking forward to your co-operation

Yours sincerely

Jeanne Kagwiza

Prof. Patricia Struthers

Supervisor

Prof. Jennifer Jelsma

Supervisor



9.3 Appendix III: Information sheets to participate in the survey



UNIVERSITY OF THE WESTERN CAPE

Private Bag X17, Bellville 7535, South Africa

Tel: +27 21-959, Fax: 27 21-959

Title of the main Research Project: Rehabilitation for people living with HIV with associated disability on antiretroviral therapy, in Rwanda.

Information sheet: for potential participants in a survey about “determining disability among people living with HIV and who are on antiretroviral treatment.

My name is Jeanne N. Kagwiza and I am a postgraduate student (PhD), in the physiotherapy Department at the University of the Western Cape, Cape Town, South Africa. I am currently conducting a study in Rwanda in the field of disability, HIV and rehabilitation. The aim of the study is to determine **“the profile and the prevalence of disability among PLWH, by measuring impairment, activity limitation and participation restriction amongst PLWH who are also on Antiretroviral Treatment”**.

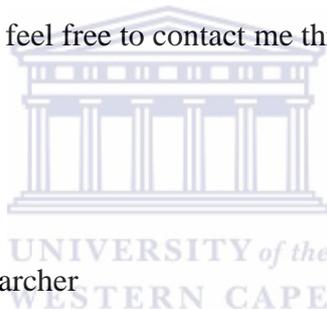
The whole study is divided in three parts. You are **kindly invited** to participate in the second part of this study, which is “the prevalence and profile of disability among PLWH, in Rwanda. In this study, you will be interviewed, to find out prevalence and profile of disability and the questionnaire will be assessing a number of items such as pain, mobility of joint, walking, self-care activities, community life, recreation and leisure, maintaining a friendship etc. It will take approximately 45 minutes to answer questions. I will also like to look at your medical record/file to take note of any information that is required for this study. The study will be done at the ARV clinics of the fifteen hospitals selected for this study. All information you provide will be kept confidential and anonymity will be maintained. Your name will not be included on the questionnaire; a code will be placed on the questionnaire; through the use of identification key, the researcher will be able to link your questionnaire to

your identity; and only the researcher will have access to the identification key. Also the results of this research may be published but you will not be identified as an individual. Nevertheless, the information you give may be disclosed if required by the law.

The results of the whole study may help the investigator to find out the extent of disability among PLWH. We hope that in the future, other people might benefit from this study through improvement of rehabilitation services to PLWH associated with disability. There are no known risks associated with participating in this research project. However you reserve the right to withdraw from the study at any time and thus will not have any effect on continuing accessing your usual treatment or decisions for being referred for treatment where necessary. You will continue getting updates of the study both during the course of the study and after.

Please read and sign the attached consent form if you agree to participate in the study. If you require further information please feel free to contact me through my contact details below.

Yours sincerely



Date

Physiotherapist and principal researcher

Jeanne N. Kagwiza Tel: (250)08755364

E-mail: jkagwiza@yahoo.fr/jkagwiza@uwc.ac.za

Kigali/Rwanda

9.4 Appendix IV: Informed consent to participate in the survey



UNIVERSITY OF THE WESTERN CAPE
Private Bag X17, Bellville 7535, South Africa
Tel: +27 21-959, Fax: 27 21-959

CONSENT FORM

Title of Research Project: Rehabilitation for people living with HIV with associated disability on antiretroviral treatment, in Rwanda.

Phase two, Survey: Prevalence and profile of disability among people living with HIV associated disability in Rwanda.

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

Participant's name.....

Participant's signature.....

Date.....

Witness name.....

Witness signature

Date

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

Study Coordinator's Name: Jeanne N. Kagwiza

Physiotherapist and principal researcher. Cell phone: (250) 08755364

E-mail: jkagwiza@yahoo.fr/jkagwiza@uwc.ac.za

Kigali/Rwanda

9.5 Appendix V: Screening checklist

Demographic and Background information

Respondent Identity number:.....

Date:

1. How old are you now? Age in years.....

2. Gender:

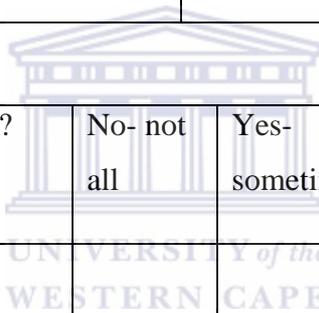
Male

Female

The next questions ask about difficulties you may have doing certain activities because of a **health problem**.

| Do you have difficulty in doing the following? | No- no difficulty | Yes- some difficulty | Yes- a lot of difficulty | Too much difficulty |
|---|-------------------|----------------------|--------------------------|---------------------|
| 3. Seeing, even if wearing glasses? | | | | |
| 4. Hearing, even if using a hearing aid? | | | | |
| 5. Problem with tolerance to food? | | | | |
| 6. Walking? | | | | |
| 7. Climbing stairs? | | | | |
| 8. Standing for long periods such as 30 minutes? | | | | |
| 9. Remembering or concentrating? | | | | |
| 10. Self-care; e.g. washing your body, dressing? | | | | |
| 11. Household activities? | | | | |
| 12. Work or school activities? | | | | |
| 13. Communicating by using your customary language, | | | | |

| | | | | |
|---|--|--|--|--|
| for example understanding or being understood? | | | | |
| 14. Things for relaxation or pleasure? | | | | |
| 15. Sexual activities? | | | | |
| 16. Living with dignity because of the attitudes and actions of others? | | | | |
| 17. Difficulty because of barriers or hindrances in the world around you? | | | | |
| 18. Getting along with people; e.g. immediate family, friends, community members? | | | | |
| 19. Getting financial resources? | | | | |

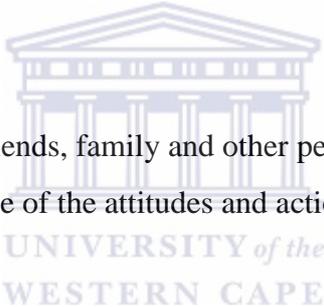


| Do you experience the following problems? | No- not all | Yes- sometimes | Yes- a lot | Too much |
|---|-------------|----------------|------------|----------|
| 20. Pain, e.g., headache, backache? | | | | |
| 21. Abnormal/unusual skin sensations, e.g., pins & needles, numbness, tingling? | | | | |
| 22. Fatigue? | | | | |
| 23. Emotional problems? | | | | |

9.6 Appendix VI: Focus group interview guide

1. Are there things that you could do in the past and are no longer able to do since you became ill?

Probes:

- Walking for some distances
 - Climbing stairs
 - Standing for long periods
 - Going to work or school
 - Household activities
 - Sexual activities
 - Activities for relaxation or pleasure
 - Going to church
 - Visit friends sometimes
 - Visit your families
 - Getting along with your friends, family and other people in your community
 - Living with dignity because of the attitudes and actions of others
- 
- UNIVERSITY of the
WESTERN CAPE
2. How did taking medication change any of the things mentioned above?
 3. Can you describe your experiences with how the hospital health care providers tried to assist you with the problems you have described above?

Probes:

- Which health care providers do you usually see to help you with the problems you have mentioned?
- Do you think you get chance to speak about your problems?
- If yes, what do you tell them?
- What do they do?
- What are the problems do you find difficulty to tell them?

- What are the problems do you have and you think they do manage?
 - What are the problems do you have and you think they do not manage?
 - Do they refer you to other health care provides for those problems they are not able to manage?
4. Can you give your opinions or views on what can be done to improve the hospital services so as to assist you with your problems and to improve your quality of life?

I appreciate your time and your contribution





9.7 Appendix VII: Information sheet to participate in the screening

UNIVERSITY OF WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959, Fax: 27 21-959

Title of the main Research Project: Rehabilitation for people living with HIV with associated disability on antiretroviral treatment, in Rwanda.

Information sheet: for potential participants in a screening recruiting people living with HIV with associated disabilities to participate in a focus group discussion

My name is Jeanne N. Kagwiza and I am a postgraduate PhD student, in the Physiotherapy Department at the University of the Western Cape, Cape Town, South Africa. I am currently conducting a study in Rwanda on the provision of rehabilitation services for people living with HIV who have difficulties associated with HIV. I would like to invite you to answer some questions about difficulties you may experience related to daily activities. Depending on what I learn I may invite you to take part in a group discussion.

All the information you provide will be kept private and confidential. Your name will not be included in the report. The results will only be looked at, by the researcher and the research assistant. The results of this screening may be published but you will not be identified as an individual. Nevertheless, the information you give may be disclosed if required by the law.

There are no known risks associated with participating in this screening. However, you reserve the right to withdraw from the screening at any time and this will not have any effect on continuing your usual treatment or on decisions for being referred for treatment where necessary.

Please read and sign the attached consent form if you agree to participate in the screening. If you require further information please feel free to contact me through my contact details below.

Yours sincerely

Date

Physiotherapist and principal researcher Kigali/Rwanda

Jeanne N. Kagwiza Tel: (250)08755364

E-mail: jkagwiza@yahoo.fr/jkagwiza@uwc.ac.za

9.8 Appendix VIII: Informed consent to participate in the screening



UNIVERSITY OF THE WESTERN CAPE

Private Bag X17, Bellville 7535, South Africa

Tel: +27 21-959, Fax: 27 21-959

CONSENT FORM

Title of Research Project: Rehabilitation for people living with HIV with associated disability on antiretroviral treatment, in Rwanda.

Screening for focus group discussion: The screening is to select participants for a focus group discussion involving PLWH with associated disability on antiretroviral treatment.

The procedure and the aim of the screening have been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the screening have been answered. I understand that my identity will not be disclosed and that I may withdraw from the screening without giving a reason at any time and this will not negatively affect me in any way. I agree to keep everything I hear confidential.

Participant's name.....

Participant's signature to participate in the screening.....

Date.....

Witness name.....

Witness signature

Date

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

Study Coordinator's Name: Jeanne N. Kagwiza Physiotherapist and principal researcher. Cell phone: (250) 08755364 Kigali-Rwanda

E-mail: jkagwiza@yahoo.fr/jkagwiza@uwc.ac.za

9.9 Appendix IX: Information sheet to participate in the focus group discussion



UNIVERSITY OF WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959, Fax: 27 21-959

Title of the main Research Project: Rehabilitation for people living with HIV with associated disability on antiretroviral treatment, in Rwanda.

Information sheet: for potential participants in a focus group discussion exploring the perceptions of people living with HIV with associated disabilities on how the hospitals services address their functional limitations.

My name is Jeanne N. Kagwiza and I am a postgraduate PhD student, in the Physiotherapy Department at the University of the Western Cape, Cape Town, South Africa. I am currently conducting a study in Rwanda on the provision of rehabilitation services for people living with HIV who have difficulties associated with HIV. The aim of the study is to explore how you feel the hospital services is addressing your functional limitations or problems. I hope this information will be used to improve the rehabilitation service for people living with HIV.

You are **kindly invited** to participate in the group discussion. During the discussion, notes will be taken and I would like to use an audiotape recorder to ensure that I can remember all that the participants in the group say. All the information you provide will be kept private and confidential. Your name will not be included in the report. The recording and the notes taken will only be listened to, or looked at, by the researcher and her supervisors. The results of this research may be published but you will not be identified as an individual. Nevertheless, the information you give may be disclosed if required by the law.

We hope that you will benefit from this study through the improvement of referral for rehabilitation. There are no known risks associated with participating in this research project. However, you reserve the right to withdraw from the study at any time and this will not have any effect on continuing your usual treatment or on decisions for being referred for treatment where necessary.

In the consent form you will be asked to agree to keep all that is discussed confidential to protect other participants or other people who may be discussed.

Please read and sign the attached consent form if you agree to participate in the study, and to be audio-taped during your participation in this study. If you require further information please feel free to contact me through my contact details below.

Yours sincerely

Date

Physiotherapist and principal researcher



Jeanne N. Kagwiza Tel: (250)08755364 **Kigali/Rwanda**

E-mail: jkagwiza@yahoo.fr/jkagwiza@uwc.ac.za

9.10 Appendix X: Informed consent to participate in the focus group



discussion

UNIVERSITY OF THE WESTERN CAPE
Private Bag X17, Bellville 7535, South Africa
Tel: +27 21-959, Fax: 27 21-959

CONSENT FORM

Title of Research Project: Rehabilitation for people living with HIV with associated disability on antiretroviral treatment, in Rwanda.

Qualitative study; focus group discussion: The focus group discussion is to explore the perceptions of PLWH about how hospital services address their functional limitations.

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

Participant's name.....

Participant's signature to participate in the study.....

Participant's signature to be audio-taped.....Date

Witness name.....

Witness signature Date

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

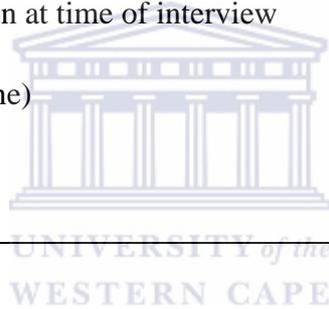
Study Coordinator's Name: Jeanne N. Kagwiza. Physiotherapist and principal researcher. Cell phone: (250) 08755364 Kigali/Rwanda

E-mail: jkagwiza@yahoo.fr/jkagwiza@uwc.ac.za

9.11 Appendix XI: English outcome instrument for translation

Section 1. Face sheet

| Complete items F1-F4 before starting each interview | | | | |
|---|--|--------------------------|-------|------|
| F1 | Respondent identity number | | | |
| F2 | Interview identity number | | | |
| F3 | Assessment time point (1, 2, etc.) | | | |
| F4 | Interview date | | | |
| | | Day | Month | Year |
| | Living situation at time of interview (Circle only one) | Independent in community | | 1 |
| | | Assisted living | | 2 |
| | | Hospitalised | | 3 |



Section 2. Demographic and Background information

Instructions

Dear respondent,

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

| | | | |
|-----|--|-----------|---|
| A.1 | Interviewer: record the gender of the respondent as observed | 1. Male | 1 |
| | | 2. Female | 2 |

| | | | |
|-----|--------------------------------------|------------------------|---|
| A.2 | How old are you now? | Age completed in years | |
| A.3 | What is your current marital status? | 1. Never married | 1 |
| | | 2. Currently married | 2 |
| | | 3. Separated | 3 |
| | | 4. Divorced | 4 |
| | | 5. Cohabiting | 5 |
| | | 6. Widowed | 6 |

| | | | |
|-----|---|---|---|
| A.4 | Which describes your main work status best? | Paid work | 1 |
| | | Self employed, such as own your business or farming | 2 |
| | | Non-paid work, such as Volunteer or charity | 3 |
| | | Student | 4 |
| | | Keeping house/homemaker | 5 |
| | | Retired | 6 |
| | | Unemployed (health reasons) | 7 |
| | | Unemployed(other reasons) | 8 |
| | | 9.Other (Specify) | 9 |

A5. What is your monthly income?

1. None
2. Less than 50.000frw
3. 51.000-100.000frw
4. 101.000-150.000frw
5. More than 150.000frw

A6. What is your level of education?

1. None
2. Primary education (1-6)
3. Secondary school (S1-3)
4. Secondary (S4-6)
5. Tertiary education

A7. How many years in all did you spend studying in school college or University?

Number of years.....

The information below could be checked in the patient record

A8. When were you diagnosed from HIV?

1. Less than one month
2. 1-6 months ago
3. 6-12 months ago
4. 1-3 years ago
5. 4-6 years ago
6. 7-9 years ago
7. 10-15 years ago
8. More than 15 years ago



A.9 What is your HIVserostatus? Asymptomatic/Symptomatic/AIDS converted

A.10 Are you on ARVs? Yes/No

A.11 For how long have you been on the ARVs?

1. Less than a month
2. 1-6 months
3. 6-12 months
4. 1-3 years
5. 4-6 years
6. 7-9 years
7. 10-15 years
8. More than 15 years

A.12 What type of ARVs do you take?

1. Triviro-30 (D4T+3TC+NVP)
2. Duovir-N (AZT+3TC+NVP)
3. TDF+3TC+NVP
4. TDF+3TC+EFV
5. TDF+3TC+Kaletra
6. D4T+3TC+EFV
7. ABC+3TC+EFV
8. ABC+DDI
9. DT4+AZT+Kaletra
10. AZT+3TC+ Stocrin
11. 3TC+NVP



A.13 What is your CD4 cell count?

1. Less than 200
2. 201-350
3. 351-500
4. More than 500

Section 3. Impairments of body functions

Instructions

Section 3 is about difficulties or changes people have in body structure or body function because of health conditions. By health conditions I mean diseases or illnesses, or other health problems that may be short or long lasting; injuries, mental or emotional problems, and problems with alcohol or drugs.

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

Increased effort

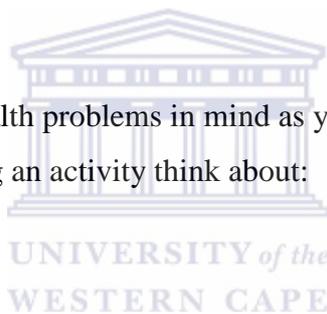
Discomfort or pain

Slowness

Changes in the way you do the activity

When answering, I do like you to think back over the past 30days. I would also like you to answer these questions thinking about how much difficulty you have had, on average, over the past 30 days, due to the health conditions mentioned below in the table.

Use this scale when responding: None, mild, moderate, severe, extreme or cannot do.



| Domain | None | Mild | Moderate | Severe | Extreme or cannot do |
|--|------|------|----------|--------|----------------------|
| D.1 Mental Functions | | | | | |
| Energy and drive functions | 1 | 2 | 3 | 4 | 5 |
| Sleep Functions | 1 | 2 | 3 | 4 | 5 |
| Memory Functions | 1 | 2 | 3 | 4 | 5 |
| Emotional functions | 1 | 2 | 3 | 4 | 5 |
| Body Image | 1 | 2 | 3 | 4 | 5 |
| D.2 Sensory Functions and Pain | | | | | |
| Pain | 1 | 2 | 3 | 4 | 5 |
| D.3 Functions of Cardiovascular and Respiratory Systems | | | | | |
| Heart Functions | 1 | 2 | 3 | 4 | 5 |
| Blood Pressure functions | 1 | 2 | 3 | 4 | 5 |
| Haematological system functions | 1 | 2 | 3 | 4 | 5 |
| Immunological system functions | 1 | 2 | 3 | 4 | 5 |
| Respiration (Breathing) | 1 | 2 | 3 | 4 | 5 |
| Fatigability | 1 | 2 | 3 | 4 | 5 |

| D.4 Functions of the Digestive System | | | | | |
|---|---|---|---|---|---|
| Digestive functions | 1 | 2 | 3 | 4 | 5 |
| Tolerance to food | 1 | 2 | 3 | 4 | 5 |
| Defecation | 1 | 2 | 3 | 4 | 5 |
| Weight Maintenance | 1 | 2 | 3 | 4 | 5 |
| Sensations associated with the digestive system | 1 | 2 | 3 | 4 | 5 |
| Sensation of nausea | 1 | 2 | 3 | 4 | 5 |
| General metabolic functions | 1 | 2 | 3 | 4 | 5 |
| Fat metabolism | 1 | 2 | 3 | 4 | 5 |
| Endocrine gland functions | 1 | 2 | 3 | 4 | 5 |
| D.5 Reproductive Functions | | | | | |
| Sexual Functions | 1 | 2 | 3 | 4 | 5 |
| Menstruation functions | 1 | 2 | 3 | 4 | 5 |
| Regularity of menstrual cycle | 1 | 2 | 3 | 4 | 5 |
| Sensations associated with genital and reproductive functions | 1 | 2 | 3 | 4 | 5 |
| Discomfort associated | 1 | 2 | 3 | 4 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| with sexual intercourse | | | | | |
| D.6 Neuromusculoskeletal and Movement related Functions | | | | | |
| Mobility of Joint | 1 | 2 | 3 | 4 | 5 |
| Muscle Power | 1 | 2 | 3 | 4 | 5 |
| D.7 Functions of the Skin | | | | | |
| Skin functions | 1 | 2 | 3 | 4 | 5 |
| Sensation related to the skin | 1 | 2 | 3 | 4 | 5 |

Thank you. We will now go to the second questionnaire



Section 4. Activity limitations and Participation restrictions

Instructions

I would like to remind you that the information that you provide in this interview is confidential and will be used only for research.

The interview in Section 4 is also about difficulties people have because of health conditions.

Hand flashcard #1 to respondent and say:

Remember by health conditions, I mean diseases or illnesses, or other health problems that may be short or long lasting, injuries, mental or emotional problems and problems with alcohol or drugs. I remind you to keep all of your health problems in mind as you answer the questions, and like before, when I ask you about difficulties in doing an activity think about:

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

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

Say to respondent:

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

Hand flashcard #2 to respondent and say:

Use this scale when responding: None, mild, moderate, severe, extreme or cannot do.

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

DOMAIN REVIEWS

DOMAIN 1 Cognition

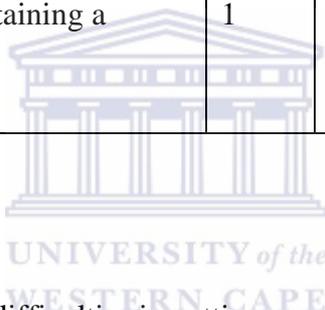
I am now going to ask some questions about understanding and communicating

Show flashcards #1 and #2 to respondent

In the past 30 days, how much difficulty did you have in:

| | | None | Mild | Moderate | Severe | Extreme/ Cannot do |
|------|--|------|------|----------|--------|-----------------------|
| D1.1 | <u>Concentrating</u> on doing something for <u>ten minutes</u> ? | 1 | 2 | 3 | 4 | 5 |
| D1.2 | Remembering to do important | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|------|---|---|---|---|---|---|
| | things? | | | | | |
| D1.3 | Analysing and finding solutions to problems in day to day life? | 1 | 2 | 3 | 4 | 5 |
| D1.4 | <u>Learning a new task</u> , for example, learning how to get to a new place? | 1 | 2 | 3 | 4 | 5 |
| D1.5 | Generally understanding what people say? | 1 | 2 | 3 | 4 | 5 |
| D1.6 | Starting and maintaining a conversation? | 1 | 2 | 3 | 4 | 5 |



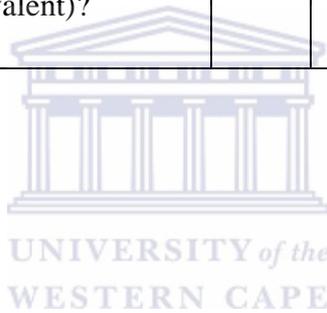
DOMAIN 2 Mobility

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

Show flashcards #1 and #2

In the past 30 days, how much difficulty did you have in:

| | | No | Mild | Moderate | Severe | Extreme/ Cannot do |
|------|---|----|------|----------|--------|-----------------------|
| D2.1 | Standing for long periods such as 30 Minutes? | 1 | 2 | 3 | 4 | 5 |
| D2.2 | <u>Standing up</u> from sitting down? | 1 | 2 | 3 | 4 | 5 |
| D2.3 | Moving around inside your home? | 1 | 2 | 3 | 4 | 5 |
| D2.4 | Getting out of your home? | 1 | 2 | 3 | 4 | 5 |
| D2.5 | <u>Walking a long distance</u> such as a kilometre (or equivalent)? | 1 | 2 | 3 | 4 | 5 |



DOMAIN 3 Self- care

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

Show flashcards #1 and #2

In the past 30 days, how much difficulty did you have in:

| | | No | Mild | Moderate | Severe | Extreme/ Cannot do |
|------|--------------------|----|------|----------|--------|-----------------------|
| D3.1 | Washing your whole | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|------|---|---|---|---|---|---|
| | body? | | | | | |
| D3.2 | Getting <u>dressed</u> ? | 1 | 2 | 3 | 4 | 5 |
| D3.3 | Eating? | 1 | 2 | 3 | 4 | 5 |
| D3.4 | Staying by <u>yourself</u> for a <u>few days</u> ? | 1 | 2 | 3 | 4 | 5 |

DOMAIN 4 Getting along with people

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

Show flashcards #1 and #2

In the past 30 days, how much difficulty did you have in:

| | | None | Mild | Moderate | Severe | Extreme/ Cannot do |
|------|--|------|------|----------|--------|--------------------------|
| D4.1 | Dealing with people you do not know? | 1 | 2 | 3 | 4 | 5 |
| D4.2 | Maintaining a friendship? | 1 | 2 | 3 | 4 | 5 |
| D4.3 | <u>Getting along</u> with people who are | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|------|----------------------|---|---|---|---|---|
| | <u>close to you?</u> | | | | | |
| D4.4 | Making new friends? | 1 | 2 | 3 | 4 | 5 |
| D4.5 | Sexual activities? | 1 | 2 | 3 | 4 | 5 |

DOMAIN 5 Life activities

It includes:

1. Household Activities

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

Show flashcards #1 and #2

Because of your health condition, in the past 30 days, how much difficulty did you have in:



| | | None | Mild | Moderate | Severe | Extreme/ Cannot do |
|------|---|------|------|----------|--------|--------------------------|
| D5.1 | Taking care of your household responsibilities? | 1 | 2 | 3 | 4 | 5 |
| D5.2 | Doing your most important household tasks <u>well</u> ? | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|------|---|---|---|---|---|---|
| D5.3 | Getting all the household work <u>done</u> that you needed to do? | 1 | 2 | 3 | 4 | 5 |
| D5.4 | Getting your household work done as <u>quickly</u> as needed? | 1 | 2 | 3 | 4 | 5 |

If any of the responses to D5.2-D5.4 are rated greater than none (coded as “1”), ask:

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

If respondent works (paid, non-paid, self-employed) or goes to school, complete questions

D5.5-D5.10. Otherwise, skip to D6.1

2. Work or school activities

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

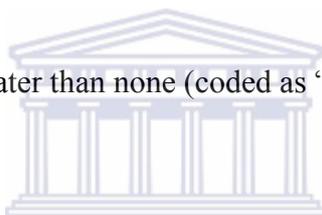
Show flashcards #1 and #2

Because of your health condition, in the past 30 days how much difficulty did you have in:

| | | None | Mild | Moderate | Severe | Extreme or Cannot do |
|------|---|------|------|----------|--------|----------------------------|
| D5.5 | Your day-to-day <u>Work/School</u> ? | 1 | 2 | 3 | 4 | 5 |
| D5.6 | Doing your most important work/School tasks <u>well</u> ? | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|-------|---|---|---|---|-----|---|
| | | | | | | |
| D5.7 | Getting all the work done that you need to do? | 1 | 2 | 3 | 4 | 5 |
| D.8 | Getting your work done as <u>quickly</u> as needed? | 1 | 2 | 3 | 4 | 5 |
| D5.9 | Have you had to work at a <u>lower level</u> because of a health condition? | | | | No | 1 |
| | | | | | Yes | 2 |
| D5.10 | Did you <u>earn less money</u> as the result of a health condition? | | | | No | 1 |
| | | | | | Yes | 2 |

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



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

Domain 6 Participation

Now, I am going to ask you about **your participation in society** and **the impact of your health problems on you and your family**. Some of these questions may involve problems that go beyond the past 30 days, however in answering, please focus on the past 30 days.

Again I remind you to answer these questions while thinking about health problems: physical, mental or emotional, alcohol or drug related.

Show flashcards #1 and #2

In the past 30 days

| | | None | Mild | Moderate | Severe | Extreme/ Cannot do |
|------|---|------|------|----------|--------|--------------------------|
| D6.1 | How much of a problem did you have <u>joining in community activities</u> (for example, festivities, religious or other activities) in the same way as anyone else can? | 1 | 2 | 3 | 4 | 5 |
| D6.2 | How much of a problem did you have because of <u>barriers or hindrances</u> in the world around you? | 1 | 2 | 3 | 4 | 5 |
| D6.3 | How much of a problem did you have <u>living with dignity</u> because of the | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|------|---|---|---|---|---|---|
| | attitudes and actions of others? | | | | | |
| D6.4 | How much <u>time</u> did <u>you</u> spend on your health condition, or its consequences? | 1 | 2 | 3 | 4 | 5 |
| D6.5 | How much have <u>you</u> been <u>emotionally affected</u> by your health condition? | 1 | 2 | 3 | 4 | 5 |
| D6.6 | How much has your health been a <u>drain</u> on the <u>financial resources</u> of you or your family? | 1 | 2 | 3 | 4 | 5 |
| D6.7 | How much of a problem did your <u>family</u> have because of your health problems? | 1 | 2 | 3 | 4 | 5 |
| D6.8 | How much of a problem did you have in doing things by <u>yourself</u> for | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|--|--------------------------------|--|--|--|--|--|
| | <u>relaxation or pleasure?</u> | | | | | |
|--|--------------------------------|--|--|--|--|--|

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

This concludes our interview, thank you for participating.

9.12 Appendix XII: Kinyarwanda outcome instrument

URUTONDE RW'IBIBAZO

Urutonde rw'ibibazo numero.....Tariki ya...../...../.....

Icyiciro 1. URUPAPURO RW'IBANZE

URUTONDE RW'IBIBAZO

| Uzuza kuva kuri numero F1 kugeza kuri F4 mbere yo gutangira buri bazwa | | | |
|--|--|-------------------------|---|
| F1 | 1.Nomero iranga ubazwa na | 1. | |
| | 2. Nomero ya telephone | 2. | |
| F2 | Nomero iranga ubaza | | |
| F3 | Inshuro ibazwa rikoreshejwe (1, 2 etc.) | | |
| F4 | Uko ubayeho mu gihe cy'ibazwa (shyira akaziga ku mubare umwe) | Wibeshejeho mu muryango | 1 |
| | | Urafashwa mu buzima | 2 |
| | | uba mu bitaro | 3 |

Icyiciro 2. UMWIRONDORO N'IMIBEREHO BY'UBAZWA

Amabwiriza

Muvandimwe,

Iri bazwa ryateguwe n’Umuryango mpuzamahanga wita ku buzima mu rwego rwo kurushaho kumenya ingorane abantu baba bafite zishingiye ku ndwara zitandukanye. Amakuru utangaza muri iri bazwa ni ibanga kandi azakoreshwa mu bushakashatsi gusa. Ibazwa rigusaba kwigomwa iminota iri hagati ya 25 na 30.

| | | | |
|-----|----------------------------------|--|-------------|
| A.1 | Ubaza: andika igitsina cy’ubazwa | 1. Gabo | 1 |
| | | 2. Gore | 2 |
| A.2 | Ufite imyaka ingahe? | Umubare w’imyaka |Imyaka |
| A.3 | Umwimerere wawe ni uwuhe? | 1. Ingaragu | 1 |
| | | 2. Warashatse | 2 |
| | | 3. Muba ukubiri | 3 |
| | | 4. Mwaratandukanye | 4 |
| | | 5. Mubana n’undi by’ighe gito | 5 |
| | | 6. Umupfakazi | 6 |
| A.4 | Ukora akahe kazi? | 1. Akazi k’umushahara | 1 |
| | | 2. Urikorera, nk’imirimo yawe bwite cyangwa umuhinzi mworozu | 2 |
| | | 3. Akazi kadahemberwa nk’umukorerabushake cyangwa ibikorwa by’urukundo | 3 |

| | | | |
|-----|---|--|---|
| | | 4.Umunyeshuli | 4 |
| | | 5. Ukora imirimo yo mu rugo | 5 |
| | | 6. Uri mu kiruhuko cyi'zabukuru | 6 |
| | | 7.Ntukora (kubera ibibazo by'uburwayi) | 7 |
| | | 8.Ntukora (kubera izindi mpamvu) | 8 |
| | | 9. Ibindi (sobanura) | 9 |
| A.5 | Ugereranije winjiza amafaranga angahe mu kwezi? | Ntayo | 1 |
| | | munsi ya 50.000frw | 2 |
| | | Hagati ya 51.000-100.000 frw | 3 |
| | | Hagati ya 101.000-150.000 frw | 4 |
| | | Hejuru ya 150.000 frw | 5 |
| A.6 | Ufite amashuri angahe? | 1. Ntiwize | 1 |
| | | 2. Abanza, 1-6 | 2 |
| | | 3. Ayisumbuye, 1-3 | 3 |
| | | 4. Ayisumbuye, 4-6 | 4 |

| | | | |
|-----|---|-------------|------------------|
| | | 5. Kaminuza | 5 |
| A.7 | Wamaze imyaka ingahe mu buzima bw'ishuli? | | Umubare w'imyaka |

A.8 Niba wibuka neza, hashize igihe kingana iki umenye ko ufite ikibazo cy'ubwandu bw'agakoko gatera SIDA?

1. Minsi y'ukwezi 1
2. Hagati y'ukwezi 1 - n'amezi 6
3. Hagati y'amezi 6 - n'amezi 12
4. Hagati y'umwaka 1 - n'imyaka 3
5. Hagati y'imyaka 4 - n'imyaka 6
6. Hagati y'imyaka 7 - n'imyaka 9
7. Hagati y'imyaka 10 - n'imyaka 15
8. hejuru y'imyaka 15



Amakuru akurikira ashobora gushakirwa mu ifishi y'umurwayi

A.9 Uburwayi bwawe buhagaze bute? ntabimenyetso, hari ibimenyetso by'uburwayi, uburwayi bukabije

A.10 Waba ufata imiti igabanya ubukana? Yego/oya

A.11 Umaze igihe kingana iki ufata imiti igabanya ubukana?

1. Minsi y'ukwezi 1

2. Hagati y'ukwezi 1 - n'amezi 6

3. Hagati y'amezi 6 - n'amezi 12

4. Hagati y'umwaka 1 - n'imyaka 3

5. Hagati y'imyaka 4 - n'imyaka 6

6. Hagati y'imyaka 7 - n'imyaka 9

7. Hagati y'imyaka 10 - n'imyaka 15

8. hejuru y'imyaka 15

A.12 Ni ubuhe bwoko bw'imiti igabanya ubukana ufata?

1. Triviro-30 (D4T+3TC+NVP)

2. Duovir-N(AZT+3TC+NVP)

3. TDF+3TC+NVP



4. TDF+3TC+EFV
5. TDF+3TC+Kaletra
6. D4T+3TC+EFV
7. ABC+3TC+EFV
8. ABC+ddI
9. D4T+AZT+Kaletra
10. AZT+3TC+Stocrin
11. 3TC+NVP

A.13 Ufite abasirikare bangahe?

1. Minsi cyangwa bangana na 200
2. Hagati ya 201-350
3. Hagati ya 351-500
4. Hejuru ya 500



Icyiciro cya 3. IBIBAZO BY'UMUBIRI *UNIVERSITY of the*
WESTERN CAPE

Amabwiriza

Icyiciro cya 3 kirarebana n'ingorane cyangwa impinduka abantu bagira ku miterere cyangwa ku mikorere y'umubiri, bitewe n'ibibazo by'uburwayi. Ibibazo by'uburwayi nshaka kuvuga ni nk'indwara cyangwa ibindi bibazo by'ubuzima byaba iby'igihe gito cyangwa kinini; nko gukomereka, ibibazo byo mu mutwe cyangwa by'ihungabana, ndetse n'ibiterwa n'inzoga nyinshi cyangwa ibiyobyabwenge.

Ugerageze kwibuka ibibazo byose ufite by'ubuzima mu gihe usubiza ibibazo. Mu gihe nkubaza ingorane ugize icyo ukora utekereze kuri ibi bikurikira: bigusaba imbaraga nyinshi, birakubangamira/birakubabaza, ubikora buhoro, bigusaba guhindura imikorere.

Mu gihe usubiza, nifuzaga ko watekereza mu minsi 30 ishize. Nkifuza nanone ko wasubiza uzirikana ku ngorane wagiye uhura nazo mu minsi 30 ishize, bitewe n'impinduka z'imiterere n'imikorere y'umubiri ivugwa hasi.

Koresha ibibigereranyo mu gihe usubiza: nta na rimwe, buhoro, biringaniye, cyane, bikabije.

| Ishami | | Nta na rimwe | Buhoro | Biringaniye | Cyane | Bikabije | NA |
|---------------------------|------------------------|--------------|--------|-------------|-------|----------|----|
| D.1 Imikorere yo mu mutwe | | | | | | | |
| | Imbaraga n'umwete | 1 | 2 | 3 | 4 | 5 | 6 |
| | Ibijyanye no gusinzira | 1 | 2 | 3 | 4 | 5 | 6 |
| | Kwibuka ibyakubayeho | 1 | 2 | 3 | 4 | 5 | 6 |
| | Kwakira ibikubayeho | 1 | 2 | 3 | 4 | 5 | 6 |
| | Imihindukire y'umubiri | 1 | 2 | 3 | 4 | 5 | 6 |

| | | | | | | | |
|---|-----------|---|---|---|---|---|---|
| D.2 Imikorere y' Ibyumviro by'umubiri n'ububabare | | | | | | | |
| | Ububabare | 1 | 2 | 3 | 4 | 5 | 6 |
| D.3 Imikorere y' Urwungano rw'amaraso n'ihumeka | | | | | | | |



| | | | | | | | |
|-----------------------------------|-------------------------------|---|---|---|---|---|---|
| | Imikorere y'umutima | 1 | 2 | 3 | 4 | 5 | 6 |
| | Umuvuduko w'amaraso | 1 | 2 | 3 | 4 | 5 | 6 |
| | Ibigize amaraso | 1 | 2 | 3 | 4 | 5 | 6 |
| | Ubudahangarwa bw'umubiri | 1 | 2 | 3 | 4 | 5 | 6 |
| | Guhumeka | 1 | 2 | 3 | 4 | 5 | 6 |
| | Umunaniro | 1 | 2 | 3 | 4 | 5 | 6 |
| D.4 Imikorere y'Urwungano ngogozi | | 1 | 2 | 3 | 4 | 5 | 6 |
| | Igororwa ry'ibiryo | 1 | 2 | 3 | 4 | 5 | 6 |
| | Kubasha no kuyobokwa n'ibiryo | 1 | 2 | 3 | 4 | 5 | 6 |
| | kujya kwituma | 1 | 2 | 3 | 4 | 5 | 6 |
| | Kudahinduka kw'ibiro | 1 | 2 | 3 | 4 | 5 | 6 |
| | Kugubwa nabi mu nda | 1 | 2 | 3 | 4 | 5 | 6 |
| | Kugira isesemi | 1 | 2 | 3 | 4 | 5 | 6 |
| | Uko umubiri ukoresha ibyo | 1 | 2 | 3 | 4 | 5 | 6 |

| | | | | | | | |
|-------------------|---|---|---|---|---|---|---|
| | wariye | | | | | | |
| | Uko umubiri ukoresha ibinure | 1 | 2 | 3 | 4 | 5 | 6 |
| | Imikorere y'imisemburo | 1 | 2 | 3 | 4 | 5 | 6 |
| D.5 Imyorokere | | | | | | | |
| | Imikorere y'imyanya ndangabitsina | 1 | 2 | 3 | 4 | 5 | 6 |
| | Kujya mu mihango | 1 | 2 | 3 | 4 | 5 | 6 |
| | Ukudahinduka kw'iminsi y'imihango | 1 | 2 | 3 | 4 | 5 | 6 |
| | Kumererwa nabi bitewe n'imyanya ndangabitsina | 1 | 2 | 3 | 4 | 5 | 6 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | n'imyororokere | | | | | | |
| | Kumererwa nabi bitewe n'imibonano mpuzabitsina | 1 | 2 | 3 | 4 | 5 | 6 |
| D.6 Imikorere y'amagufa, ingingo n'imitsi | | | | | | | |
| | Imikorere y'ingingo | 1 | 2 | 3 | 4 | 5 | 6 |
| | Imbaraga z'imitsi/ z'imikaya | 1 | 2 | 3 | 4 | 5 | 6 |
| D.7 Imikorere y'uruhu | | | | | | | |
| | Imikorere y'uruhu | 1 | 2 | 3 | 4 | 5 | 6 |
| | Imyumvire idasanzwe y'uruhu | 1 | 2 | 3 | 4 | 5 | 6 |

Murakoze. Noneho tujye ku rutonde rw'ibibazo numero 2

Icyiciro cya 4. Ingorane mu mikorere yawe n'ubwitabire mu bikorwa mu buzima busanzwe

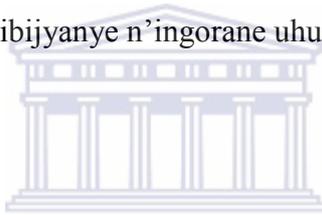
Amabwiriza

Nagiragango nkwiutse ko amakuru utangaza muri iri bazwa ari ibanga kandi ko azakoreshwa mu bushakashatsi gusa.

Ibazwa ryo mu cyiciro cya 4 naryo riribanda ku ngorane abantu bahura nazo kubera ibibazo by'ubuzima.

Hereza ubazwa ikarita # 1 hanyuma uvuge:

Wibuke ko iyo mvuze ibibazo by'ubuzima mba nshaka kuvuga uburwayi cyangwa ibindi bibazo by'ubuzima byaba iby'igihe gito cyangwa kinini, gukomereka, ibibazo byo mu mutwe cyangwa iby'ihungabana hamwe n'ibiterwa n,inzoga nyinshi cyangwa ibiyobyabwenge. Ndakwibutsa gukomeza kuzirikana ibibazo by'ubuzima ugira, usubiza ibibazo nk'uko wabigenje mbere. Igihe nkubajije ibijyanye n'ingorane uhura nazo mu gukora akazi utekereze kuri ibi bikurikira:



Erekana ikarita #1 hanyuma usobanure ko “ingorane mu gikorwa bivuga: bigusaba imbaraga nyinshi, birakubabaza/birakubangamira, gukora buhoro, bigusaba guhindura imikorere.

Bwira usubiza:

Mu gihe usubiza, nifuzaga ko watekereza mu minsi 30 ishize. Nkifuza nanone ko wasubiza uzirikana ku ngorane wagiye uhura nazo mu minsi 30 ishize, igihe wagiraga icyo ukora nk'uko bisanzwe.

Hereza ubazwa ikarita # 2 hanyuma uvuge:

koresha ibi bipimo mu gihe usubiza: Nta na rimwe, buhoro, biringaniye, cyane, bikabije.

Umenye neza ko usubiza ashobora kubona ku buryo bworoshye amakarita iya 1 n'ya 2 mu ibazwa ryose uko ryakabaye.

AMASHAMI Y'IBANDWAHO

Ishami 1 UBWENGE N'UBUMENYI

Ubu ngiye kubaza ibijyanye no gusobanukirwa, gusobanura, kumvikana n'abandi

Ereka ubazwa amakarita iya 1 n'ya 2



Mu minsi 30 ishize wahuye n'ingorane zo kuruhe rwego mu gukora ibi bikurikira:

WESTERN CAPE

| | | Nta na rimwe | Buhoro | Biringaniye | Cyane | Bikabije |
|------|--------------------------------------|--------------|--------|-------------|-------|----------|
| D1.1 | Kumara iminota 10 ukora ushishikaye? | 1 | 2 | 3 | 4 | 5 |
| D1.2 | Kwibuka gukora ibintu | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|------|---|---|---|---|---|---|
| | by'ingenzi? | | | | | |
| D1.3 | Gusesengura no kubona ibisubizo by'ibibazo byo mu buzima bwa buri muni? | 1 | 2 | 3 | 4 | 5 |
| D1.4 | Kwiga igikorwa gishya, urugero kwiga ukuntu wagera ahantu utari uzi? | 1 | 2 | 3 | 4 | 5 |
| D1.5 | Gusobanukirwa muri rusange nibyo abantu bavuga? | 1 | 2 | 3 | 4 | 5 |
| D1.6 | Gutangira no gukomeza ikiganiro? | 1 | 2 | 3 | 4 | 5 |

Ishami 2 KUGENDAGENDA/ KUNYEGANYEGA

Ubu ngiye kubaza ibijyanye no kugendagenda/ kunyeganyega

Ereka ubazwa amakarita iya 1 n'iya 2

Mu minsi 30 ishize wahuye n'ingorane zo kuruhe rwego mu gukora ibi bikurikira:

| | | Nta na rimwe | Buhoro | Biringaniye | cyane | Bikabije |
|------|---|--------------|--------|-------------|-------|----------|
| D2.1 | Guhagarara umwanya munini nk'iminota 30? | 1 | 2 | 3 | 4 | 5 |
| D2.2 | Guhaguruka wari wicaye? | 1 | 2 | 3 | 4 | 5 |
| D2.3 | Kugendagenda mu rugo? (urugero; kuva mu cyumba kugera muri douche, kuva mu cyumba kugera k' musarani, n'ahandi) | 1 | 2 | 3 | 4 | 5 |
| D2.4 | Kuva mu rugo? | 1 | 2 | 3 | 4 | 5 |
| D2.5 | Kugenda intera ndende n'amaguru nka kilometero 1? | 1 | 2 | 3 | 4 | 5 |

Ishami 3 KWIYITAHO

Ubu noneho ngiye kukubaza ku ngorane uhura nazo mu kwiytaho.

Mu minsi 30 ishize wahuye n'ingorane zo kuruhe rwego mu gukora ibi bikurikira:

| | | Nta na rimwe | Buhoro | Biringaniye | cyane | Bikabije |
|------|-------------------------------|--------------|--------|-------------|-------|----------|
| D3.1 | Kwiyuhagira umubiri wose? | 1 | 2 | 3 | 4 | 5 |
| D3.2 | Kwiyambika? | 1 | 2 | 3 | 4 | 5 |
| D3.3 | Kwigaburira/kwitamika? | 1 | 2 | 3 | 4 | 5 |
| D3.4 | Kubaho wenyine mu minsi mike? | 1 | 2 | 3 | 4 | 5 |

Ishami 4 Kubana n'abandi

Ubu noneho ngiye kukubaza ingorane uhura nazo mu mibanire n’abandi. Rwose wibuke ko ibyo nkubaza biganisha gusa ku ngorane ufite ziterwa n’ibibazo by’ubuzima. Aha ndashaka kuvuga indwara, gukomereka, ibibazo byo mu mutwe n’ibyihungabana hamwe n’ibijyanye n’inzoga nyinshi cyangwa ibiyobyabwenge.

Erekana amakarita #1 na #2

Mu minsi 30 ishize wahuye n’ingorane zo kuruhe rwego mu gukora ibi bikurikira:

| | | Nta na rimwe | Buhoro | Biringaniye | cyane | Bikabije |
|------|------------------------------------|--------------|--------|-------------|-------|----------|
| D4.1 | Kumvikana/gusabana n’abantu utazi? | 1 | 2 | 3 | 4 | 5 |
| D4.2 | Gukomeza ubucuti? | 1 | 2 | 3 | 4 | 5 |
| D4.3 | Gusabana n’abantu bawe bahafi? | 1 | 2 | 3 | 4 | 5 |
| D4.4 | Gushaka inshuti shya? | 1 | 2 | 3 | 4 | 5 |
| D4.5 | Kugira imibonano mpuzabitsina? | 1 | 2 | 3 | 4 | 5 |

Ishami 5 IMIRIMO ISANZWE YO MU BUZIMA

Iyo mirimo irimo:

1. Imirimo yo mu rugo

Ndagirango noneho nkubaze ibijyana n'imirimo yo kwita ku rugo ndetse no gufata neza abo mubana cyangwa abantu bawe ba hafi. Iyo mirimo ni nko guteka, gusukura, guhaha, kwita ku bandi no ku byawe.

Erekana amakarita #1 na #2

Mu minsi 30 ishize wahuye n'ingorane zo kuruhe rwego mu gukora ibi bikurikira:

| | | Nta na rimwe | Buhoro | Biringaniye | Cyane | Bikabije |
|------|--|--------------|--------|-------------|-------|----------|
| D5.1 | Kwita ku nshingano zawe mu rugo? | 1 | 2 | 3 | 4 | 5 |
| D5.2 | Gukora neza imirimo yawe y'ingenzi yo mu rugo? | 1 | 2 | 3 | 4 | 5 |
| D5.3 | Kurangiza imirimo yo mu rugo yose nk'uko wabyifuzaga | 1 | 2 | 3 | 4 | 5 |
| D5.4 | Kurangiza imirimo yo | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|--|-------------------------------|--|--|--|--|--|
| | murugo vuba nk'uko bikwiye | | | | | |
|--|-------------------------------|--|--|--|--|--|

Niba hari ibisubizo kuva kuri D5.2 Kugeza kuri D5.4 byabaye byinshi kurusha “nta na rimwe” (igaragazwa na nomero “1”) baza

| | | |
|-------|---|----------------------------------|
| D5.01 | Mu minsi 30 ishize, n'iminsi ingahe wagabanije cyangwa waretse burundu imirimo yo mu rugo bitewe n'uburwayi bwawe | Andika umubare w'iminsi |
|-------|---|----------------------------------|

Niba ubazwa ari umukozi (uhembwa, ubwitange/umukorerabushake, wikorera) cyangwa wiga, uzuza ibibazo kuva kuri D5.5 kugera kuri D5.10. Nibitaba ibyo usimbuke ufate D6.1

2. Imirimo isanzwe cyangwa yo ku ishuli

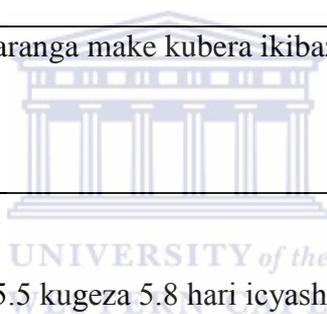
Noneho ngiye kukubaza ibijyanye n'imirimo isanzwe cyangwa yo ku ishuli

Erekana amakarita #1 na #2

Mu minsi 30 ishize wahuye n'ingorane zo kuruhe rwego mu gukora ibi bikurikira bitewe n'ibibazo by'ubuzima:

| | | Nta na rimwe | Buhoro | Biringaniye | cyane | Bikabije |
|------|--------------------------------|--------------|--------|-------------|-------|----------|
| D5.5 | Imirimo/amasomo ya buri munsu? | 1 | 2 | 3 | 4 | 5 |
| D5.6 | Gutunganya neza | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|-------|--|---|---|---|------|---|
| | imirimo/amasomo yawe y'ingenzi? | | | | | |
| D5.7 | Kurangiza ibyo ugomba byose neza? | 1 | 2 | 3 | 4 | 5 |
| D5.8 | Kubona umurimo wawe ukozwe vuba nk'uko byakagombye? | 1 | 2 | 3 | 4 | 5 |
| D5.9 | Waba warakoze bidahagije bitewe n'uburwayi? | | | | Oya | 1 |
| | | | | | Yego | 2 |
| D5.10 | Waba warinjije amafaranga make kubera ikibazo cy'uburwayi? | | | | Oya | 1 |
| | | | | | Yego | 2 |



Niba muri ibi bibazo kuva kuri D5.5 kugeza 5.8 hari icyashubijwe hejuru ya “nta na rimwe” (igaragazwa na “1”) baza:

| | | |
|-------|---|----------------------------------|
| D5.02 | Mu minsi 30 ishize ni iminsi ingahe wasibye akazi igice cy'umunsi cyangwa kirenga bitewe n'uburwayi | Andika umubare w'iminsi |
|-------|---|----------------------------------|

Ishami 6 UBWITABIRE MU BIKORWA BYO MU BUZIMA BUSANZWE

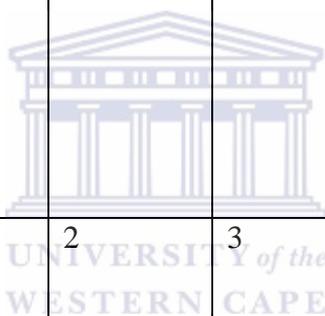
Noneho ngiye kukubaza uruhare ugira mugufatanya n’abandi n’ingaruka byaba bigira ku buzima bwawe no ku muryango wawe. Ndagusabye wibande ku minsi 30 ishize. Nanone wibuke gusubiza utekereza ku bibazo by’ubuzima nk’uburwayi bw’umubiri, gukomereka, ibibazo byo mu mutwe n’ibyihungabana hamwe n’ibijyanye n’inzoga nyinshi cyangwa ibiyobyabwenge

Erekana amakarita #1 na #2

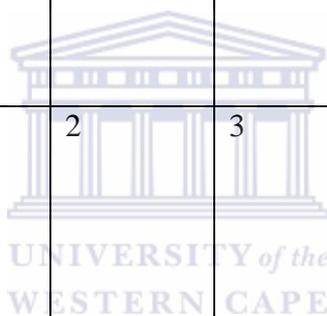
Mu minsi 30 ishize wahuye n’ingorane zo kuruhe rwego mu gukora ibi bikurikira:

| | | Nta na rimwe | Buhoro | Biringaniye | Cyane | Bikabije |
|------|---|--------------|--------|-------------|-------|----------|
| D6.1 | Ni kuruhe rugero wahuye n’ikibazo igihe wifatanyaga n’abandi mu mirimo (nko mu minsi mikuru, mu masengesho cyangwa ibindi) wakoze ku buryo bumwe n’undi wese? | 1 | 2 | 3 | 4 | 5 |
| D6.2 | Ni kuruhe | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|------|---|---|---|---|---|---|
| | <p>rugero wahuye n'ikibazo bitewe n'inzitizi zaho uba n'ibigukikije?</p> | | | | | |
| D6.3 | <p>Ni kuruhe rugero ubwisanzure n'icyubahiro byawe byabangamiwe n'ibikorwa cyangwa imytwarire n'ibikorwa by'abandi?</p> | 1 | 2 | 3 | 4 | 5 |
| D6.4 | <p>Byagutwaye igihe kingana iki wita k'uburwayi bwawe cyangwa ingaruka zabwo</p> | 1 | 2 | 3 | 4 | 5 |
| D6.5 | <p>Ni kuruhe rugero wahungabanye mu bitekerezo bitewe n'uburwayi</p> | 1 | 2 | 3 | 4 | 5 |



| | | | | | | |
|------|--|---|---|---|---|---|
| | bwawe? | | | | | |
| D6.6 | Ni kuruhe rugero imiterere y'ubuzima bwawe yakubujije kwikungahaza ubwawe cyangwa umuryango wawe? | 1 | 2 | 3 | 4 | 5 |
| D6.7 | Ni kuruhe rugero umuryango wawe wahuye n'ibibazo bitewe n'uburwayi bwawe? | 1 | 2 | 3 | 4 | 5 |
| D6.8 | Ni mubuhe buryo wahuye n'ikibazo igihe wakoraga ugamije kwidagadura cyangwa kwishimisha? | 1 | 2 | 3 | 4 | 5 |



| | | |
|----|---|-----------------------|
| H1 | Hejuru y'ibi byose , mu minsi 30 ishize ni iminsi ingahe wahuye n'izi ngorane zavuzwe? | Umubare w'iminsi..... |
| H2 | Mu minsi 30 ishize, ni iminsi ingahe wananiwe burundu kurangiza imirimo yawe bitewe n'imwe mu mpamvu z'uburwayi? | Umubare w'iminsi..... |
| H3 | Mu minsi 30 ishize, ukuyemo iyo waretse burundu, ni iminsi ingahe wagabaniye imirimo yawe cyangwa akazi usanzwe ukora ku mpamvu y'uburwayi? | Umubare w'iminsi..... |

Aha niho dusoreje ibazwa, tubashimiye uruhare mwagize. Mwakoze

