VALIDATION AND LONGITUDINAL APPLICATION OF THE WHOQOL-HIV QUESTIONNAIRE AMONG PEOPLE LIVING WITH HIV AND AIDS IN LIMPOPO PROVINCE, SOUTH AFRICA

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DECLARATION

I, **Jude Ofuzinim Igumbor**, hereby declare that this thesis is my own work in design and in execution and that it has not previously been submitted for any degree or examination at this or any other university. I also affirm that all reference material(s) contained herein have been duly acknowledged.

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Signature

September 6, 2011

ABSTRACT

The rate of HIV infection in South Africa remains high despite the continued efforts to prevent its transmission. Conversely, the rate of AIDS related mortality has been on the decline since the country introduced its comprehensive care and treatment plan. Among other things, the comprehensive plan seeks to coordinate activities to prevent further infection and facilitate health and social support services for the infected and affected. Despite this, South Africa has an increasing number of people living with HIV (PLWH) and is home to the largest population of HIV infected people in the world. Consequently, there is a growing shift of focus of HIV/AIDS response programmes from issues of survival and death prevention to the quality of survival of PLWH. This point accentuates the need for patient evaluation of their wellbeing and quality of life in the context of the country's HIV/AIDS response services. There are HIV-specific quality of life assessment tools like the WHOQOL-HIV, but these tools are subject to cultural variations and have not been validated across South Africa's multicultural society. The available tools are often too long and cannot be used in routine care and support of PLWH. In the absence of validated and efficient quality of life assessment tools, there is over reliance on biomedical markers of HIV/AIDS like the CD4 cell count and viral load. These biomedical indicators do not provide a complete view of the impact of the disease given the multidimensional consequences of HIV and AIDS.

With the above background, this study sought to firstly explore the health related quality of life (HRQOL) and the experiences of PLWH in seeking care and support services, and secondly, to validate the ability of the WHOQOL-HIV instrument to measure the health related quality of life of PLWH among the three cultural groups in Limpopo Province over a specified time period.

The study was divided into two, with the first and second studies using qualitative and quantitative research approaches respectively. Both studies divided their participants into three groups, with each group representing each of the three main ethnic groups in Limpopo Province (Pedi, Tsonga and Venda). The qualitative study used focus group discussions (FGDs) to solicit information and grounded theory to guide its participant selection, number of FGDs conducted and the interpretation of its findings.

The second study was a longitudinal follow up of participants in the three groups from the point of treatment initiation over 12 months. In the second study, there were three points of data collection (baseline, six and twelve months). The participants were conveniently selected and interviewed repeatedly with the WHOQOL-HIV and MOS-HIV instruments. The study findings were mostly presented in tables and t-tests and ANOVA were used to compare quality of life scores in different groupings while correlation and limits of agreements were used to establish instrument validity. Item-total correlation coefficient and alpha if item deleted, was used to explore the possibility of shortening the WHOQOL-HIV instrument in an attempt to suggest a shorter and more user friendly version of the instrument.

The key findings of the qualitative study are that the quality of life of PLWH in Limpopo is determined by three groups of factors (physical, mental and external). The frequency and severity of these factors are determined by the participants’ duration on treatment, disclosure of their HIV status and socioeconomic status. The physical factors were mostly constituted by biological symptoms of the disease. The most commonly cited symptoms were diarrhoea, pain and fatigue. The study also noted marked differences in the occurrence of the symptoms through the trajectory of the disease revealing four main stages: pre-treatment; treatment initiation; early treatment; and treatment maintenance stages. The study also noted that the impact of the determinants of the quality of life on an individual is influenced by intervening factors which can be altered by a set of modifying factors. In all, the quality of life determinants identified by this study replicates those that constitute the WHOQOL-HIV instrument. This finding hence obviates the need for the modification of existing quality of life instruments to suit the three South African ethnic groups investigated by this study.

The quantitative study showed high reliability of the WHOQOL-HIV among the three ethnic groups with alpha ranging from 0.79 to 0.94 in the six domains of the instrument. The study also showed that the quality of life varied by socio-demographic characteristics such as ethnic group, sex, marital status, number of children, employment status and membership of HIV/AIDS support groups. The observed difference reflects poor financial capacity and activity tolerance across the various categories of the participants and at different times. While significant changes in the quality of life was noted between the baseline data and the six and twelve months data respectively, little or no improvements were seen between the six and twelve months data. The participants were actually more likely to have a better quality of life at six months when compared to their quality of life at twelve months. In the same manner, the median CD4 cell count and viral load were very similar at six and twelve months but differed significantly with the baseline reports. Over time and across cultural groups, the participants reported lower quality of life in the level of dependence domain and financial support subscale. There were little or no associations between the biomedical markers and HRQOL indicators. In addition, the quality of life tended to increase with increase in CD4 cell count. The validation of the WHOQOL-HIV using the MOS-HIV through a correlation of similar domains and their limits of agreement largely suggests that the WHOQOL-HIV is valid but both instruments are not exact replicas in their measurements. The multidimensional nature hypothesized by the original WHOQOL-HIV instrument study was also demonstrated by the factor analysis component matrix. Attempts to shorten the WHOQOL-HIV proved to be impossible as the items with highest item-total correlation varied with the participants' duration on treatment.

In conclusion, this study suggested the needs and factors that contribute to the quality of life of PLWH in Limpopo and how those factors can be harnessed through a set of modifying factors. With this, an individual's quality of life is determined by the delicate balance between intervening and modifying factors. The linkages between the observed determinants of quality of life suggest a vicious circle where one determinant may exacerbate the effect of another determinant. The study also showed that the WHOQOL-HIV instrument is valid and reliable in measuring the quality of life of PLWH in the province. The observed poor to no associations between the health related quality of life indicators and the biomedical makers show that they cannot be direct proxies of each other. Finally, the study discourages any further shortening of

the WHOQOL-HIV instrument on the basis that HIV-infected people are not a homogenous group as their bio-psychosocial needs vary with time and their position along the trajectory of the disease.

DEDICATION

I wish to humbly dedicate this project to the Almighty God whose bountiful and unmerited favours saw me through this research project and the degree programme.

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ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
ART or	Antiretroviral treatment
ARV	Antiretroviral treatment
DOH	Department of Health
FGD or FGDs	Focus group discussions
HIV	Human immuno virus
HREC	Health Research Ethics Committee
HRQOL	Health related quality of life
HSRC	Human Sciences Research Council
MOS	Medical outcome study
NDOH	National Department of Health
PLWH	People living with HIV
PLWH	People living with HIV/AIDS
QOL	Quality of life
RDP	Reconstruction and development plan
SD or s.d.	Standard deviation
SF-36	Short form 36
SRPB	Spirituality/Religion/Personal Beliefs
STATSA	Statistics South Africa
WHO	World Health Organisation

CHAPTER ONE

INTRODUCTION

1.1 Background

1.1.1 HIV and AIDS epidemic in South Africa

South Africa faces a mature and generalized HIV and AIDS epidemic which has also been described as one of the worst AIDS epidemics in the world (UNAIDS, 2006). It was estimated that 5.5 million South Africans were living with HIV in 2005 while about 320,000 people died of AIDS-related illnesses in South Africa in 2005 alone. AIDS related mortality in South Africa however dropped to about 250,000 in 2008 (STATSA, 2009). In 2009, about 5.7 million people were living with the virus in South Africa (UNAIDS, 2010). These figures suggest a rising prevalence of HIV infection and decreasing AIDS related deaths. HIV prevalence in the country also varies with age and sex with higher prevalence noted among females and people in the childbearing age group. For instance, about 15% of persons aged between 15 and 49 are known to be HIV positive and approximately one-in-three females aged between 25 and 29 are HIV infected (HSRC, 2009).

In response to the HIV epidemic, the South African government has instituted various policies and programmes to halt and begin to reverse the epidemic. One of the key HIV response document in the country is the Operational Plan for Comprehensive Care and Treatment (DOH, 2003).

The Operational Plan for Comprehensive Care and Treatment was launched in 2003. The plan hopes to:

- ensure that the majority of South Africans who are currently not infected with HIV remain uninfected, through effective interventions to change lifestyles and behaviour and through programmes that reduce poverty and inequity;
- increase efforts to provide prophylaxis and treatment of opportunistic infections, improved nutrition and lifestyle options; and

- promote the effective management of those HIV infected individuals who have developed AIDS-defining illnesses, through appropriate treatment of AIDS-related conditions (including using antiretroviral therapy to prolong life), and providing suitable palliative and terminal care.

To complement the operational plan, the HIV & AIDS and STI Strategic Plan for South Africa for 2007 to 2011 was introduced in 2006 (DOH, 2006). The strategic plan highlights the country's multi-sectoral response to the HIV/AIDS epidemic. The National Strategic Plan (NSP) hopes to provide clarity and guidance to all government departments and civil society on what needs to be done and how to build on the gains of various response initiatives. The NSP focuses on four key priority areas namely, prevention; treatment, care and support; human and legal rights; and research, monitoring and surveillance (DOH, 2006).

The above documents created the platform for the comprehensive implementation of South Africa's ART programme which is described as the largest in the world. It was estimated that 28 percent of HIV infected people were receiving ART at the end of 2007. This number has continued to increase with the accreditation and opening of more treatment sites in the country in an effort to meet the growing demand for ART.

When the ART programme was launched in South Africa in 2003, it was recommended that patients should be initiated to treatment when their CD4 cell count falls below 200 cells/µl. This recommendation was changed to 350 cells/µl in 2010 given the known benefits of early treatment initiation. This concession applies to pregnant women and people co-infected with tuberculosis and HIV. Despite this, late treatment initiation remains widespread due to health systems related and psychosocial barriers to accessing treatment, including stigma. The new policy on early treatment initiation, however, comes with economic costs to the country and more pressure on an over stretched health system (HSRC, 2009).

The combination of the array of the health and social services available through the policies and programmes is meant to prolong life and ameliorate the impact of HIV and AIDS. The gains of the policies and programmes can already be seen in improved survival of people living with HIV (PLWH) in South Africa. There is, however, very limited evidence to substantiate the extent to which the available services target the preferred health outcome of PLWH. Ditto et al (1996) explained that, in general, patients may wish to maintain a tolerable quality of life than go through the pain of seeking certain services. This assertion is worrying given the reported difficulties associated with seeking care and support services by PLWH in South Africa (Maluleke et al., 2006; UNAIDS, 2006). Other authors have raised concerns that modern medical practice, policies and guidelines do not adequately consider patients' health related needs, choices and the relative importance patients place on different health dimensions (Sherbourne et al., 1999; Owen 1998; Nease et al, 1995; Kleinman, 1981). These issues have a major bearing on the mental health of patients, which is a known determinant of health related quality of life (HRQOL) and utility of service (Wells et al., 1996; Fryback et al., 1993).

In the context of the above concerns, Coulter (2005) provided a model to help explore factors affecting care and support services. This model interrogates specific patient experiences with elements of care and support, such as access to services, effectiveness of treatment, patient and family involvement in care activities, comprehension of information, attention to physical and environmental needs and continuum of care. These points underscore the need for a comprehensive exploration of similar circumstances within the framework of the South African HIV and AIDS response paradigm and in its socio-cultural milieu.

1.1.2 Linking biological markers of HIV and AIDS with measures of quality of Life

Against the above considerations, surrogate measures such as the CD4 count and viral burden have remained the major markers of disease progression and wellbeing of PLWH. Such clinical indicators have also been deemed to provide an incomplete view of disease impact (Katz et al., 2004; Blaiss et al., 1997). To bridge this gap, HRQOL measures are increasingly being incorporated in the traditional clinical measures of health. This shift is aimed at providing a greater depth of information on the impact of the disease on the physical, social and emotional wellbeing of individuals (Katz et al., 2004). This kind of information is essential to ensure a higher efficiency, responsiveness and precision of the delivery of care and support services such as counselling, treatment of opportunistic infections, nutritional interventions, the provision of disability grants and anti-retroviral therapy (ARV). These services are the key components of South Africa's comprehensive HIV and AIDS care plan (DOH, 2003).

The value of HRQOL measurement in HIV and AIDS management is again heightened by the improved survival of PLWH and the need to measure their quality of survival and support requirements. There are various instruments and methods of measuring HRQOL and these include the standard gamble (SG); visual analogue scale (VAS); medical outcome study (MOS); health utility index (HUI); EuroQol and the quality of well-being scale (Rashidi et al, 2006; Wu et al, 1998). These instruments were developed in recognition of the importance of patient reported information such as experiences with seeking care, long term health outcomes as well as the effectiveness and efficiency of health care interventions (Horsman et al, 2003; Revicki, et al, 1998). The usefulness of HRQOL instruments is, however, predicated on the extent to which they have been standardized together with their level of reliability and validity (Schwartz et al, 1999). On the basis of this requirement, the World Health Organisation developed a HRQOL instrument for PLWH (WHOQOL-HIV) (WHO, 2004). The WHOQOL-HIV is made up of 120 questions, and 30 questions in its long and brief versions respectively and these are divided into six domains, namely: physical, psychological, level of dependence, social relationships, environment and spirituality. The long length of the WHOQOL-HIV questionnaire may prohibit its use in the routine health services in South Africa given the large number of PLWH, their vast social and health care needs and the limited number of health workers.

The WHOQOL-HIV has been validated across different cultures and settings around the world (WHOQOL-HIV Group, 2004). The cross-cultural validation of the instrument is in view of the widely reported cultural variations and limitations of HRQOL instruments (Collinge et al, 2002; de Haes and Olschewski, 1998; Vanhem et al, 1996). This concern is underscored by the definition of HRQOL as “an individual’s perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”. With this, the value of validating the WHOQOL-HIV becomes critical in South Africa given its multicultural composition. The only known use of the WHOQOL-HIV in South Africa was in IsiXhosa Language in the Eastern Cape Province (Peltzer and Phaswana-Mafuya, 2008; Friend-du Preez and Peltzer; 2009). The later study showed that the tool had moderate to low reliability in some domains. On the converse, a pilot study of the tool in Zambia found the tool to be highly reliable (Mweemba *et al*., 2011).

Furthermore, quality of life studies in HIV have mostly been cross-sectional in nature and focused mainly on issues such as functioning, adherence to treatment and perceptions about HRQOL (Louwagie et al., 2007; Hughes et al., 2004; Nicholas et al., 2004; O’Keefe and Wood., 1996; Phaladze et al., 1996). The use of cross-sectional designs contradicts the argument that authenticating the relationship between clinical measure of HIV and AIDS and HRQOL would require concurrent repeated measurements of the variables (Weinfurt et al, 1999). This assertion should also be read against the backdrop that the bio-psychosocial effects of HIV vary over time (Gurunathan et al., 2009; Murdaugh., 1998). The available literature in South Africa mostly used the EuroQol, visual analogue scale (VAS) and medical outcome study (MOS) instruments in their measurement of HRQOL among PLWH at one point in time. These instruments are generic and have their limitations in measuring HRQOL in specific situations such as HIV and AIDS (Rutishauser, 1998; McSweeny and Creer, 1995; Guyatt et al, 1993). Among the limitations of generic tools are their inability to measure change following defined interventions over time and their failure to capture specific disease related parameters.

1.2 Problem statements and research opportunities

There is no record of a qualitative identification of quality of life determinants as well as the health and social support needs and constraints of PLWH in the context of the country’s HIV/AIDS response programmes. This gap does not allow for a proper understanding of the scope and effect of the known quantitative determinants of quality of life and the responsiveness of the existing programmes. Such information is also needed to validate the application of existing HRQOL instruments in South Africa and suggests the need for a new or revised quantitative instrument. The study background also highlighted the usefulness of the WHOQOL-HIV questionnaire. There is, however, no record of its validation across South Africa's multicultural societies. Without this information, it becomes difficult to establish if the questionnaire can be used in South Africa given its unique HIV/AIDS response programmes, cultural diversity and state of its AIDS epidemic. In the same context, very few studies have tried to link biomedical markers of the HIV and AIDS disease progression and HRQOL in developing counties in comparison to the number of such studies conducted in developed countries where the health and social support systems are well established. In this regard, the available body of knowledge about the link between both markers may not be applicable to developing countries. In addition, the long length of the existing WHOQOL-HIV questionnaire does not permit its use in routine patient care. Given that the biomedical and HRQOL markers of HIV infected people also vary over time, there is also a limited record of studies that have examined how both measures change or interact over time. The WHOQOL-HIV instrument has never been tested over time among PLWH to assess its stability and applicability through the bio-psychosocial trajectory of HIV/AIDS.

1.3 General Objective

The general objective of this study was firstly to identify factors influencing the HRQOL of PLWH and their experiences with seeking care and support services and, secondly, to validate the ability of the WHOQOL-HIV instrument in measuring HRQOL of PLWH among the three cultural groups in Limpopo Province.

The specific objectives of this study were grouped into Study I and II:

1.3.1 Study I specific objectives

Study I specific objectives were further divided into Parts A and B

Part A: Identification of factors influencing the HRQOL of PLWH and their experiences with care and support services

. The objectives of study I, Part A were to:

1. explore the HRQOL, health care needs, constraints and experiences with HIV and AIDS care and support services;
2. explore cultural definitions and quantifications of HRQOL; and
3. code participants' report into items and categories to constitute the psychometric instruments for HRQOL and experience with HIV and AIDS care and support services.

Part B: Piloting of items identified in Part A in the development of psychometric instruments for HRQOL and experiences with care and support services. According to Petersen et al., (2005), the aim of the piloting of a newly identified psychometric test included to:

1. determine the nature of scaling;
2. determine the ease or difficulty with which questions are answered;
3. analyze the scale structure with exploratory confirmatory factor and Rasch analyses; and
4. choose the most relevant items for a field test version of the instruments.

1.3.2 Study II specific objectives

The objectives Study II were to:

1. describe the health related quality of life of people living with HIV and AIDS in Limpopo Province;
2. establish the relationship between changes in CD4 count, viral burden and HRQOL over time;
3. Validate the index instruments for HRQOL developed in study I Part B;
4. validate the WHOQOL-HIV in the predominantly spoken local languages in Limpopo province which are, Northern Sotho, Tshivenda and Xitsonga; and

5. develop a shorter version of the WHOQOL-HIV that adequately replicates the domains of the long versions of the WHOQOL-HIV through item removal techniques.

1.4 Significance of the study

The significance of this study is that it seeks to develop a comprehensive and responsive health assessment instrument based on the opinions and perceptions of PLWH in South Africa. This effort will help articulate the intricate health care needs, choices and constraints of PLWH within the South African HIV and AIDS response paradigms. This effort is important, given the value of patient reported information in ensuring the quality, effectiveness and efficiency of care delivery (Horsman et al, 2003; Revicki, et al, 1998).

This study's plan to develop a shorter version of the WHOQOL-HIV is geared towards the promotion of efficiency in its use in routine health surveys and screening activities. The shorter WHOQOL-HIV will augment the current dependence on CD4 count as the eligibility criterion for disability grants in South Africa. In this regard, the shorter WHOQOL-HIV may serve as a measure of function, the ability to withstand accessing care and support services or earn a livelihood in the absence of a government grant. Such an alternative or complementary measure is important as there are suggestions that South Africa's reliance on CD4 count as the eligibility criterion for disability grants could be discouraging adherence to treatment among PLWHA and may not be a true reflection of the ability of these individuals to support themselves (Nattrass, 2006).

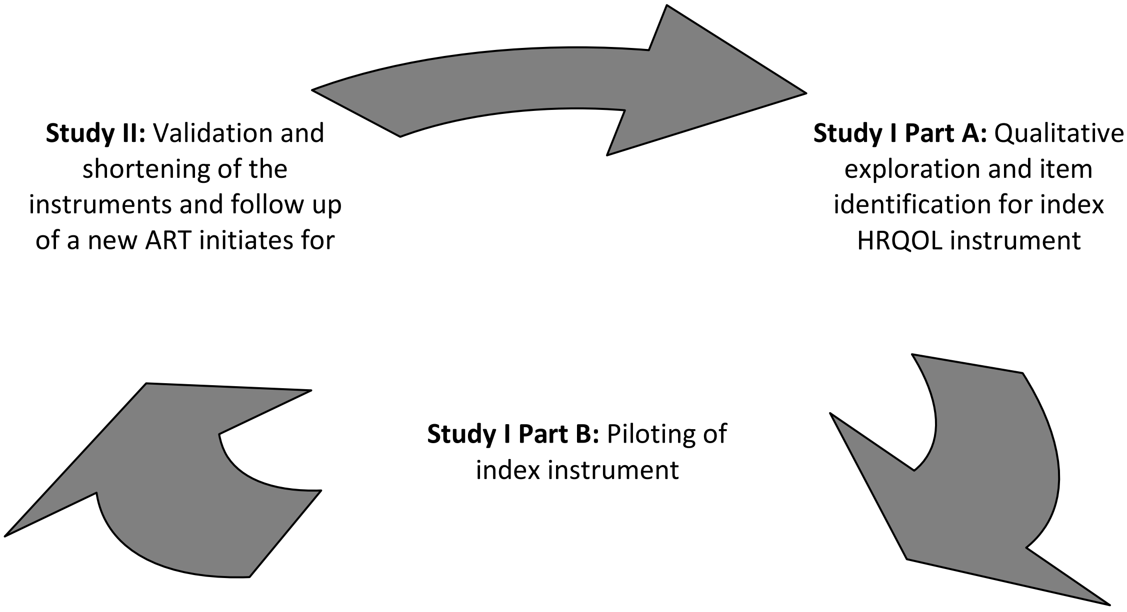
In all, the instrument to be developed in this study could be used in routine patient care to accurately measure relevant parameters of care and hopefully help to improve the quality of care "through the eyes of the patients" and perhaps help ensure a more tolerable HRQOL and optimum CD4 counts and viral burden among PLWHA.

1.5 Study outline

Given the background and objectives, this study was divided into Study I and II. Study I was a qualitative exploration of HRQOL, access to services, health care needs and constraints of PLWHA and the development and texting of psychometric instruments to measure the variables. Study I was also in two parts: Part A involved item generation while Part B was designed to focus on piloting the items generated. Study II was a follow-up of a cohort of PLWHA that has been newly commenced on ARV treatment to describe, validate and shorten the WHOQOL-HIV and measure changes in CD4 counts, viral load and HRQOL over time

Study II followed up PLWHA from the point of treatment initiation through a period of twelve months. This effort was to help gain a better understanding of their health care needs, constraints and how the HRQOL and biomedical markers of HIV and AIDS disease progression of the study cohort changed over time. The decision to follow the study cohort over a period of twelve months was based on experiences from previous studies that have reported changes in CD4 count and viral load within an average of twelve months following the initiation of treatment (Schiffer et al., 2004; Weinfurt et al., 2000). The main components and stages of this research project are illustrated by Figure 1.1 below

Figure 1.1: Illustration of the different stages of the research project



Following the figure above, the contents of this report are structured into the following chapters:

- Chapter One contains the introduction, problem statements, objectives, significance and outcome;
- Chapter Two is the literature review focusing on the key components of the study;
- Chapter Three contains research methodology used in the study;
- Chapter Four presents the findings and discussions of Study I;
- Chapter Five details the findings and discussions of Study II; and
- Chapter Six provides the conclusions and recommendations of Study I and II

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter provides a literature overview of the key components of this study which are the biological and psychological trajectory of HIV and AIDS; the determinants of HIV disease progression; biological markers of HIV disease progression; antiretroviral treatment; the definitions of quality of life; effect of culture on the perceptions of health related quality of life; and the considerations for instrument development, selection and modification.

The decision to cover the above subjects is to provide relevant information on them given this study's focus on HIV and AIDS in South Africa with a view to better understand the trajectory of HIV disease progression from the point of treatment initiation over a 12 month period across three cultural groups. This is also linked to the fact that the quality of life will be measured together with how the study cohort's biological and psychological markers of disease progression may have changed from the point of treatment initiation. This chapter also covers the considerations for instrument selection and development given its intention to compare quality of life measuring instruments and explore the possibility of removing some of the items in the instruments to ensure their better efficiency.

2.2 Biological trajectory of HIV infection

AIDS is a syndrome caused by the human immunodeficiency virus. This syndrome is marked by a continuous reduction of the CD4 T-lymphocytes. The resulting depletion is followed by a commensurate reduction of the individual's immuno-competence and increased susceptibility to infections. Various research efforts have tried to understand the natural history of HIV infection, a collection of such studies was presented in a desk review by Gurunathan et al., (2009). The clinical trajectory of HIV infection has been divided into three phases, including the acute phase, the chronic/clinically latent phase and AIDS in the absence of treatment.

2.2.1 The Acute Phase

The manifestations of the acute stage or primary infection will vary from asymptomatic seroconversion to severe illness. The symptoms of this phase include viral infections, fever, lymphadenopathy, headache, generalized body pain and weakness, anorexia, rash and diarrhoea (Grossman et al., 2006; Hel et al., 2006; Picker 2006). During this stage, the infected person also experiences high titres of plasma vireamia resulting from the HIV infection. Viral replication and dissemination is high and widespread at this stage (Pilcher et al., 2004; Stafford et al., 2000; Little et al., 1999; Kaufmann et al., 1998). The viral load in the acute stage can range from 100,000 to 10,000,000 copies/ml. The noted increase in viral load is sharp during the second to the fourth week post-exposure to the infection. The increase declines and stabilizes in four to six months after the infection. The stabilization of viral replication and dissemination will mark the beginning of the latent phase. The acute phase also experiences transient decrease in the CD4 cells with small increase in viral load which may allow opportunistic infections to begin to develop (Vento, 1993).

2.2.2 The Chronic Phase

The chronic phase is mainly characterized by the absence of symptoms. In the absence of treatment, this phase has been noted to have a median duration of about 10 years before progressing to AIDS in young adults (Gupta et al., 2007; Djomand et al, 2006; Gray et al., 2005; Grobler et al., 2004). This duration may range from six months to 28 years. The viral load in this phase can also range from undetectable to several thousands and varies from person to person (Lyles et al., 2000). Another study showed a 0.15% increase in viral load per week (Schacker et al., 1998). The reported viral load among HIV infected individuals in this phase has been noted to be lower in developing countries when compared to the figures from developed countries (Gray et al., 2005). The variations have been further attributed to set-point definitions in techniques used for viral load determination, virus subtypes, as well as other intrinsic factors (Gurunathan et al., 2009).This phase sees a progressive weakening of the immune system following the gradual depletion of the CD4 cells. HIV infected people in the stage have also been shown to have a CD4 cell count that is below the mean CD4 cell count of sero-negative individuals (Moss et al., 1988).

2.2.3 The AIDS Phase

In the absence of treatment, the clinically latent phase will progress to AIDS (CDC 1987, 1993). At this stage, the CD4 cell count is often <200 cells /µl. This is followed by an increase in viral load and AIDS by two to five years. This progression has been altered by the introduction of antiretroviral treatment (ART). The initiation of ART has been based on a prognosis of disease free survival determined by the CD4 cell count. Other considerations for ART initiation are viral burden, treatment readiness, possible risks and benefits of starting treatment for asymptomatic people (including short and long term side effects), availability of psychosocial and treatment adherence support (Phillips, 2004; Egger et al, 2002). ART drastically reduces viral load to very low or undetectable levels to allow for immune reconstruction and recovery.

2.3 Determinants of HIV disease progression

The progression of HIV to AIDS is driven by various factors most of which have been grouped under host and viral factors. The host factors include things like age at infection, gender, ethnicity, mode of acquisition, and genetic factors. Age at infection determines whether a person gets infected through blood transfusion, blood products or sexual intercourse (Gurunathan et al., 2007; Morgan et al., 2002; Hessol et al., 1994). For instance, perinatally infected infants will progress either early or late. Early progression involves a median progression to AIDS at four months while the late progression has a median onset of AIDS in 6 years (Berk et al., 2005; Faye et al., 2004). Age also plays a key role considering the function of the thymus in the reconstitution of CD4 cells that are depleted by the infection (Haynes et al., 2000; Douek et al., 1998). A 25 year old with a CD4 cell count of less than 200/µl has about a thirty percent chance of progressing to AIDS when compared to a person aged 55 years old. In addition, older people are more likely to have a lower CD4 count at similar times from seroconversion (Geskus et al., 2005; Touloumi et al., 1998). The age differences are, however, minimized by the introduction of ART (Geskus et al., 2005; CASCADE collaboration, 2003).

The mean HIV-RNA has been noted to differ between males and females at a given CD4 strata (Touloumi et al., 2004; Sterling et al., 2001[1]; Anastos, 2000). For instance, a low CD4 cell count in females is associated with higher mean HIV-RNA when compared to males with similar CD4 cell counts. In the same way, it was added that females have higher viral load if their CD4 cell count was <50 cells/µl and lower viral load if their CD4 cell count was >350 cells/µl when compared to males (Donnelly et al., 2005). Despite the variations by sex, studies have not been able to show differences in the rate of disease progression at a given CD4 cell count (Donnelly et al., 2005; Sterling et al, 2001[2]).

In terms of ethnicity, the rate of progression has been noted to be shorter in Haiti when compared to Thailand (Rangsin et al., 2004; Deschamps et al., 2000). These differences have been attributed to host immunogenetics, co-infections, viral and environmental factors. Other factors like poor satisfaction with health services, low psychosocial support, stressful life events, depression and denial based coping strategies have all been associated with poor treatment outcomes (Ironson et al., 2005; Ashton et al., 2005). Studies have also linked poor adherence with singleness, depression and homelessness (Parruti et al., 2006; Anastos et al., 2005).

There is growing evidence of the role of genes in HIV disease progression. Currently, there is an increasing list of AIDS restricting genes (ARGs). Some of these genes affect a person's susceptibility to HIV infection, rate of progression from HIV to AIDS and pathogenesity at different stages of the disease (Hutcheson et al., 2008). People with two copies of CCR5-Δ32 allele are highly resistant to HIV -1 infection while a copy of the same gene provides minimal resistance (Liu et al., 1996; Dean et al., 1996; Huang et al., 1996). People with mutated copies of CCR2 have demonstrated a slow progression to AIDS (Smith et al., 1997). Similarly, individuals with copies of CCR5-Δ32 and CCR2-Δ641 alleles have low risk of progression to AIDS (Ioannidis et al., 2001).

While the HLA-B*27 and *57 have been linked to low viral load and good prognosis, HLA-B*35 have been associated with rapid progression to AIDS (Gao et al., 2005; Carrington and O'Brien, 2003; Tang et al., 2002).

With regards to the virus, differences in its biological properties such as its replication rate, syncytium-inducing (SI) capacity and cytotrophism contribute to its infectivity and progression to AIDS in infected people (Tersmette et al., 1989). SI isolates have been observed among individuals who have progressed rapidly to AIDS. In the same way, subtype D has been found to cause a faster progression to AIDS when compared to subtype A (Kaleebu et al., 2002; Kaleebu et al., 2001). Another study in Thailand has shown a faster progression from HIV infection to AIDS or death with HIV-1 subtype E (Todd et al., 2007; Rangsin et al., 2004; Costello et al., 2004).

2.4 Markers of HIV disease progression

Different indicators of HIV disease progression have been suggested. The various factors can be grouped as clinical or biological markers. Multiple research studies have demonstrated the link between the severity and duration of illness in the acute phase with the rate of HIV progression to AIDS (Lavreys et al., 2006; Pedersen et al., 1989). In this regard, it has been shown that the speed of HIV progression to AIDS is higher among people with symptom duration greater than 14 days when compared to those who have a mild illness or who are free of symptoms (Henrard et al., 1995).

Similarly, the progression of HIV infection to AIDS can be shown by changes in biological markers like CD4 cells, viral load, combination of viral load and CD4 count, HIV-1 proviral DNA levels and generalized immune activation. Low CD4 count remains the first and most popularly used biological marker of HIV progression to AIDS (Giorgi et al., 2002; Anastos et al., 1999). CD4 cell count percentages are known to correlate with AIDS defining conditions (Mellors et al., 1997). CD4 cell counts are hence recommended for case definition of AIDS and criterion for decision-making for HIV treatment. With this, newly HIV-infected people with low CD4 count at baseline are known to advance to AIDS in two to three years (Goujard et al., 2006; Rouzioux et al., 2005). Furthermore, the ability of CD4 count to predict HIV infection is also known to be poor in the early part of the infection. The mucosal tissues also experience CD4 cells count depletion three weeks after the HIV infection and this can be used as an early prognostic marker but will need early detection of infection and endoscopic biopsies from the colon mucosa (Brenchley et al., 2004; Mehandru et al., 2004; Veazey et al., 2004). In all, HIV-infected persons with a CD4 cell count of 350 – 500/µl have demonstrated a risk of less than or equal to 5% of progressing to AIDS and the risk is much greater when the CD4 cell count falls below 200/µl (CASCADE collaboration, 2004).

Furthermore, CD4 cell count has been effectively used to monitor the efficacy of treatment (Bartlett et al., 2005; Moore and Chaisson, 1999). CD4 values at six months after treatment initiation have been described as predictors of further viral suppression and immunological progression (Duncombe et al., 2005; Grabar et al., 2000). On the other hand, very low CD4 cell counts have been linked with virologic failure (Battegay et al., 2006). This finding emphasizes the benefits of early treatment initiation before a total depletion of the immune system response to therapy.

Viral load measurement through the quantification of HIV RNA was made possible through new laboratory technology. Among such technology are reverse transcriptase polymerase chain reaction (RT-PCR), branched DNA and the nucleic acid sequence-based assay (NASBA). These assays allow for the measurement of the HIV RNA circulating in the plasma. Changes in daily viral load are known to be very small to negligible at approximately $0.4\log_{10}$. However, the natural history of HIV infection has shown that peak viral load is reached within 30 days of exposure to HIV-infection (Little et al., 1999; Kaufman et al., 1998; Piatak et al., 1993). On the other hand, a viral load set point is reached within 4 to 6 months after HIV infection.

Best practice evidence is increasingly suggesting that the prognosis of HIV infected people is more accurate through the combination of CD4 cell count and viral load (Madec et al., 2005;

Buchacz et al., 2004). Despite this, the correlation between the viral load and progression to AIDS is weaker when the viral load is evaluated late in the course of the infection and in patients with low CD4 cell counts (Cozzi et al., 1998). In the combined use of both markers, the viral load indicates the extent of destruction of the immune systems while the CD4 cell count reflects the rate of immunodeficiency (Simon et al., 2006).

Peripheral blood mononuclear cells (PBMC) are also used to study the cell-associated reservoir among HIV infected people (Gibellini et al., 2008; Sarmati et al., 2005; Gougeon et al., 2001). Like the earlier methods discussed, the values of the PBMC has been effectively used to predict disease progression, absolute point for treatment initiation and success of ART. In this context, different studies have shown an association between HIV DNA loads and the risk of disease progression independent of CD4 cell counts and viral load (Katzenstein et al., 2002; Kostrikis et al., 2002). In all a combination of the CD4 cell count, viral load and HIV DNA values have been reported as the best measure of HIV disease progression (Peter and Sevall 2004).

HIV-1 infection causes significant increases in immune activation with resulting proliferation and turnover of CD4 cells and other markers of immune activation. Among asymptomatic persons a number of markers have also been noted and include: serum β2 microglobulin, serum and urine neopterin soluble CD8, soluble IL-2 receptor, interferon-α and serum levels of IgA (Ullum et al., 2000; Liu et al., 1997). Other markers like CD38 molecules per CD8 T lymphocytes are very useful markers in the later stage of the infection but may be equally useful during the early stage (Roussanov et al., 2007).

2.5 The psychosocial trajectory of the disease

Similar to the trend seen in the biological trajectory and markers of HIV and AIDS, there is growing evidence of such effect on the psychological domain of HIV infected people. This is evidenced by the observed changes in the psychological wellbeing of HIV infected persons (Murdaugh, 1998). Living with HIV/AIDS challenges the entire existence of the infected person. The absence of a cure and chronic nature of the disease through the support of antiretroviral therapy (ART) hence demand that the infected person will need to make adjustments in order to live effectively with the disease. Living with this condition is however, compounded by the sense of loss and social stigma associated with the disease (Cochran and May, 1991). The stress on family units and the complexities of interacting with the health system all add to the challenges of living with HIV/AIDS.

Furthermore, there is a growing understanding on adaptive responses to HIV and AIDS and their consequences. One such early studies was qualitative and naturalistic, identifying five themes: mastery over the disease, spiritual journey towards understanding, self acceptance, staying active and involved and positive thinking (Kendal et al., 1989). In another study on the uncertainties of living with HIV/AIDS, it was noted that uncertainty and its ramifications had greater impact on the quality of life of HIV infected people when compared to people with other chronic conditions (Weitz, 1989). The study by Nokes and Carver (1990) reported recurring themes like: thoughts about mortality surface and subside, relationships fluctuate and priorities change and shifting expectations lead to thoughts of spirituality. A phenomenological study on coping with HIV identified three processes: living with dying, fighting the sickness and getting worn out (McCain and Gramling, 1992).

Murdaugh (1998) describes the trajectory of events associated with optimally adjusting to the challenges of living with HIV/AIDS. In her writing, she describes the combination of events as “achieving a balance” and to include processes of constantly adjusting to the demands of the disease without letting the disease dominate one’s life. This process creates a sense of control, predictability in the face of the many changes and the disease progression patterns. This process involves the trajectory of psychosocial experiences with adjusting to the disease from the point of diagnosis to the respective stage of disease progression in relation to their quality of life. Through this, the adjustment process highlights factors that may positively or negatively alter the quality of life over the HIV-illness trajectory.

According to Murdaugh (1998), the process of achieving a balance occurs in four stages. She added that the process does not necessarily occur in one direction but that people move forth and back. With this, people move in and out of balance as a result of the disease and its emotional and physical consequences. The stages are disintegrating, renormalizing, coming to terms and creating meaning.

During the disintegration stage, the person is destabilized and out of balance following a HIV positive diagnosis. This stage is characterized by hopelessness, devastation, disappointment and preoccupation with the anticipation and fear of dying. Two key elements of this stage are mourning loss and finding relief. In this stage, people are purported to mourn the loss of future hopes and plans following HIV diagnosis and its potential effect on their health, well-being and survival. Despite this, people are also expected to get a sense of relief knowing that the fear of being HIV positive is true.

Following the above, it is expected that people gradually begin to move towards renormalizing as they begin to seek information about the disease. Social support was noted to be essential in this stage and that people begin to use the available information to consider how to live with the disease. Such support could come from friends, family, support groups of people living with HIV and health care workers. With these changes, the person begins to rebalance their activities to become as normal as possible. This stage is hence characterized by the individual's attempt to control the disease, reduce abnormality, involve in regular activities and maintain social networks (Murdaugh, 1998; Davis, 1963). Unlike the previous stage, this stage is hopeful about the future. The key elements of this stage are focusing on self, containing investment (or making short term goals), keeping up with activities and pacing to accommodate the disease.

The third stage or coming to terms results from repeated failed attempts to renormalize. The un-resolving realities of the disease progression force the individual to begin to appreciate and accept the manifestation of HIV/AIDS. The individual accepts that life cannot return to absolute normal with the experiences of fatigue, weight loss, treatment regimen demand and complex interaction with health systems. The key elements of this stage are “putting one’s house in order” and “changing priorities”. People may write their wills at this stage, make funeral arrangements, make plans for the future of their children and changing jobs to meet their new capabilities and health status.

In the fourth stage, individuals begin to create meaning in their life beyond HIV. People here begin to make the best of every moment and reach out to others. This stage is a reflection, the restoration of self-worth and purpose in life. Furthermore, persons at this stage begin to value good quality life against quantity.

The stages described above provide good information to guide the planning of a more responsive psychosocial intervention to deal with the mitigating manifestation of each stage proactively and potentially fast track HIV infected persons from the “disintegration” stage to the “creating meaning” stage.

2.6 Antiretroviral treatment

2.6.1 Timing ART initiation

Choosing when to initiate patients on ART requires clinicians to weigh the benefits of the treatment outcome against its risks like toxicity, resistance, drug interaction, costs and the inconvenience of lifelong treatment. The goal of treatment of ART is to restore and/or preserve immune function, decrease opportunistic infection and mortality. The motivation for using antiretroviral drugs is in their ability to suppress viral replication. Furthermore, a near-perfect adherence to ART is required for an optimal treatment outcome. On the other hand, the failure to attain the required level of adherence has been linked with aggravated immunosuppression, the development of drug resistant strains of HIV and the increased risk of viral transmission (Bangsberg et al.,2001; Paterson et al.,2000; Mannheimer et al., 2002; Howard et al, 2002; Walsh & Sherr 2002). Other benefits of adherence in AIDS treatment include that:

- there is a far higher likelihood of virologic failure among non-adherent patients when compared to adequately adherent patients (Igumbor et al., 2011; Mannheimer et al., 2002; Howard et al, 2002; Walsh & Sherr 2002; Paterson et al., 2000);
- suitable improvement in adherence will result in a reduction in the risk of progression to AIDS (Bangsberg, 2000; 2001);
- increase in adherence will result in increased CD4 count (Haubrich et al., 1999);
- non-adherence has been associated with increased frequency of hospitalisation and longer stay on hospital admission (Paterson et al., 2000);
- in the event of virologic failure, persistent use of antiretroviral drugs by optimally adherent patients may delay patients' progression to AIDS (Deeks et al., 2000);
- the odds of developing viral resistance increase with the level of non-adherence and this occurrence has the propensity to exhaust the treatment options of HIV-infected persons (Pach et al., 2003);
- .

Recent advances in ART have continued to provide treatment combinations that promote adherence, improve treatment potency, tolerance, more stable viral suppression and better safety with early treatment initiation. These gains have seen the reduction in the risks of ART but increased concerns about the risks of prolonged untreated viraemia (Thompson et al., 2010). It has been shown that unmanaged HIV proliferation and immune activation results in chronic inflammation and subsequently in end-stage organ damage and other co-morbidities that are not directly related to AIDS. This chain of events perpetuates chronic immune activation and potentially permanent immune damage associated with protracted immune depletion (Harrison et al., 2010; Bhaskaran et al., 2008; Lohse et al., 2007). With this, it has been found that mortality from non-AIDS related morbidities is higher when compared to the morbidities from AIDS related opportunistic diseases (Palella et al., 2010; Kitahata et al., 2009).

Consequently, many recent studies support early initiation of treatment (Levin, 2010; Johansson et al., 2010). It has for example, been demonstrated that initiating treatment at CD4 cell counts of 500/µl and from 350/µl to 500µl decreased mortality by 94% and 69% respectively (Kitahata et al., 2009; Hammer et al., 2008). The study also showed that the majority of the deaths resulted from non-AIDS defining conditions. These studies have also shown poor treatment outcome among patients who received treatment at CD4 cell counts of less than 350/µl. Some considerations for initiating treatment regardless of CD4 cell count are rapid decline in CD4 cell count and high HIV-1 RNA (Hammer et al., 2008). Old age is also a risk factor for rapid progression to AIDS and non-AIDS related deaths. Pregnant women should be treated at least by the second trimester and treatment continued after delivery (Bhaskaran et al., 2008; Ferry et al., 2009; Monforte et al., 2008).

2.6.2 Choice of initial treatment

The choice of treatment on which to initiate HIV-infected people has serious implications for future treatment options (Thompson et al., 2010). Best practice expects that the choice of initial treatment should be based on resistance testing results, predicted virologic efficacy, toxicity, tolerability, pill burden, dosing frequency, drug-drug interaction, comorbidity as well as patient and health practitioners' preference (Thompson et al., 2010). Other considerations are availability and affordability.

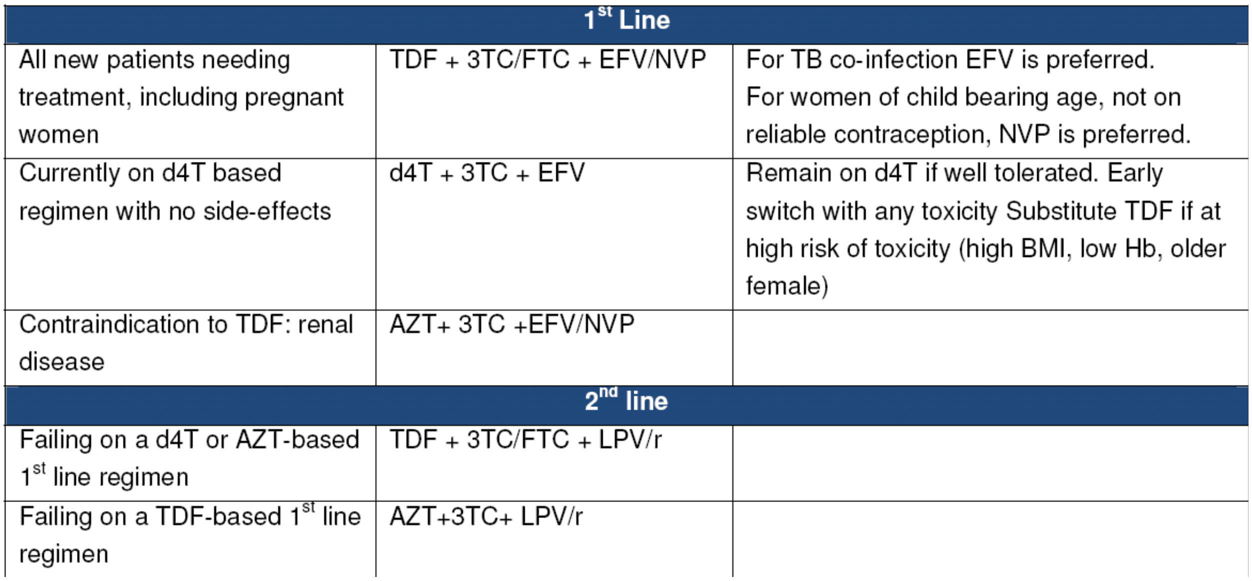
Nucleoside and nucleotide reverse transcriptase inhibitors (nRTI) like Tenofovir are active against HIV-1 and have long intercellular half life. The potency of the nRTI (like Tenofovir and Emtricitabine) is increased when a third agent is added. This combination better sustains viral suppression and CD4 cell count increases (Zimmermann, 2006). A combination of three or four nTRI is, however, not advised given its low virologic potency and high toxicity (Cooper, 2009; Hammer et al., 2008). Tenofovir is available in fixed-dose, once daily treatments with Emtricitabine and with Emtricitabine and Efavirenz. Tenofovir may, however, not be a safe option for people with renal dysfunction. Prolonged use of Abacavir has also been associated with myocardial infarction (Worm et al., 2010). Lamivudine and Emtricitabine are notably well tolerated in most of the above studies. On the other hand, Zidovudine as an initial treatment is restricted by concerns about its tolerance and risks for lipodystrophy and hyperlipdemia (Hammmer et al., 2008).

Many studies have shown very positive treatment outcomes of using nonnucloeside reverse transcriptase inhibitor (NNRTI) like Efavirenz as an initial regimen (Cassetti et al., 2008). Efavirenz is known to be a more effective antiretroviral drug than Ritonavir-boosted Lopinavir and similar to Atazanavir and Raltegravir (Daar et al., 2010; Sax et al., 2009; Lennox et al., 2009). Some of the side effects noted with Efavirenz are rash and central nervous system problems and are contraindicated during the first trimester of pregnancy and among women trying to conceive (Perinatal HIV Guideline Working Group, 2010). NNRTI has also been reported to have strong virologic potentials but has been linked with serious hepatic side effects within the first few weeks of treatment initiation (Hirsch et al., 2008).

Protease inhibitors like Atazanavir have been reported to have stronger virologic properties when they are boosted by two nRTI (Malan et al., 2008). Patients on Atazanavir have shown hyperbilirubinemia, sclera icterus or frank jaundice. On the other hand, boosted Lopinavir has lesser virologic abilities but has better CD4 count response and fewer resistant mutations than Efavirenz (von Wyl et al., 2007). Some side effects of boosted Lopinavir may include diarrhoea, insulin resistance and hyperlipidaemia and increased risk of cardiac problems (Lang et al., 2009).

In all, fixed dose combinations are better for convenience and to promote adherence to treatment with less pill burden. With this, it is recommended to use the Tenofovir and Emtricitabine in the initial therapy (A1a) (Thompson et al., 2010). If this combination cannot be used, Abacavir can be used with Lamivudine. A combination of Zidovudine and Lamivudine should be reserved for when Tenofovir and Abacavir cannot be used. Boosted Lopinavir are good alterative third-component choices and Nevirapine can be used as an initial pretreatment option in circumstances defined by CD4 cell count levels. Table 2.1 provides South Africa’s treatment guideline for adults and adolescents.

Table 2.1: Standardised national ART regimens for adults and adolescents in South Africa



1st Line		
All new patients needing treatment, including pregnant women	TDF + 3TC/FTC + EFV/NVP	For TB co-infection EFV is preferred. For women of child bearing age, not on reliable contraception, NVP is preferred.
Currently on d4T based regimen with no side-effects	d4T + 3TC + EFV	Remain on d4T if well tolerated. Early switch with any toxicity Substitute TDF if at high risk of toxicity (high BMI, low Hb, older female)
Contraindication to TDF: renal disease	AZT+ 3TC +EFV/NVP	
2nd line		
Failing on a d4T or AZT-based 1st line regimen	TDF + 3TC/FTC + LPV/r	
Failing on a TDF-based 1st line regimen	AZT+3TC+ LPV/r	

Source: DOH, 2010. *The South African Antiretroviral treatment guideline 2010*. Pretoria: DOH

2.6.3 Treatment monitoring

Effective treatment should bring about a reduction in branched DNA to less than 75 copies/µl or PCR to less than 50 copies/mL in less than six months after treatment initiation (Thompson et al., 2010). For timely detection of treatment failure, frequent monitoring of the biological markers is recommended during the first year of treatment (Gupta et al., 2009). The CD4 cell count should be monitored at three to four months intervals in the first year of treatment initiation particularly among people with CD4 cell counts of less than 200. This is to establish the patients’ need for continued opportunistic infection prophylaxis (Kaplan et al., 2009; Aberg et al., 2009). The monitoring interval can be increased to every six months if there is viral suppression and the CD4 cell count is over 350/µL. This change is on the basis that patients who maintain a stable viral load and increased CD4 cell count in one year are more likely to remain stable (Reekie et al., 2008). More monitoring may however be required for patients who may have changed treatment regimens (Reekie et al., 2010).

The drug toxicity monitoring is based on the known toxicity level of the particular drug and its underlying comorbidity. It has however been suggested that drug toxicity monitoring should be done between two and eight weeks after treatment initiation and six to 12 months after the patient has become stable (Aberg et al., 2009).

2.6.4 Treatment change

Treatment change is often warranted by virologic failure or adverse reactions. It is, however, encouraging to note that advances in ART almost guarantee viral suppression even in cases of multi-treatment failures but viral rebound remains equally common (Wittkop et al., 2009; Yazdanpanah et al., 2009; Steigbigel et al., 2008). Some causes of viral rebound include poor adherence, drug-drug interaction, concurrent infections and recent vaccinations. Given the transient nature of these causes, they need to be established before initiating an unnecessary treatment change. In making this decision, clinicians need to consider the stage of the disease, CD4 cell count, comorbidity, treatment history, current and previous drug resistance tests and concomitant medications (Thompson et al., 2010). Any change resulting from a full consideration of the above factors should include three or at least two fully active drugs from new classes. Stavudine and Didanosine should not be hastily included in the revised treatment given known higher level of toxicity. NNRTI failures are usually treated with combinations of two active nRTI and a PI. In the event of PI failure, sequencing of PIs can be used because of their varying tolerance and toxicity. If this is not feasible, a NNRTI may be included after considering the drug interactions of such combinations.

2.7 Definitions and Components of Quality of Life

The role of treatment is to bring about total healing or symptom alleviation and hopefully improve on the quality of life of ailing individuals. This may not always be the case as the meaning and definition of quality of life is complex and contentious. This assertion is largely due to the multidimensional views regarding its contributors and determinants (Tyrrell et al., 2005; Kimmel 2000; Ferrans and Power 1992). This position challenges efforts to quantify, compare and fully understand the concept of quality of life (Kring, 2008).

Despite the continued obscurity on global and precise definitions of the quality of life concept, efforts have continuously been made to describe it. Ferrans and Power (1992) have for instance, presented it as a concept that reflects an individual’s state of satisfaction and happiness. Kring (2008) adds that happiness and satisfaction are not direct synonyms but expressions of pleasure originating and manifesting at different psychosocial domains. Upon this premise, happiness was viewed to manifest as a fleeting unstable emotion while satisfaction is mostly a permanent feelings arising from a person’s core values and beliefs. Health professionals have taken note of both concepts given their key importance in measuring health care outcomes.

In the context of the above, a few more components have been added to the definition of quality of life in an effort to better contextualize the concept in terms of the health and well-being of an individual (Ferrans, 2005). The added components are psychosocial adjustment, physical functioning, symptoms, well-being and health status. An earlier literature review by Ferrans and Power (1985) added that the above components of quality of life are driven by factors like socioeconomic status, physical health, perceived stress, friendship, family, marriage, life goals, housing and neighborhood, city and nation, self esteem, depression, psychological defense mechanism and coping.

The added components all seek to provide better clarity to the definitions of quality of life with regards to health. This effort narrows the definition of quality of life on the basis that a person’s health is only a part of the sum of the person. This narrowed description led to the term “health related quality of life” to refer to the role of health, illness and health interventions on the quality of life of an individual (Ferrans, 2005; Philips, 2001). This may, however, be restrictive given the strong links and interplay of other attributes of the sum of an individual such as their political, cultural and social attributes (Kring, 2008).

The phrase "quality of life" and "health related quality of life" are often used interchangeably (Drayer et al., 2006; Morsch et al., 2006). Kring (2008) adds that the phrases are often used to describe (i) "a holistic global framework" or (ii) "a disease-based, deficit framework", respectively and that it is critical to specify which framework is implied in their use. This assertion was further illustrated by Wilson and Cleary's (1995) health related quality of life conceptual model focusing on the disease-based, deficit framework (Figure 2.1). This model concentrates on the physical aspects of the individual and the impact of health and disease on the quality of life.

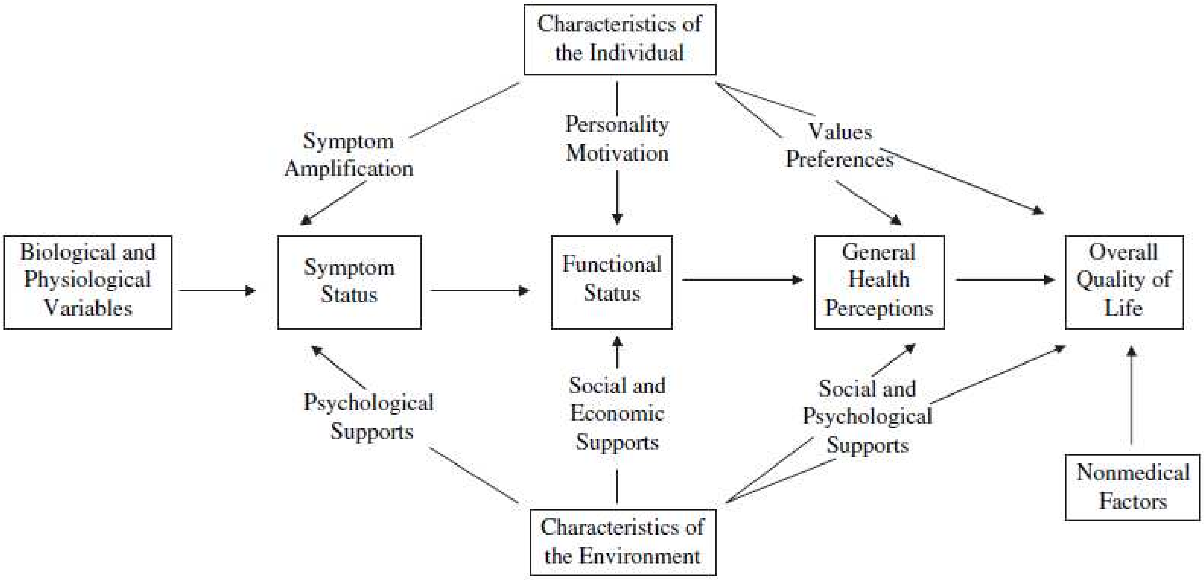


Figure 2.1: Interplay between the quality of life domains by Wilson and Cleary

Source: Wilson IB and Cleary PD (1995) Linking clinical variables with health-related quality of life: a conceptual model of patient outcomes. *Journal of American Medical Association,* 273:59 – 65.

The challenge with defining this concept is also reflected in the efforts to measure it. The various measures of health related quality of life have incorporated different measurement scales and domains (Guillemin et al., 1993). Over 160 different measure of quality of life were used in articles published in 1991 alone (Spiker et al., 1992). Despite these differences, the common domains that characterize QOL tools are the physical, psychological, spiritual, social, economic and family domains (Ferrans, 2007). In addition, each domain is often constituted and defined by its subscales (Ferrans, 2007). For instance, a physical domain may contain items assessing symptoms, functioning, adjustment or illness.

The interconnections between the various domains are illustrated by Wilson and Cleary's (1995) patient model linking the biological, physical, psychosocial and general wellbeing domains (Figure 2.1). The model also emphasizes that the domains are influenced by individual and environmental characteristics.

2.8 Effect of culture on the perceptions of health and health related quality of life

Quality of life measurement is known to vary across cultures given the differences in disease expression among cultural groups (Guillemin et al., 1993). This assertion stems from the fact that culture prescribes the way of life of a people partly with the aim of ensuring their survival and well-being (Spector, 2004; Kagawa-Singer, 2006). The ability of culture to perform these functions is routed in its strong beliefs and values that give meaning and purpose to the different aspects of life and existence. In the same context, culture defines behaviours as either "good" or "bad" and hence defines strategies that promote health and prevent diseases (Kagawa-Singer, 1995). These contributions of culture to health also tie in with the definitions of HRQOL as "an individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 1993). The above definition is clearly open-ended to allow for cultural variations in the definition of quality of life.

The above descriptions of culture and their implications for health should also be viewed against the backdrop that each culture has its distinguishing beliefs, values and practices (Kawage-Singer et al., 2010). Even when different cultures share certain attributes, such similarities may occur with varying graduation of differences. Eventually, the vast or subtle cultural differences result in variations in personal goals, expectations and concerns and hence differences in health practices and definitions of health, well-being and quality of life. This assertion is in agreement with schools of thought that have recognized that culture contributes to perceptions of health and illness, interpretation of symptoms, HRQOL and expectations of care (Berzon et al., 1995).

The four commonly cited domains of quality of life (including physical, mental/psychological, social and global perception of function and well-being) are mostly culturally defined (Kagawa-Singer et al., 2010). Furthermore, individuals’ HRQOL of life is formed as they strive to fulfill needs of (1) safety and security, (2) a sense of integrity and (3) a sense of belonging as an integral member of one’s socio-cultural network (Kagawa-Singer, 2002). Similarly, the Ashing-Giwa (2005) model of HRQOL has described culture as a macro component of HRQOL. It was further proposed that examining HRQOL across cultures will provide a better understanding of the constructs and its utility for specific groups.

The debates around culture and HRQOL question the validity of most instruments used for measuring instruments (Kagawa-Singer et al., 2010). Universally applicable or cross-culturally valid instruments can be developed through rigorous multi-culture testing of guiding assumptions. Studying cross-cultural differences and similarities is vital as it provides a better understanding of cross-cutting psychosocial problems and forms the basis for further examination of culture specific determinants of psychosocial well-being (Collings, 1994).

2.9 Considerations for instrument selection, development and modifications

There are many health related quality of life assessment questionnaires and with varying subscales and dimensions. This trend provides a variety of questionnaires to choose from but making the choice between questionnaires can be daunting for researchers and a wrong questionnaire can compromise an intended study or measurement. Pesudovs et al. (2007) have suggested a variety of considerations to guide the selection of an appropriate questionnaire, including the need to:

1. select an instrument that is suitable for the measurement objectives;

2. ensure that the instrument can be used for the target population i.e. the instrument was developed for a target population similar to the proposed study's target population;
3. ensure that the proper item selection and reduction techniques have been used; and
4. ensure that the instrument is sufficiently reliable and valid.

Different methods and statistical techniques have also been suggested to guide the efficiency of the above considerations, and such components and techniques are:

- Intended population characteristics,
- Actual content area,
- Item identification,
- Item selection,
- Unidimensionality, and
- Instrument validity and reliability (Pesudovs et al., 2007)

2.9.1 Intended population characteristics

Pesudovs et al., (2007) emphasize that the above criteria should facilitate a systematic review of instruments to identify those that are best suited for a defined research intention and target population. They stress that instruments are not universal and may not apply to all populations as some populations may have unique components that may be missing in the instrument. An example of this could be the poor performance of the visual impairment questionnaire among people with clinical glaucoma (Lamoureux et al., 2007). This instrument was originally designed to target people with low vision. Pesudovs et al., (2004) add that variations still exist within subsets of a population. This consideration calls for a careful inclusion of all subsets of the particular population in the design of an instrument to ensure its generalisability in the target population. For example, an instrument for measuring the quality of life in the different modes of correction of refractive error should take into consideration all the different items relevant to all forms of refractive correction (for instance, spectacles, contact lenses and corrective surgery) to better guarantee that the items in the questionnaire are relevant to all subsets in this population (Pesudovs et al., 2007). This consideration may also apply to HIV and AIDS. This is on the basis that an instrument specifically designed to measure the quality of life of treatment naïve people with AIDS may not be very helpful in measuring the quality of life of HIV infected persons who have successfully been on treatment for over 12 months.

2.9.2.1 Reliability

Reliability of an instrument is the degree of consistency or dependability with which an instrument measures the attribute it is designed to measure (Polit and Hungler, 1995). There are two main methods of measuring reliability: the inter- and intra- rater reliability methods. The inter-rater reliability is calculated by having two or more trained data collectors monitor the same event at the same time and independently scoring the same event using a predetermined coding system. The independent scores are then used to compute an index of equivalent or agreement. Correlation techniques are often used to compute such indexes that demonstrate the strength of the relationship between the rating of the observers (Polit and Hungler, 1995). Unlike the inter-rater reliability, the intra-rater reliability uses the repeated ratings of a single observer to measure the index of agreement or equivalence of the instrument of interest.

2.9.2.2 Validity

The validity of an instrument is important in the selection of questionnaires. The commonly used measures of validity are face, construct and content validity (Katzenellenbogen et al., 1997; Polit and Hungler, 1995). The face validity says that an instrument should appear to measure what it seeks to measure and this is simply done by inspecting the instruments. Face validity may be the weakest form of validity assessment but it establishes if the instrument makes logical sense and assesses the overall structure of the instrument, including the scales and wordings of the instrument (Katzenellenbogen et al., 1997; Polit and Hungler, 1995).

Construct validity is used to describe the extent to which an instrument measures what it intends to measure. Testing construct validity will require that an instrument or item should correlate with another instrument or item that has been validated and known to measure the construct of interest. There are different methods of construct validity testing such as concurrent, convergent, predictive and discriminant validities. These various forms of validity all contribute to the establishment of the construct validity of an instrument or item (Katzenellenbogen et al., 1997; Polit and Hungler, 1995).

Convergent validity is a form of validity testing involving the correlation of the index instrument or item with a standard measurement of the construct of interest. This method uses statistic tests like Pearson correlation coefficient for continuous variables, chi-square analysis for dichotomous data and Phi coefficient as a measure of correlation. In assessing convergent validity, a correlation of >0.9 may not be as good as it may suggest because of the fact that the instrument is so similar to the gold standard that it may not be providing more information. In this regard, a moderate correlation may be more useful than a high correlation. On the other hand, a low correlation may mean that the items or factors of interest may not be well correlated. Pesudovs et al. (2007) have suggested a cut off of 0.3 as the minimum correlation between two different items or latent factors measuring the same construct.

Discriminant validity is the extent to which an instrument differs from an instrument that measures a different construct. Unlike the convergent validity test, a low correlation coefficient will be desirable in discriminant validity testing (Katzenellenbogen et al., 1997; Polit and Hungler, 1995).

Predictive validity seeks to establish if the instrument can make future predictions with some degree of accuracy. For instance, a score on physical function can be used to predict the need for financial and social support. This is very important in the application of assessment instruments into therapeutic decision making. Basic correlation is also very important in establishing the predictive validity of an instrument. Dichotomous variables can rely on the chi-square tests and odd ratios in demonstrating the predictive power of an instrument (Katzenellenbogen et al., 1997; Polit and Hungler, 1995).

Concurrent validity is used to demonstrate an instrument's capacity to differentiate groups that it is theoretically designed to distinguish. This may involve distinguishing between individuals with or without a specific condition (Katzenellenbogen et al., 1997; Polit and Hungler, 1995).

2.9.3 Item identification

In the context of quality of life assessment, one can only say that quality of life has been measured if all the dimensions of quality of life have been covered. Construct under-representation is used to describe instances when an instrument fails to cover all the dimensions of the phenomenon of interest (Downing & Haladyna, 2004). While the inclusion of the same number of important items is important in an instrument, all the items included should also be relevant. A good instrument should therefore strive to balance these considerations. Item generation techniques are essential in ensuring that only relevant items are included in the questionnaire. The commonly used item generation techniques are the statements and opinions of the target population, from key informants and experts, and through the literature. Focus group discussions (FGD) are useful in eliciting the opinions at the individual and expert level. FGD's help to obtain responses common to a group of individuals and may be a more useful source of information than in-depth individual interviews (Krueger, 1994). For a more robust instrument, it is important to include the opinion of the patients and experts for better item inclusion. Studies have, for instance, shown that instruments developed by talking to clinicians tended to focus more on symptoms and problems (Garamendi et al., 2006). On the other hand, instruments developed from the patients' opinion mostly covered issues like convenience, cost, heath concerns and wellbeing (Pesudovs et al., 2004).

The next logical step after item generation will be a pilot of the items identified. The item generation results in collecting so many items of which some may be redundant and irrelevant. Piloting the questionnaire helps to remove poorly discriminating, invalid and unreliable items.

2.9.4 Item reduction

Item reduction is important in instrument development to improve item quality, measurement precision and targeting of items to persons (Pesudovs et al., 2007). Item reduction seeks to ensure the unidimensionality of instruments by grouping items into unique constructs. This allows the possible summation of related items into latent scores (Streiner et al., 2003; Tennant et al., 2004). The following mathematical tools are used for item reduction: Cronbach's alpha, factor analysis and Rasch analysis. These methods indicate the performance of items and guide the removal of items that do not fit. Descriptive statistics have also been applied in item reduction (Day et al., 2002; Jutai et al., 2003). The commonly used descriptive statistical methods are the extent of missing data and the normality of the items. These methods can be tested using histogram plots, Kolmogorov-Smirnov, Kurtosis and Skewness tests. The Cronbach alpha assesses the association between each item in each construct with every other item in the same construct. The Cronbach alpha runs from 0 to 1 and the higher the score the higher the internal consistency of the set of items. The Cronbach alpha is the same as the average correlation between the items in a scale or factor. In the context of this, a very high alpha (>0.9) may indicate redundancy. In this regard, the scale may be unidimensional but may have too many items representing the same measure. An ideal Cronbach alpha should be between >0.7 and <0.9 (Pesudvos et al., 2007). Low reliability has severe implications on the entire instrument as the instrument may not correlate with a gold standard instrument or may also have implications for the instrument's convergent and concurrent validity.

It is important to note that Cronbach alpha falls under one of the two categories of tests used to determine reliability. The two methods are essentially the single and multiple administration techniques. The Cronbach analysis falls under the single administration techniques based on the split half or internal consistency tests. The multiple administration involves the test-retest method. These methods rely on the Pearson product-moment correlation coefficient, and intra-class correlation coefficient (ICC; McDowell and Newell, 1878; Bravo and Potvin, 1991), Bland-Altman limits of agreement (Bland and Altman 1986; Bland and Altman 1991) or Kappa statistics. The ICC measures the ratio of the between-group variance to the total variance. The

Bland-Altman limit of agreement is the range of values over which 95% of the differences between the two measures should lie (Bland and Altman 1986; Bland and Altman 1991). The Bland-Altman test strength lies in its ability to use a wide range of data as well as its ability to detect and manage biases. The Kappa statistics is used when comparing categorical measurements. It seeks to demonstrate the level of agreement between two measures using the same nominal scale with corrections for likelihoods of chance. The Kappa weighted statistics has been designed for ordinal scale variables.

Factor analysis is another statistical tool used to explain variations within a group of items and to reduce similar items into factors or groups measuring a similar construct. Through this process, unidimensional constructs are identified (McDowell and Newwell, 1987). Factor analysis also allows for the rotation of items in order to identify more commonalities between items and more factors can be identified through this process. The factors proposed by exploratory factor analysis can only be justified by confirmatory factor analysis (Lamoureux et al., 2007). The reduction process can also be used to eliminate items that fail to fit if they contribute less than 0.40 to the variation of that factor or redundant if they contribute over 0.80.

The Rasch analysis is increasingly being used as an item reduction technique (Massof et al., 2007; Massof et al 2005a, Massof et al., 2005b; Stelmack et al., 2004). The Rasch analysis uses modeling and item fit statistics to better guide the identification of unidimensional items or factors (Massof, 2002). In the Rasch analysis, a p-value higher than 0.05 suggests a deviation from the model and indicates unidimensionality (Lamoureux et al., 2006). Furthermore, the infit and outfit statistic is used to identify which item contributed more to the latent score. Rasch analysis can also be used to assess the performance of a scale by iteratively removing items. Lastly, Rasch analysis can assess the item difficulty to person ability and this can be used to remove items from an instrument or factor to ensure the relevance and meaningfulness of the items retained. The application of Rasch analysis can therefore result in the selection of a minimum set of items most relevant to a construct or factor. Pesudovs et al. (2007) reiterate the benefits of item removal to include optimum instrument efficiency, shortening of time and reducing user/respondent's burden. Suggestions have been made by Linacre (2007) to guide item removal using Rasch analysis:

1. Infit mean square outside 0.7 to 1.30.
2. Outfit mean square outside 0.7 to 1.30.
3. Item which is furthest from the subject mean.
4. High proportion of missing data (>50%).
5. Ceiling effect – a high proportion of responses in item and response category (>50%).
6. Item with markedly different standard deviation of items scores to other items.
7. Items that do not demonstrate a normal distribution as identified using histogram plots and other tests of normality.

2.10 Questionnaires selected for this study

With the above considerations in mind, this study used the WHOQOL-HIV and the MOS-HIV questionnaires. This selection was made from the QOL-HIV instruments available like the AIDS health assessment questionnaire (Lubeck & Fries 1997), the HIV/AID-Targeted Quality of Life Instrument (HAT-QOL) (Holmes and Shea, 1997), the HIV-QL31 (Lepledge et al., 1997), the General Health Assessment (Lenderking et al., 1997) and the Multidimensional Quality of Life Questionnaire for HIV/AIDS (Smith et al., 1997). The major criticism with these instruments is that they were developed in developed countries and among whites, HIV positive homosexuals and a middle to high income group. They may therefore not be suitable for this study's target population (O'Connell, 2003).

The later set of instruments listed above all preceded the WHOQOL-HIV in terms of when they were developed. The inadequacies of each of the tools were also considered in the development of the WHOQOL-HIV instrument (O'Connell, 2003). The decision to use the WHOQOL-HIV was also in view of its growing global application, particularly across African populations. In this regard, the WHOQOL-HIV has been found to be valid and reliable by a study conducted in Zambia (Nweemba et al., 2011) while another study conducted in one of the

South African ethnic groups (Preez and Peltzer, 2009) had concerns about the reliability of some of its domains. Similarly, the MOS-HIV was chosen to validate the WHOQOL-HIV. The selection of MOS-HIV was based on the extensive validation and use of its generic version across cultural groups and the growing application of the HIV specific version among African populations (Babikako et al., 2010; Lara et al., 2006; Taffa et al., 2004; Wu, 1999).

The WHOQOL-HIV was developed out of the WHOQOL-100 following the same process (WHOQOL Group, 1995, 1996). It was based on an international collaboration involving 15 culturally diverse countries and 40 different languages. Qualitative methods were used for item selection and this led to the identification of 115 HIV/AIDS specific items. These items were added to the 100 items of the WHOQOL-100 and resulted in an initial instrument with 215 items. Further trial and testing of these tools saw the reduction of the 215 items into 120 and resulted in the WHOQOL-120 HIV. This instrument is further broken down into 29 facets and 6 domains (Appendix 2.1). The domains are physical, psychological, level of dependence, social relationships, environmental and spiritual/religion/personal beliefs. The initial multi-country and cross cultural trial of the questionnaire showed an excellent internal consistency with an alpha of 0.98. At domain level, the alpha ranged from 0.87 to 0.94.

The Medical Outcome Study HIV Health Survey (MOS-HIV) was mainly introduced to help test the validity of the WHOQOL-HIV. The MOS-HIV questions were selected from a pool of existing questions that have been extensively tested for use for the Medical Outcome Study (Wu, 1999). MOS-HIV has 35 questions assessing 10 main dimensions including key dimensions like physical function, social and role function, cognitive function, pain, mental health, energy, health distress, quality of life, overall heath and heath transition (Wu et al., 1991).

2.11 Conclusion

This literature review has among other things shown that HIV and AIDS prevalence in South Africa is on the increase but with a declining mortality rate as a result of the improved access to antiretroviral treatment and support. This trend, however, increases the burden of care on the health and social support systems. The literature review also showed that this challenge could be alleviated by addressing the socio-economic barriers to treatment, support and early treatment initiation. Such efforts will minimize the risk of early progression of HIV to AIDS, increase the chance of effective immune reconstruction and reduce the risk for virological failure and development of drug resistance. With this information, the available information on the determinants of disease progression is also important for treatment, care and support planning. This chapter showed variations in disease progression based on age, sex, mode of infection, genetic predispositions and the environment. The section of this chapter on biological markers of disease progression shows the efficacy of CD4 cell count and viral load in monitoring disease progression. The importance of using a standardized method of measuring the biological markers to ensure a more accurate comparison was also highlighted.

The review also showed the progressive effect of HIV and AIDS on the psychological wellbeing of the infected. The review described a process of "achieving a balance" that moves forth and back between four main stages including disintegration, re-normalizing, coming to terms and creating meaning. Similar to the biological trajectory, the psychological trajectory can be used to better plan the care, support and treatment of the infected. This information is also useful in understanding and tackling the mediating factors with a view to facilitate quick and effective immune reconstruction and recovery.

The importance of patients' perception and measurement of their level of recovery was underscored by this review. The measurement of such constructs presents many complexities given its broadness and constitutes the measures of health related quality of life. This complexity can however be addressed by developing more focused instruments to measure well defined constructs through a rigorous process of collecting the opinions of key stakeholders and the statistical evaluation and testing of the information collected.

In the context of this study, people with HIV infections are living longer with the virus due to better access to treatment and this shifts the focus of care to the quality of survival of these individuals. It becomes important to measure such constructs through a combination of biological and psychological markers as perceived by the participants. This assertion serves to guide the responsiveness of support intervention in the context of limited resources. Health related quality of life questionnaires will serve this purpose and need to be carefully selected to ensure that they meet the needs of the target population, are valid and reliable, efficient and easy to use. With this and the issues discussed in the review, this study's effort to remove items from the instruments used should consider the essential techniques required for item reduction and removal. This effort should also bear in mind that the very transient and evolving nature of HIV and AIDS disease may result in many sub-populations of people living with HIV and AIDS. In this regard, any item reduction or removal effort should generate an instrument that adequately covers the concerns of all the subsets of people living with HIV and AIDS in the different stages of the disease.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter is divided into two parts with each part covering the methodology of Study I and Study II respectively. The following subheadings are presented under each part: study design, target population, sampling and sampling procedure, instrumentation and data collection procedure, selection and training of data collectors, data analysis and ethical considerations.

The decision to divide this chapter into two parts is to allow for clarity given that Study I used a qualitative research approach while Study II used a quantitative research approach. The reason for separating the two studies is because they have different objectives and use different methods and designs in collecting information to answer the main objective of the combined study. Study I will involve a qualitative exploration of quality of life in the South African context and identify useful elements to develop a valid quality of life tool. Study II uses quantitative designs to validate and shorten quality of life tools and measure the change in health related quality of life and biomedical markers of HIV over time.

3.2 Part One: Study I: Identification of factors influencing the HRQOL of PLWH and their experiences with care and support services

3.2.1 Study design

Study I was a qualitative study based on grounded theory. The study used focus group discussions to elicit the definitions of health, the perceived factors contributing to the health related quality of life (HRQOL) and the general wellbeing of the study participants.

The inclusion of a qualitative research component to this study was driven by the intention to generate HRQOL items in the context of the determinants of the local HIV and AIDS epidemic and response paradigms and across the variations of cultural definitions of health and wellbeing. This effort draws on the qualitative method's intrinsic flexibility and iterative approach to item identification, verification and categorization (Caledron, 2000).

It was also envisaged that the inclusion of qualitative methods would help establish the extent to which conventional HRQOL assessment tools for people with HIV/AIDS cover the scope of HRQOL determinants and definitions as perceived by the different cultural groups in Limpopo Province. This effort is premised on the widely described differential values placed on health and health care by different socio-cultural groups (Chesney et al., 1982). The proponents of a combination of qualitative and quantitative methods emphasize quantitative methods' limitations to adequately incorporate cultural diversities (Giachello, 1996). The findings of qualitative methods thus become important in accepting, rejecting or modifying quantitative survey tools (Calderon et al., 2000). On the other hand, the subsequent and extensive use of quantitative methods in Study II serve to address common concerns relating to the over reliance and over interpretation of the findings of qualitative methods like their validity, generalisability and reliability (Mays and Pope, 2000).

3.2.2 Target populations

This study targeted people aged 18 years old and above, living with HIV/AIDS and receiving ART in public health facilities in the Limpopo Province. Limpopo is one of South Africa's nine (9) provinces; it is the northernmost province and borders Mozambique, Zimbabwe and Botswana from east to west. Limpopo is the fourth most populated province in South Africa with about 5.3 million inhabitants and constitutes approximately 12% of South Africa's total population (LPG, 2007). This population is distributed across Limpopo's five districts serviced by close to 4600 health facilities. The clinic person ratio was 1:10,707 in 2005 with 2.7 clinic visits per person in the same year. Limpopo has also been described as the poorest province in South Africa with most of its districts falling into the lowest quintile in South Africa (HST, 2007). Limpopo is also the third lowest province in terms of access to piped water at 83.6% coverage. Government is the major provider of health services in the province as close to 93% of people in the province did not have a medical aid scheme in 2007 (HST, 2007). About 19% of its antenatal care (ANC) attendees were estimated to be HIV positive in 2007 while about 10.9% of its entire population were estimated to be HIV positive in 2008 (HSRC, 2009).

3.2.3 Sampling

Three hospitals that met the study criteria were randomly selected from a list of hospitals in the area. Each participating hospital represented each of the three language groups in the province which are Sipedi, Xitsonga and Tshivenda. Public health facilities accredited to provide ARV were then clustered according to the predominant language group around their respective catchment areas. This led to three clusters representing the three predominant language groups in the province and a hospital was selected randomly from each cluster. To ensure better access to a sufficient number of study participants, only hospitals with a cumulative ARV enrolment of over 500 were included in the sample frame.

Following the selection of the study sites, a theoretical sampling method was used to select individual participants at the respective study sites. Theoretical sampling is a process that combines data collection, coding and analyses with the intention of suggesting the kind of data to collect and the target groups for subsequent interviews in an attempt to fully understand theories emerging from each completed interview (Glaser and Strauss 1967). Through this process, theoretical sampling also helps to identify data categories, their properties and interrelationships (Tavakol, 2006).

At this stage of the study, only ambulant people visiting the ARV Clinics within the designated study sites (hospitals) were targeted. Study I participants were HIV positive people on ART, people of the same language group (Sipedi, Xitsonga and Tshivenda) and who spoke and understood the local language. The groups were heterogeneous in terms of the participants' health status, duration on treatment and length of diagnosis of HIV status. The decision to assemble heterogeneous groups was in an effort to promote discussion and generate a broader range of HRQOL determinants across the various stages of HIV infection/AIDS (Wong, 2008). This consideration is also cognizant of the longitudinal nature of this study and hence the need to have a more inclusive scope of HRQOL items across the natural history of HIV infection, pattern of progression to AIDS or participants' response to ART.

Given the sensitive nature of the research topic, the focus groups were constituted by members of an existing HIV/AIDS support group in the three hospitals. An HIV/AIDS support group is a group of people living with HIV/AIDS who come together to help each other bear the challenges of living with HIV/AIDS by sharing experiences, knowledge and providing other kinds of support that are often non-professional and non-material. Support groups are built on trust, understanding and familiarity between members over time. These dynamics hopefully encourage honest and spontaneous discussions (Raibee, 2004). In line with the need for heterogeneous set of participants, each existing support group was continued by people of different ages, sex and treatment and health histories.

Each of the focus groups was constituted by 8 to 12 people. This size was to ensure a manageable group that has enough people to generate a wide range of opinions and perspectives (Kruger and Casey 2000). To encourage attendance, the list of each focus group participants was structured around the support group members' routine clinic visit dates, so that as they came in for their routine clinic visit they could participate in the focus group discussions if they were willing. The invitation to participate in the study was made by the support group leader and each person could only take part in one focus group discussion in the study.

The number of focus group discussions conducted was not predetermined; it was based on the emerging information, and continued until no new information was obtained with successive interviews. At this point, the data collection and analysis reached its saturation point and continuation was unnecessary (Tavakol et al., 2006).

3.2.4 Setting and conducting the discussions

The focus group discussions were conducted at the health facilities on the day that the participants came in for routine services. The discussions were held in adequately spaced rooms that provided for comfort, privacy, good ventilation and lighting. Light refreshments (of fruit juice and snacks) were provided before the start of the discussion because most of the participants may have already been at the health facility on that day for a long time. The discussions were facilitated by a moderator and a note taker. The participants and facilitators sat in a circle in an effort to create a friendly and non-threatening environment and to allow all participants and facilitators to see and hear one another clearly.

The roles of the facilitators in this study are as described by Wong (2008). The moderator was mandated to guide the discussion, ensure that the participants were engaged and prevent domination by some participants (Smithson 2000). In this study, the note taker documented the non-verbal expressions, the moods and other physical gestures. Before the discussion, the note taker also made a list of the participants, including their names, age, marital and employment status, duration on treatment CD4 counts and viral loads. During the interview, the note taker was also responsible for controlling the tape recorder.

Each focus group discussion began with a word of welcome by the moderator. This was followed by the introduction of the facilitators, the research study, the intentions and procedures for the focus group discussion including the ground rules, expectations, discussion, duration and ethical considerations. This was followed by the self introduction by the group participants. This activity helped the facilitators to know the participants and served as an 'ice breaker'.

Another key aspect of the preparatory phase was the explanation of the tape recording process and assigning identification numbers to participants as a way of ensuring confidentiality by masking their identity in the audio tape. This is because participants were expected to introduce themselves using the unique numbers allocated to them by the moderator before they contributed to the discussions.

3.2.5 Instrumentation and data collection

Given the intention to collect, code and analyze data, two instruments were used in this study. The first focus group discussions were prompted with questions on how the respective participants view their health and common health problems that they encounter (Petersen et al, 2005). The interview schedule covered the participants' ability to carry out activities of daily living, including eating and drinking, sleeping, breathing, elimination, movement, communication and relationships, sexuality, self care ability, endurance with daily work and household responsibilities. The frequency and severity of the concerns raised by the participants were further explored. Participants' obstacles to achieving optimum health and coping mechanisms were examined, including the effect of stigma and level of social support on participants' health and ability to seek help. Cultural definitions and quantification of participants' perceptions were also solicited.

The additional questions explored during the first focus group discussions were participants' experience with support services in terms of cost, time and distance. The services included the provision of counseling support and health education, treatment of opportunistic infections, nutritional support, disability grant and ART. The participants' perceived benefits and access to services were further explored and ranked. The follow up interviews focused on core themes that emerged from the first focus group discussions. This mostly covered the description, severity and frequency of occurrence of the themes identified during the first interviews.

3.2.6 Selection and training of facilitators

Individuals who were native users of the respective languages and fluent in English were recruited to participate in the study as facilitators. The facilitators had background training and knowledge in health and human research ethics; the conduct of one-on-one interviews and focus group discussions; soliciting case study information and HIV/AIDS counseling. Six facilitators were involved in the study. Teams of facilitators consisting of a moderator and a note taker were sent to each study site.

The three moderators were researchers working at academic institutions with a minimum of masters degrees in health related disciplines and with many years of experience in health care provision. The three note takers were honours degree holders in clinical psychology, HIV and

AIDS counsellors, masters of public health students and currently serving as research-assistants at a health research and training centre in Limpopo Province.

As part of the facilitators' training for this study, they were oriented to the objectives and salient components of the study. Mock focus group discussions were conducted to familiarise each of the teams with the instruments in the respective languages.

The deployment of the bilingual facilitators to the various sites is due to the fact that the researcher does not speak any of the local languages in Limpopo Province. It was also envisaged that the use of local facilitators /researchers would facilitate the referral of study participants to the available sources of psychological and social support in the area if the need arose during the data collection. In addition, the local facilitators were expected to have a better understanding of the cultural perspectives of the data collected. This knowledge was essential to ensure that the participants were protected during the data collection processes and for a better interpretation of the participants' opinions during the data analysis.

3.2.7 Data analysis

The grounded theory qualitative data analysis model was used at this stage of the study. 'Grounded theory is a qualitative inquiry method that looks systematically at qualitative data aiming at the generation of a theory that accounts for a pattern of behaviour that is relevant and problematic for those involved' (Glaser, 2005). Grounded theory uses a model of negotiation and renegotiation by means of follow up interviews to better understand human phenomena (Tavakol et al., 2006). Through this, grounded theory strives to explain key social processes that are grounded in empirical data (Hutchinson, 2001).

Against this background, this study's data were tape recorded, transcribed verbatim, translated into English and analyzed by following the steps recommended by grounded theory. The process started with re-reading the field notes and transcripts to fully understand their contents and contexts. This was followed by the coding of the data in an attempt to identify the concepts and constructs in the data.

The coding occurred at three levels (Tavakol et al., 2006). Level I coding sought to identify the substance of the data as described by the participants' own words or phrases. These are referred to as substantive codes or *in vivo* codes. The goal at this stage was to identify as many codes as possible. Level II coding involved the condensation or collapsing of similar level I codes into bigger categories (Hutchinson, 2001). This was followed by the level III coding involving the development of theoretical constructs that are high level interpretation of the level two codes (Glaser, 1978).

The above step concluded the analysis of the first set of interviews and suggested the kind of data that needed to be further collected for the purpose of saturating the data categories and identifying core variables. This effort draws on the function of core variables: in accounting for some of the variations in a pattern of behaviour; facilitating the integration of other categories in the data and generating the grounded theory (Hutchinson, 2001; Mullen & Reynolds, 1978). The conclusions reached about the categories and core variables were also based on the memos collected during the analysis. The use of memos was based on their function in "theorizing write up of ideas about codes and their relationship as they strike the analyst" (Glaser 1978). In other words, the memos helped to put data together up to a conceptual level, identify properties of each category and suggest hypotheses about linkages and interrelationships between categories (Glaser 1978).

The use of multiple data collectors and sites was a way to ensure the trustworthiness of the data and results. The study was conducted in multiple sites by different highly trained and competent FGD facilitators and this provided an opportunity for checking the credibility of the study findings. The use of grounded theory also allows for member checking of data collected through follow up interviews used in grounded theory. The data collected was also scrutinized independently by the four different researchers, including the student and the three supervisors at the time of the data collection.

3.2.8 Ethical considerations

Efforts were made to protect the rights and dignity of study participants, including their rights to confidentiality, anonymity, informed consent and the right to withdraw from the study. This information is in the information sheet and consent forms (Appendix 3.1). There was no invasive test on the participants as the biomedical information used in the study was obtained from medical records of routinely collected patient information. Permission was obtained from the Limpopo Provincial Department of Health and Social Development and designated hospital authorities. Ethical approval for the study was granted by the University of the Witwatersrand Human Research Ethics Committee (HREC). The study was executed in close consultation with support groups and organizations of PLWHA, mainly to ensure that study participants were duly protected. For easy understanding, the consent forms and information sheet was made available in English and the three predominantly spoken languages in the province (Sipedi, Xitsonga and Tshivenda) which are the focus of this study. Participants were requested to choose the language of preference for the consent forms and information sheets.

Informed consent forms were signed in duplicate; a copy was kept by the researchers while the second copy was kept by the respective participant. The invitation to participate in the study was made by the support group leader and only those willing to participate availed themselves to the study facilitators. This process was aimed at further ensuring participants' confidentiality and autonomy.

The participants' study records (such as audiotapes, transcripts and interview schedules) are being kept by the researcher for a minimum of six years following the study's completion. In line with the agreements with the participants as detailed in the consent forms, the records will be kept by the researcher in a safe, suitable, sizeable, durable and locked container. The records will be protected from any form of damage, unauthorized use, removal and disclosure of the information they contain (JISC InfoNet, 2007). At the end of the six years storage period, the record will be destroyed by the researcher in a manner that continues to protect the anonymity and dignity of the participants.

3.3 Part Two: Study II: Description, validation and shortening of the WHOQOL-HIV and measurement of changes in CD4 counts, viral load, HRQOL over time

3.3.1 Study design

A cohort study design was used in Study II. The study cohort was made up of treatment naïve HIV positive people who were being initiated to ART. The participants were recruited on their first day of treatment initiation and followed up over a twelve month period. There was no selection process used; instead all patients who were ready to commence treatment based on the treatment initiation criteria and who may have gone through the treatment readiness assessment and training processes were co-opted into the study.

In order to deal with challenges of cohort attrition, the study used the clinic based counsellors to follow up on the study cohort during their monthly visits for treatment collection. The clinic based counsellors came from community based organisations and with the consent of the patient could follow up on them through their community based treatment support networks or via telephone calls.

3.3.2 Target population

All persons aged 18 years and above and living with HIV and AIDS accessing care in public health facilities were targeted. The participants were HIV positive, treatment naïve persons and about to be initiated to ART. Such people will ideally have a CD4 cell count of < 200 cells/µl, presenting with symptoms attributable to or complicated by HIV infection and people being initiated to treatment for the first time. The target patient population is consistent with one of the categories of the Center for Disease Control and Prevention (CDC) Classification System for HIV-Infected Adults and Adolescents. The focus on one category of patients is to facilitate the selection of a highly homogenous population that will serve as a control for itself through repeated measurements of the study variables over time.

3.3.3 Sampling criteria and sample size

The study was located in the original study sites as described in Part A of Study I and participants were conveniently selected to participate in the study from the ARV and Wellness Clinics of the designated health facilities. The adoption of convenient sampling method in Study II is due to the absence of a sampling frame to be used for probability sampling methods. ARV clinics do not have a waiting list for treatment initiation. Patients are placed on treatment as soon as they meet the requirement for ARV treatment initiation.

An average of 150 participants were selected at baseline to participate from each of the sites. This resulted in at least 450 participants. It was anticipated that 12 items would be retained in the index instruments and the WHOQOL-HIV instrument. Between 5 and 10 participants are needed to demonstrate levels of variation per variable. This study will therefore require a maximum of 120 participants per language. This sampling approach is known as variable sampling and its total size is a function of the number of variables (Velicer and Fava, 1998; Marascuilo and Levin 1983). It is often used in factor analysis and item reduction; a minimum of 100 and a maximum of 200 participants is generally recommended when using this approach (Comrey, 1973; 1988). The decision to recruit about 450 participants was to cater for attrition and accrue statistically adequate numbers of participants to allow for site comparison. Follow-up through home and hospital visits helped to minimize participant attrition and loss to follow-up.

3.3.4 Instrumentation

The instruments used in this study were the WHOQOL-HIV (Appendixes 3.2) and MOS-HIV (Appendixes 3.3). The health and demographic data formed part of the instruments used in Study II (Appendix 3.4). The participants’ CD4 counts and viral load were also solicited in Study II. These clinical measures were collected from patients’ medical records from the routinely collected tests. Using these instruments, data was collected at three points over a period of 12 months. The baseline data was collected during treatment initiation. Subsequent follow up occurred at six and twelve months after the initiation of treatment for each study participant.

The instruments used in this study were all administered in the respective study's site's local language. With this, the instruments were forward and backward translated by a team of professional language speakers and health care workers. The translation instructions provided by the instrument developers were followed (Wouter and Marc, 2004). The translated instruments were then piloted in each language and further revised by the team as necessary.

3.3.5 Data analysis

The study data were managed using the Statistical Package for Social Sciences (SPSS) for windows. Basic descriptive analysis of the participants' socio-demographic and quality of life measures was done and compared across the three times of data collection (baseline, six and 12 months). This was followed by internal consistency assessment using Cronbach alpha to assess the reliability of the instruments. t-tests and analysis of variance were used to compare the average HRQOL subscale and domain scores between times, cultural groups, key demographic characteristics and the biological markers. The instrument's convergent validity was tested by comparing WHOQOL-HIV and the MOS-HIV instruments using Pearson's correlation coefficient and the Bland-Altman Limits of Agreement. The initial plan was to reduce the WHOQOL-HIV to two items per domain for each of the six domains to form the new shortened version. It was hoped that this process would help retain a minimum of 12 items from the long WHOQOL-HIV. The item selection was done using the item-total correlation coefficients and the Cronbach alpha if item was deleted. Finally, the number of factors in the respective domains was established through principal component analysis.

3.3.6 Ethical considerations

Efforts were made to protect the rights and dignity of study participants, including their rights to confidentiality, anonymity, informed consent and the right to withdraw from the study. This information is detailed in the information sheet and consent forms (Appendix 3.5). There was no invasive test on the participants as the biomedical information used in the study was obtained from medical records of routinely collected information in patient care. Permission was solicited from the Limpopo Provincial Department of Health and Social Development and designated hospital authorities (Appendix 3.6). Ethical approval for the study was obtained from the University of the Witwatersrand Human Research Ethics Committee (Appendix 3.7). The study was executed in close consultation with support groups and organizations of PLWHA, mainly to ensure that the study participants were duly protected. For easy understanding, the consent forms and information sheets were available in English and the three predominantly spoken languages in the province (Sipedi, Xitsonga and Tshivenda) which are the focus of this study. Participants were then requested to choose the language of preference for the consent forms and information sheets. Informed consents were signed in duplicate. A copy was kept by the researcher while the second copy was given to the respective participant. The consent was done at the three points of data collection i.e. before every interview conducted in this study. To avoid any intrusion or invasion of the privacy of the participants, the interviews were conducted by the clinic based lay counselors who already knew the study participants.

The participants' study records (such as the interview schedules) will be safely kept by the researcher for a minimum of six years following the study's completion. In line with the agreements with the participants as detailed in the information sheet and consent forms, the records will be kept under a safe, suitable, sizeable, durable and locked container which will be kept by the researcher. The records will be protected from any form of damage, unauthorized use, removal and disclosure of the information they contain (JISC InfoNet, 2007). At the end of the six years storage period, the record will be destroyed by the researcher in a manner that continues to protect the anonymity and dignity of the participants.

CHAPTER FOUR

FINDINGS AND DISCUSSION OF STUDY I: IDENTIFICATION OF FACTORS INFLUENCING THE HRQOL OF PLWH AND THEIR EXPERIENCES WITH CARE AND SUPPORT SERVICES

4.1 Introduction

This chapter presents the findings and discussion of the qualitative aspect of this report. The contents of this chapter are structured around the main specific objective of Study I which was to identify HRQOL items that can be used to develop an index HRQOL questionnaire. In this regard, the results and discussion are presented around the items and determinants of the HRQOL of PLWHA identified. The results section hence consists of the items identified and their respective literature justification. The result section also attempts to link the various items by highlighting the intervening and modifying factors identified by the study and the suggested effect of time and treatment on the HRQOL of PLWHA. Following the results, the discussion section brings the various items together and highlights the care and support implications of items as well as their implications for the survival and overall wellbeing of PLWHA. The discussion also presents the factors that impact on the items identified.

4.2 Results

A variety of factors were perceived to contribute to the health and wellbeing of the participants. Based on the participants’ remarks, these factors tended to impact on their ability to carry out routine activities of living and overall health related quality of life. It was also clear that while there was often consensus in the groups on the different factors, the perceived degree of effect of most of the factors varied. The observed variation is based on the fact that the groups were mostly heterogeneous based on the participants’ duration on treatment, age, sex, viral burden and length of diagnosis of a positive HIV status. The participants’ duration on treatment was often the determinant of concurrence or discordance among the group members. Such divisions suggested the alleviation to total absence of some factors with longer duration on treatment. This observation reemphasizes the importance of ART.

Fourteen core variables were identified and have been grouped into three main categories namely physical, mental and external factors (Table 4.1). The physical factors include the differential signs and symptoms of underlining pathological conditions and/or physiological imbalances. The mental factors are the different fears, anxieties, concerns and worries expressed by the participants as well as the manifestations of such fears and anxieties. The external factors are the environmental factors which are often beyond the control of the participants and influence their response to health, disease and illness. The 14 core variables identified by this study are similar to those identified by the WHO in the *WHOQOL-HIV: Users Manual* (2004) as well as the categories of the MOS SF-36 (Ware & Sherbourne, 1992). Similarly, another study conducted in South Africa reported similar core variables as key symptoms experienced by PLWHA on ART (Bhengu et al., 2009). Bhengu et al., (2009) also found a strong relationship between the intensity of the symptoms and the tolerance of routine activities of daily living. The identification of items was facilitated by open-ended questions that required the participants to rank the items based on their perceived severity and frequency of occurrence. This question also helped to identify the commonly cited items.

Table 4.1: Factors perceived to contribute to health and well being

Main category	**Factors and core variables**
Physical factors	1. Diarrhoea
	2. Pain
	3. Fatigue
	4. Cough and dyspnea
	5. Insomnia
Mental factors	6. Body image disturbance
	7. Fear
	8. Perceived psychological effect of AIDS on the family
	9. Disclosure of HIV status
	10. Level of psychological adjustment and acceptance of HIV status
	11. Anger
External factors	12. Stigma and discrimination
	13. Perceived attitude of health workers
	14. Social support structures and the needs of people living with HIV/AIDS

While the findings of this study confirm widely documented concerns of people living with HIV and AIDS, it further exposes perceived causes of the concerns, how the concerns influence their health related quality of life and the coping strategies adopted to alleviate the concerns. These additions supplement a body of knowledge that has been mostly informed by quantitative research (Bhengu et al., 2009; Rivero-Mendez et al., 2009; Makoae et al., 2005; Shawn et al., 2005; Holzemer et al. 2001). The findings are important in providing a better understanding and helping clinician and programme planners in improving the health related quality of life as defined by the participants. This assertion also draws on the new focus on the quality of survival of people living with HIV and AIDS as it moves from being a life threatening condition to a chronic health problem due to advancements in and better access to ART (Pierret, 2007). The results of the study are presented in detail in the following sections.

Through the focus group discussions, different symptoms of pathological conditions or physiological imbalances were identified and described in terms of severity, frequency and timing of occurrence. The most commonly cited symptoms were pain, diarrhoea, fatigue, flu like symptoms, cough, and insomnia. The reported symptoms varied over time. Based on comments of the patients and observations made during the interviews, this study noted four key stages defined by the type of symptom manifested and severity of such symptoms. These stages and their characteristic symptoms are shown in the table below:

Table 4.2: Common symptoms reported from AIDS through treatment initiation and immune reconstruction

Stage	Description	Predominant symptom experienced
1	Pre-treatment stage	Pain, diarrhoea, anorexia, dermatological problems, cough and fatigue
2	Treatment initiation stage	Pain, diarrhoea, vomiting, stomach cramps, fatigue dizziness and nausea
3	Early treatment stage	Pain, diarrhoea, fatigue, insomnia, eating disorders
4	Treatment maintenance stage	Pain

The observed variations of predominant symptoms in the above stages is congruent with studies that have shown symptom variations throughout the trajectory of HIV disease (Portillo et al., 2007; Sukati et al., 2005; Tsai et al., 2002). The stages noted by this study may also be attributed to HIV related syndromes, secondary complications, changes in viral burden, immune reconstruction effects and the side effects of ART and other medications (O'Brien et al., 2009).

The symptoms listed under each of the respective stages were the predominantly reported symptoms under the particular stage and the main health concern for individuals in the respective stage. This assertion should be interpreted against the backdrop that this study requested its participants to list their priority symptoms based on perceived severity and frequency of occurrence. This was done bearing in mind that studies that have explored the scope of symptoms experienced by people living with HIV/AIDS (PLWHA) have reported over 60 different symptoms experienced by PLWHA with each participant reporting an average of about 15 symptoms (Makoae et al., 2005; Sukati et al., 2005).

4.2.1 Diarrhoea

In terms of the priority symptoms identified by this study, diarrhoea was ranked very high and has been described in similar studies as being one of the most common symptoms of disease with AIDS and is associated with decreased quality of life and survival (Henry et al., 1999). Diarrhoea is also known to occur in about 50% of PLWHA (Henry et al., 1999). The cause of diarrhoea in HIV may be due to known pathogens, side effect of treatments or simply an idiopathic HIV associated enteropathy.

In the context of the above, patients in this study were often unable to attribute the diarrhoea to any particular cause but emphasized its huge effect on their wellbeing. This can be illustrated in the accounts of two participants below:

"With diarrhoea, I do not see a specific thing that causes it because you can take several food, then after taking the food you start having diarrhoea and you stop to eat that specific food and

eat another type of food then you will experience diarrhoea again, meaning that every food that you eat, you will experience diarrhoea, then it means you will stop eating everything".

"I will talk about myself in relation to diarrhoea. It will take two weeks for me to have that diarrhoea until I feel weak and the ambulance will pick me up to the hospital. They will put a rehydration drip, and then give me Imodium, and then it will stop. But every month I experience diarrhoea".

Similar to the above, the study by Henry et al. (1999), exploring the effect of chronic diarrhoea on quality of life, reported that *"chronic diarrhoea can result in a decline in nutritional status and subsequent decline in functional status and overall quality of life"*.

All the participants reported that the use of Imodium and revision of treatment were the common responses by clinicians to the diarrhoea problem. These responses fall short of a best result pathway suggested by Jones (1997), consisting of nutritional assessment by a qualified dietician, medication review by a pharmacist, appropriate skin care measures and the use of Imodium. Following this pathway becomes important given the participants' concern that the diarrhoea may be linked to diet as shown in the statement above and anal pain reported by another participant. This suggests the need for professional dietary assessment and skin care interventions both of which were not being received by the participants.

4.2.2 Pain

While diarrhoea was spontaneously reported at the beginning of every interview as the main physical symptom experienced, pain was widely reported and in different forms and with varying levels of severity. This finding is in agreement with numerous studies that have reported the high prevalence of pain with diverse presentations. The available studies of pain in HIV/AIDS have noted it to be significantly associated with psychological and functional morbidities (Breitbart et al., 1996; Lebovits et al., 1989; O'Neil and Sherrard 1993; Singer et al., 1993). In line with earlier studies, this study observed that pain was more common among persons with advanced HIV disease or individuals who have been on treatment for a longer time, as suggested in Table 4.2 (Breitbart et al., 1996). In the context of these observations, McCormack et al. (1993) reported that 28% of asymptomatic seropositive males, 56% of males with AIDS related complex and 80% of males with AIDS reported at least one painful experience over a six month period.

The common locations of pain reported by this study’s participants were leg, back and abdominal pains. Breathing difficulty due to pain was also reported. This finding agrees with the types of pains reported by Hewitt et al. (1997), including headaches, peripheral neuropathy, abdominal cramping and rheumatologic conditions and pain tending to be of a chronic nature. This study’s participants added that the pain was more severe late at night and in the early morning and often affected their sleep and ability to function, including getting up in the morning to attend to household responsibilities, taking care of their children or taking their medications. For the few who were employed, this affected their ability to work and sometimes resulted in absenteeism over long periods. In this regard, some participants expressed that the pain they experienced discouraged them from seeking formal employment. These observations concur with studies that have demonstrated how the debilitating pain experienced has progressively compromised the enjoyment of life by PLWHA (Schofferman and Brody, 1990; Breitbart et al., 1998; Singer et al., 1993; McCormack et al., 1993).

The study participants failed to attribute the pain to any particular cause, but the time orientation of the pain experience described may guide clinicians in planning effective care measures. This information has been lacking before now and may need to be further explored. The aetiology of pain in HIV has, however, been reported to vary and may result from the effect of HIV on the central or peripheral nervous system, opportunistic infections, the use of ART or complications associated with AIDS (Lebovits et al., 1989; Hewitt et al., 1997). In the context of the aetiologies of pain, Abrams et al. (1994) reported that most underlying causes of pain in HIV are treatable but often unattended due to inadequate assessment. The observations made about pain in this study are typified in statements below:

“The problem that I have is with my legs, even now I fell that my legs are painful, even when I am sleeping they feel painful”

“My legs trouble me also, when they started they used to be hot underneath and then they became too painful to an extent that I had to cook while sitting down. It also became difficult to perform house duties, but I just told myself that it will end one day but performing daily activities is hell for me”

“My legs are very painful and they become very painful and hot when I step down or walk even when I wear shoes, my legs cause problems as they are painful and I can’t walk around without wearing shoes. The problem with this is that I have to wash my clothes, fetch water and wood; all these tasks are difficult for me”

“In addition to that, what she is experiencing is called pins and nails, which means the pain is severe, it’s very severe, you can’t put on your shoes, you can’t walk, it is very severe”.

“For me, when I go to the hospital and explain that I have problem with my legs they give me pills that I drink but I do not see their help as they do not improve my condition but it seems as if they make me worse or else”

“With me the pills just make me feel better they do not heal the symptoms to an extent that they go away”.

“To tell the truth, my painful legs really are stressing me because every day in the morning before I wake up I know I will have a problem and I am even scared to climb off the bed. And I am even thinking that this problem is caused by the ARV’s because it started immediately after I started the ARV”.

"I started having severe diarrhoea and I wouldn't even walk that where I was diagnosed and started treatment, but since I started taking treatment the problem that I am having which is severe is the deformed jaw and painful legs and also sometimes cough which is not severe after taking cough treatment I become too well".

"I had terrible sores on my back, chest and legs and they were severe and after I have started the ARV's the problems that I have is only the painful legs".

What is worrying about the last three accounts is that they may suggest treatment induced peripheral neuropathy. This assertion may emphasize the findings of Abrams et al. (1994), indicating that pains experienced by the participants may be treatable if adequately investigated. While it remains beyond the scope of this study to verify the accuracy of the accounts of its participants, such observations were always reported to the clinicians responsible for the care of the participant to ensure that the issues were further investigated and given appropriate clinical attention.

4.2.3 Fatigue

Fatigue was also widely reported by the participants. Like the pain experiences, fatigue affected the ability of the participants to function, including carrying out basic self care and household responsibilities and the essential activities of daily living. In the same manner, coping with employment was a notable difficulty because the fatigue occurred mostly in the morning and with minimal activity. The statements below highlight the nature and effect of fatigue experienced by the participants:

"I was doing catering and I had to leave it because when I work I used to feel tired and I do not have income any longer"

"I also had the same problem of tiredness and left the job"

"I had the same problem also. I left my job and now I am on computer training and I do not feel tired any longer as you always do it while seated. This illness does not want heavy job"

"Sometimes you are able to do household chores with no problems, but sometimes when you wake up you are just tired you won't do anything until you go to sleep at night"

"We always do household chores but we are not supposed to do them on a daily basis because we feel so tired"

"Tiredness makes us not to engage in daily home activities because you find that immediately you wake up in the morning, you are already tired"

Similar to the diarrhoea and pain, fatigue has been noted in prior studies as a common problem experienced by PLWHA and has been associated with reduced quality of life (Breitbart et al., 1998). It has also been described as one of the most frequent and debilitating symptoms of HIV/AIDS (Corles et al 2002 Holzemer et al., 1999). Fatigue was notably widespread among the study participants. Similarly, other studies have shown that approximately 85% of people living with HIV/AIDS experience periodic or persistent tiredness or exhaustion with varying levels of severity (Voss, 2005). The effects of fatigue implied in the above statements also agree with its definition as "extended perception of tiredness and exhaustion that persist for longer than one month, which is not relieved by additional sleep or rest" (Piper, 1998).

Similar to this study's observation of the effect of fatigue on the participants' poor tolerance of activities of living, Bailey et al., (1995) added that fatigue is one of the major obstacles to patients' adherence to treatment. Poor adherence is known to exacerbate the AIDS epidemic as it results in viral resistance, treatment failure and increased morbidity and mortality (Sterling et al., 2001; Ostrop et al., 2000).

While it was beyond the scope of this study to explore the differences in the level of fatigue by sex, other studies have noted that females have reported higher levels of fatigue when compared to males (Breitbart et al., 1998). The higher intensity of fatigue experienced by women has been further linked to hormonal effects and their "multi-tasking" life styles. This observation presents ripple effects given its timing and the role of women in catering for the family, including their male partner who may also be living with HIV/AIDS. This scenario creates a vicious circle given its contribution to these same factors which is strongly supported by the above statement that *"this illness does not want heavy job".* These assertions draw on the findings of the same study that noted that women who lived alone experienced less fatigue and this has a strong bearing in planning the "rehabilitation", care and support of women living with HIV and AIDS.

The economic, physical and mental challenges posed by HIV/AIDS are exacerbated by the loss of employment, lack of activity and possible isolation resulting from fatigue as shown by this study. Similarly, Voss (2005) has attributed depression, lipodystrophy and perceptions of physical and mental wellbeing to the reported levels of fatigue.

Winningham et al. (1994) have described a phenomenon known as secondary fatigue which results from an individual's effort to regain vitality by having more rest and instead get more fatigued. Other manifestations of secondary fatigue are sleeping difficulty and depressive symptoms. In this regard, most participants reported that they stayed in bed in order to regain strength and instead get more fatigued. This is shown by such patients reporting that they spent the whole day doing nothing due to the continued fatigue.

4.2.4 Insomnia

Insomnia was often reported by the participants. The sleeping difficulty experienced by the participants was often attributed to the physical pain they experienced, shortness of breath or the fears and worries of living with HIV/AIDS. The participants could not associate their sleeping difficulty with any factors. These views are expressed in the statements below:

“In most cases I do not sleep during the night because I keep thinking about this disease”

“I am having breathing problems especially in the night. I cannot breath well, I always take a mint and put on my nose so that I can be able to sleep. This makes us scared because when we are sleeping, we are afraid that we might end up dead, as I have already told you that I have difficulty in breathing during the night”

“I am currently trying to ascertain what is causing these after effects because I don’t have a problem with the ARV’s ,but ever since I started taking the ARV’s insomnia has been a problem, it’s starting now because I used to sleep peacefully before but for the last four months I have sleep difficulties”

“When my sleeping problem started I explained to the doctor who prescribed certain pills is just that I don’t remember their name but they gave me sleep but I complained it’s only that they made me subdued because they will make me feel tired instead of giving me sleep, so they gave me another type which did not treat me well, so now when I feel sleepless I just wake up and sweep”.

“I experience the dizziness while I am asleep”

“Like other people I will get inside the blanket with the aim of sleeping but nothing will happen, it will be 09 pm,10,11,12,01am,2,3,then I will sleep at around 4 am”

“I also had a problem with sleep, I went to the hospital and they gave me some blue pills. The problem with these blue pills is that maybe if I drink them at seven o’clock I will remain seated at the place that I took them. People will come with pillows without my awareness and I will wake up in the morning, so I think these pills are good because if I drink them early I won’t even see ‘Generations”(others laugh). The reason why I stopped using them is because when I am

sleeping I don't hear anything so things will happen around eight and nine that I will not be aware of. The other problem was that my husband usually calls around nine and by that time I am already dead so he will end up talking to the children but I explained to him that I am on medication. So that is why I stopped taking the pills, they appear to be blue on the inside, they are very strong"

"when I go inside the house it will be hot and I will just sit until 4 am. That is when I will feel sleepy and at four is my time to wake up and cook for my lunchbox but in the afternoon I will not feel the need to sleep, I will just feel tired and have a headache"

"I also have a problem with sleeping, I would sleep at around eight but when it is around twelve I will wake up and not sleep, I will not sleep for the whole night, I will be walking around and sitting, the others will just look at me sitting alone(laughter),and it does not end"

"The issue of sleep is interesting because since the insomnia started the hours that I sleep is only four, strictly four, after that at eleven o'clock I will be wide awake so it is somehow helpful because I will wake up and do some work or watch some stories on channel E. There are some nice pictures that I can see. When I get tired of watching TV I will go and take the broom and sweep which is why my place is very clean. So my wife started to complain saying that' people will say that you are a wizard' I asked her what I am supposed to do if I am feeling sleepless, she said I must stay inside the house and not go out during the night (he laughs) The issue of staying inside the house is not ok with me because I like to keep busy, there is no other way"

"When I wake up I will not feel sleepy or tired at all but I don't sleep, I explained my problem to the doctor who gave me pills that I should drink at night but even after drinking the pills there has not been any improvement as I still experience the problem. As a result I stopped using the pills. Sometimes I will walk around the house during the night so are people not going to say that I am a witch? Anyway I will walk, when I get tired I will sit down and fall asleep at 05:am"

The above remarks all bear the hallmarks of insomnia which has been defined as "unsatisfactory duration of efficient or quality sleep that is experienced three or more nights per week" (Morin, 1993). In the same context, Luce and Segal (1969) have classified insomnia into three types namely: problems with falling asleep, problems with staying asleep and problems with early waking. These problems are common in HIV/AIDS and have been described as a frequent and bothersome symptom of HIV infection and are known to impact on the quality of life of people living with HIV/AIDS (Cohen et al., 1996). Insomnia has also been associated with chronic fatigue, social and physical functioning and eventual loss of employment (Darko et al., 1995). This association was strongly suggested in the presentation of fatigue as a symptom earlier in this report.

Similar to the above remarks of the participants, Lashley (1999) reported that the lack of sleep may have resulted from other symptoms of HIV/AIDS like pain, cough, dyspnea, night sweats, anxiety, fear and depression. In the same way, insomnia is a known side effect of some antiretroviral drugs (Chohan, 1999).

4.2.5 Body image disturbance

Body image disturbances resulting from treatment induced lipodystrophy was another problem among the study participants. In this regard, different studies have found strong correlations between the severity of lipodystrophy and the level of dissatisfaction with body image (Burgoyne et al., 2005). The participants unanimously agreed that the changes in body shape resulted from the treatment that they were receiving. In the same context, other studies have noted that lipodystrophy impacts negatively on health related quality of life, erodes self-esteem, decreases desirability and attractiveness, impairs social functioning and potentially results in anxiety and depression (Collins et al., 2000). Some statements depicting participants' experience with lipodystrophy are as follows:

“These tablets affect the looks of these women, they misshape them because even when they are dressed they do not look good. Their buttocks are squeezed inside and they are having big tummies”

“We are surprised what is happening because since we took treatment our tummies are big and we do not know what the problem is. Always, even if you do not know that this person is on ARV’s, you will see her having big tummies and squeezed-in buttocks”

“She is telling the truth. Our buttocks seem as if we were beaten with a plank and our sizes have been reduced. Even our faces become too small”

“This is a side effect of the treatment because even men develop breasts and these treatments also make our veins to protrude”

The above morphological changes are in consonance with the findings of similar studies (Mutimura et al., 2007; Saint-Marc et al., 1999; Carr et al., 1998). These studies have reported peripheral fat loss of the face, buttocks and limbs as well as the accumulation of fat in the abdomen, breast and dorso-cervical spine. These changes have been viewed as hallmarks of people on treatment and they develop stigmatizing features (Guaraldi eta al., 2008). This situation may lead to forced disclosure of HIV status and increases the fear of side effects related to antiretroviral therapy (Power et al., 2003).

It was also noted that despite these morphological changes and concerns, the patients had no problem continuing with treatment given the expressed benefits which they experienced outweighed the side effects. Martinez et al. (2001), however observed that depression resulting from body image problems may lead to poor adherence to treatment.

4.2.6 Disclosure of HIV status

Disclosure rate among the study participants was high mostly because the study participants consisted of members of support groups of people living with HIV/AIDS. This means that all the members of the groups would have disclosed their status to health workers and group members at least. The participants clearly underscored the benefit of disclosing their HIV by comparing the life before and after disclosure. In terms of the radius of disclosure, the participants were more likely to disclose to their immediate family members and health service provider. This observation mainly suggests the perceived importance of such people. Some of the remarks that support these observations are presented below:

"You get support from family members and community if you have disclosed your status, then they will take care of you by buying fruits and vegetables. But if you did not disclose, no one will take you serious when you tell them that you are sick"

"If you have disclosed to your family, they are the first ones to see you when you have problems because they are checking on you on daily basis and they are able to help you quickly"

"When you arrive at a clinic and you do not disclose, they do not help you in totality, but if you disclose, they are really helpful, still some nurses never help"

"We sometimes access services because when you complain about the diarrhoea they will tell you to do rehydration solution and drink, and when you report to them that you have cough they will tell you to take a lemon until you disclose your status is then that they will help you in totality meaning if you do not disclose you will not receive the correct help"

"The difference is that when a person talks they are setting themselves free from self stigmatization which is more dangerous than being stigmatized by others, so by talking you set yourself free which also boosts the body's defence, even when they talk or laugh the person will not be affected but the one who did not disclose will have a problem because when people talk

you will think that they are talking about you, that is the difference. When you talk you are free just like me. People can say whatever I don't mind".

"Always when I wake up and I don't feel well, I tell my children who will then help me with all house chores for that day and I will rest. Even the community is supporting me because I have disclosed my status to them"

"Even the community is supporting me because when I am not well I tell them and they will come and help me with my household activities"

Similar to this study's findings, disclosure of HIV status has been repeatedly described by other studies as an essential element in the prevention, treatment, care and support of people living with HIV/AIDS (Ncama, 2007; WHO, 2004). In further agreement with this study, other studies have reported that people who do not disclose their HIV status deprive themselves of family and social support and burden themselves with the guilt and secrecy of non-disclosure (Ncame, 2007; Norman et al, 2005). Paxton (2002) has added that the suppression of one's feeling results in stress which affects physical health and wellbeing. Furthermore, inverse correlations between HIV related worries, depression and disclosure have been reported (Derlega et al., 2004).

The high family support noted in this study was also reported by Norman et al., (2005). In agreement with the study findings, Simoni et al., (1995) did demonstrate that people living with essential social support experienced better psychological wellbeing when compared to those without such support. This point goes further to implicate the inverse relationship between the number of people disclosed to and psychological wellbeing and this may explain the variations in the health status of study participants based on their implied radius of disclosure. This observation is in agreement with studies that have reported that people who have disclosed, experience better health with optimum immune and autonomic nervous system functions (Pennebaker et al., 1990). In the same context, other studies have found that satisfaction with social support following disclosure buffers the effect of HIV related physical symptoms on depressive symptomatology (Hays et al., 1993).

The findings of this study suggest the participants' initial reluctance to disclose their HIV status. This phenomenon was also noted by Norman et al., (2005), adding that disclosure is not an event but a process. The reluctance to disclose one's HIV status has been widely documented and is often attributed to the fears of loss of economic support, abandonment, blame, physical and emotional abuse, disruption of family relationships, discrimination and other forms of reprisal following HIV status disclosure (WHO, 2004; Rothenberg et al., 1995).

4.2.7 Fear

The study participants expressed different fears. The most common fears were the fear of disclosure of HIV status and the anticipated stigma, fear of HIV/AIDS related illnesses and the fear of dying. While this was the case, most of the study participants had gone beyond the expressed fear with the help of the support group, particularly the fear of disclosure. They added that the fear of falling sick and dying was a source of stress and depression. The remarks below reflect the participants' feeling with regard to their fears:

"I also feel that I do not have a problem, I used to fear people, the problem I had was at home I had a problem with how I was going to tell my parents but I told myself that it is not fair that the support group know about my status but my parents do not so I ended up telling them, now things are in order as they have accepted my status"

"In the beginning it was difficult for me to accept my status because I got tested after my husband passed away, so because I saw how he suffered I had fear that I will experience the same things and pain that he suffered, that is why it was difficult to accept but at the present moment, I am good I have accepted my status"

"I will start with the headache. It is caused by thinking a lot about this illness, meaning you are always in fear that you will die. Then you are always stressed"

"The other thing is that people perceive HIV as a threatening disease and this makes me feel depressed and fearful because people who are not infected treat us somehow"

"The community is not accepting us and I have fear of going out and this makes me feel sad always".

In the context of the above remarks, many studies have noted that the level of fear experienced by people living with HIV/AIDS causes distress, impacts on the health related quality of life and affects life satisfaction (Makoae et al., 2005; Hudson et al., 2004). Similarly, Doyal and Anderson (2005) observed the "complex feelings" that emanate from fear, uncertainty and depression. They added that this feeling was often the result of the insecurities of the limited predictability of the daily health outcome of living with HIV and AIDS. The fear of stigma is commonly reported in similar studies (Green and Sobo, 2000). Such studies further reported that the fear of stigma was often over estimated. This agrees with this study's finding given the general acceptance and support that the study participants received from their family following the disclosure of their HIV status.

Similar to other studies, the fear experienced by the participants of this study can be related to the stage of the disease, length of time since diagnosis and treatment initiation and ultimately the level of acceptance of their HIV status. In this regard, the expressed fears are likely to lessen over time (Ickovics et al., 2001).

4.2.8 Level of psychological adjustment and acceptance of HIV status

This study noted the participants' initial negative reactions to a HIV positive result. Such reactions included the loss of the will to live, depression, social and emotional distress. These reactions usually take a long time (which often ran into years) to resolve. The participants however, underscored the importance of nurses, social workers, counsellors and support groups in accepting their HIV status and resolving the negative reactions.

The period prior to the acceptance of the participants' HIV positive status was also marked by poor use and access to social and health services (largely due to the associated non-disclosure of HIV status) and the loss of the will to live. On the other hand, the participants' acceptance of their HIV status provides the energy to live and more aggressively to respond to the various health and social challenges of living with HIV/AIDS. Below are some of the comments of the participants on their psychological adjustment and acceptance of their HIV status

"I decided to get tested for HIV but after knowing my status it was difficult to accept and it took two years of not telling anyone, at the hospital nurses introduced me to support group team leader who gave us a speech to motivate me and after that I disclosed my status to my mother and started the ARV treatment"

"I got tested in 2001, February, I was pregnant but there was no problem. It took me a long time to accept it but now I am coping"

"I am coping because I have I accepted by status and I do not care about what people say"

"I have just accepted myself that I will live with this virus because I have realised that if I do not accept, I will have a problem"

"I have accepted myself that I am living with this virus and I am eating nutritious food to keep me healthy"

"I have painful legs and I came to the clinic nurses at the clinic helped me because they advised me not to work too hard and I am not stressed because I have accepted my virus and all my illnesses and I told myself I will live with this"

“I cope because I have told myself that I must accept my illness and I know that here on earth, if you do not accept your illness, you won’t live long”

“With me, also, I have accepted my illness so that I have peace with myself”

“All these services are useful like for example, counselling, where you find that pre-counselling is done before testing HIV and if the results come positive, you find that you are able to accept your status and ongoing counselling helps you to live with your virus and cope throughout with your disease process”

“I am coping because I have I accepted by status and I do not care about what people say”

“The problem is stigma and this ARV cannot work if you are not accepting the status the medicines can only work if you are accepting”

The initial negative psychological responses to HIV diagnosis are common and well documented (Coward, 1994). Furthermore, the noted psychological adjustment to a positive HIV diagnosis has been noted to be critical in developing effective coping strategies (Farber et al., 2010). The development of personal meaning of being HIV positive was noted in the study at the point of acceptance of the virus as part of their lives.

Similarly, personal meaning is increasingly being recognized as important in adjusting or coping with traumatic events and life threatening illnesses including HIV/AIDS (Janoff-Bulman and Yopyk, 2004). Personal meaning is broadly defined as “foundational beliefs that lend a sense of explanatory coherence, goal-directed purpose and emotional value to one’s life” (Wong, 1998). This definition involves the explanation that one has over a personal impact or important life events like living with HIV/AIDS (Park and Folkman, 1997). In similar studies, participants have for instance, described HIV/AIDS as a “challenge to be met” or “a source of personal growth”

(Moskowitz et al., 2005; Schwartzbege, 1993). This kind of confrontation has been positively associated with clinical benefits (Gifford et al., 1998; Lutgendorf et al., 1998). In the context of this knowledge, the study participants who reported accepting their status and the willingness to "live with their virus" often reported an improved wellbeing.

Similar to this study, social support and encouragement such as that received from health workers have been shown to be useful in improving psychological adjustment and coping (Heckam, 2003). Beyond the benefits of social support in ensuring psychological adjustment and coping, the continuous coping will require active efforts to address the stressors through processes that have been described as process or emotion focused coping (Gore-Felton et al., 2006). This kind of effort can be seen in the study participants' acceptance of their situation and resolve to respond positively in dealing with the challenges of being HIV positive.

4.2.9 Anger

Anger was a common theme among some group members. The anger was often uncontrollable and expressed towards people around the participants, such as family and work mates. The expressed anger was often attributed to the antiretroviral treatment by the participants. Most of the comments suggest that the anger stage was often after the initiation of treatment during a period that is still characterized by various opportunistic infections and AIDS defining conditions. The described pattern of anger may suggest some level of transient frustration given that it was hardly reported by participants who had been on treatment for longer periods. Some of the remarks of the participants characterizing the anger they experienced are presented below:

"I was angry about the disease and this makes me to shout at my children all the time"

"Eh, the other thing that was bothering me is short temper, I got irritated very quickly and I was also very aggressive and couldn't appreciate anything, even at home I did not appreciate my wife, there was loss of sexual appetite and loss of sleep i.e. I would wake up at night and

struggle to sleep again. I also had problem with allergy, especially meat, even at the present moment I use only yellow and white meat because red meat made me to scratch my body all over. I used to have an unpleasant smell that will not go away no matter how much I bath ,at that time I even lost my weight, but since ARV's there is improvement"

"I have a problem of short-temper; I live with my mother and I always have a short-temper towards her and it affects our relationship most especially that she is old and sick"

"It affects us at work because you are short-tempered to everybody and they move away from you"

"The steps that I have taken is that I told people I am working with that when I am short-tempered they must not take me serious because I am sick, I am on ARV's. They are the ones who make me to be short-tempered"

" People will always avoid you because you are short-tempered as they don't know that you are sick, and this affects your interpersonal relationship with everybody"

"I always avoid being with people as I am short-tempered"

"I was short tempered and having sores in my body especially at the back but after starting with the ARV treatment but now I am coping very well"

"I am agreeing to what others are saying because after taking ARV I was short tempered and cannot walk properly"

Other research studies have reported similar anger among persons living with HIV/AIDS (Kalichman and Sikkema, 1994). The anger in HIV/AIDS has often been attributed to recent HIV positive diagnosis, social rejection, shame and self devaluation (Holland and Tross, 1985). This theory may not apply to the study participants who often have known their diagnosis for a very long time. The remarks of the participants suggested that close family members were very likely to accept and support HIV positive family members who disclosed their HIV status.

Instead, the finding of this study may be better explained by other established causes like frustrations, uncertainties and a sense of the uncontrollability of HIV disease (Dilley et al., 1985).

4.2.10 Stigma and discrimination

HIV related stigma and discrimination was widely reported by the study participants. The stigmatising experiences were often described as distressing, dehumanising and resulted in social dysfunction, isolation and loss of the means of economic livelihood.

The stigma experienced was often attributed to ignorance about the modes of HIV transmission and fear of infection. The participants also reported that their family members (particularly children) were also being stigmatized by neighbours and people in their communities. The common places where the stigma occurred were at public events like funerals, parties, churches, clinics and schools. It was also noted that psychological adjustment and acceptance of HIV status helped the participants to better cope and positively respond to the acts of stigma. Below are some remarks from the participants indicating their experiences with stigma:

"Other people do not consider us as people. They think we must be taken to our own place where all HIV/AIDS infected people will stay"

"Stigmatization is a lot because they think that even when they touch us, they will be infected. That is why they do not want to move next to us"

“They think we have been infected by HIV/AIDS through sexual intercourse. They do not know that there is a lot of mode of transmission like through blood transfusion. They usually think we were running around”

“They just think we are dying by looking at us”

“The first place that they discriminate us is in the weddings and funerals when we are supposed to take knives to chop vegetables because they do not want us to touch those. They will always say we must wash dishes while we are scared to touch cold water as we catch flu easily. If you can happen to cook, they will throw away your food. The second place is at the clinics. Other nurses seem not to attend HIV courses because when you enter the consulting room, they will open windows and stay a distance from you”

“At school they call our children with names like your mom is positive and she going to die you will be left alone”

“At church because if you disclose your status to the pastor he will use you as an example like you see she is HIV and she is still breathing it means HIV does not kill and after church people will be talking about you and next Sunday they don’t want to sit next to you”

“People do not take us serious and always belittle you when you talk. We always just conform to everything that they do to us”

“Yes my neighbour said I must not pass next to their house because am HIV. (They all laugh)This is serious am not joking”

“People in my village said we have many people who are infected and they trying to depress me by saying this painful words and some said am a professor of HIV”

"Yes, we are discriminated at church, e.g. shaking hands, washing hands in the same basin and sharing same glass"

"Yes, there is discrimination in soccer teams e.g. they burn the t-shirt of the other player after knowing that he is HIV positive"

"When we attend parties they really do not want us to prepare food"

"I always do not touch the pots when I am attending funerals and parties"

"I do not care what they say about me the bottom line is that I have accepted my virus"

"Hmm, with the issue of employment we have to work but you still find that there is no place in which we can work because of our status. Even if we try to sell no one will come and buy and also when we want to work at parties or funerals as a lady you will be told to leave everything and to sit down so I end up telling myself that I will just sit down because I cannot force things and I will not kill myself because of that. I will continue living, it is just that I will be living in pain. It is very difficult because I have children whom I must help and also buy food for, so what will I use to buy as I don't have money and I am not getting any employment, there is no one who will give me money, so I find life very difficult"

Stigmatization has been defined as a process of devaluing individuals characterized by discounting, discrediting, tainting, labeling and prejudice (Thomas, 2006; Goffman, 1963). These attributes can be observed in the above accounts of the study participants. Prior work on stigma has also described three forms of stigma: (i) self stigma, manifesting as self blame and self deprecation; (ii) perceived stigma, formed from the fear of being stigmatized if they disclose their HIV status; and (iii) enacted stigma, resulting from actual discrimination due to the perceived or confirmed HIV status of the person being stigmatized (Bond et al., 2002). With these definitions, this study noted mostly enacted stigma.

The above occurrence is despite the fact that HIV related stigma remains a major obstacle to effective prevention and management of HIV (Parker and Aggleton, 2003). This fact also takes into consideration that poor physical health has been associated with lower levels of quality of life (Vassend and Esklid, 1998) and depression (Schmitz and Crystal, 2000).

Based on the reports of the study participants, the common places (like churches, funerals and other community events) where stigmatization was more likely to occur confirms the description of stigma as a social construct emanating from social, cultural, historical and situational factors (Liamputtong et al., 2009). In further agreement with similar studies, stigma was also due to public perception that HIV infection was a result of immorality, deviant behaviours and actions that are incongruent with socially accepted norms (Deng et al., 2007).

The participants who seem to have coped with responding to stigma were often as a result of their acceptance of their HIV status, and this has often occurred through the help of support groups and health care workers. This observation is in agreement with the findings of Liamputtong et al. (2009). They noted that people find different strategies to counteract the effects of stigmatization and that joining support groups was one such strategy.

4.2.11 Perceived attitude of heath workers

The participants mostly highlighted the good support they received from nurses and other health workers. These included quality health services and personalised attention, disclosure, counseling and support. Most of the participants also added that the quality of service and support received varied between nurses. With this, the participants indicated that they avoided consulting the health care workers who were less supportive. There were only a few reports of stigmatization and discrimination by health workers.

"In our hospital we have ARV clinic. Some nurses in that clinic do not take of us in a positive way. They treat us badly even if we are not feeling well. I even confronted some of them and we have solved the issue"

"When you arrive at a clinic and you do not disclose, they do not help you in totality, but if you disclose, they are really helpful. But some don't, as nurses are not the same"

"The nurses at the clinics really assist us as they always sent home based carers to come and check on how we are coping with our home chores"

"The other problem is when we come to support groups, some of us are sick so the nurses will be showing other people, it will be better if the government could arrange that we meet elsewhere but not here in this stand so that we can feel free"

The mostly good nursing support as reported by this study has been attributed by the participants of other studies to better quality of life as it reportedly diminished loneliness and improves the sense of acceptance (Ragsdale et al., 1992). This observation is also in agreement with the findings of this study that psychological adjustment to living with HIV/AIDS and acceptance of positive HIV status were often facilitated by health care workers. The study by Kermode (1995) also noted psychological support as the most important nursing action received by participants. On the other hand, the rejection of health workers by patients as a result of insecurity and lack of confidence as noted by this study has also been previously reported (Weitz 1990).

4.2.12 Support structures and needs of people living with HIV/AIDS

The common sources of support cited by the study participants were the family, support groups of people living with HIV/AIDS, counsellors and nurses. The participants added that the support received from these groups provided a sense of acceptance and cushioned against the psychological demands of living with HIV/AIDS. It was also unanimously agreed that the disclosure of HIV status was essential to obtaining full support from the different sources mentioned. The commonly cited family members who provided support were siblings, parents and children. The family members mostly donated food and provided support by helping with household responsibilities. There were mixed responses on the role of religious groups. Noting disclosure to religious leaders often resulted in the involuntary disclosure to church congregations and this often exposed the participants to acts of stigma and discrimination from members of the church.

Participants also highlighted the financial burden of living with AIDS which is compounded by their often inability to work as a result of their poor health condition. They added that the temporary disability grant provided to them was inadequate and often discontinued prematurely (that is, before they get well enough to go back to work/begin to earn a living again). The participants, however, praised the health services that they were receiving noting that they were easily accessible and often met their needs. The counselling and ART services were mostly praised.

The findings of this study largely highlight the role of social support systems (including the family, health care workers and support groups) in alleviating the impacts of HIV/AIDS on the individual.

The study participants further noted that grant services needed to be improved in terms of access, duration and that the major problems they had was securing housing and education for their children. The issues relating to social support can be noted in the comments below:

“TLC, support groups and family members help me to cope with the disease”

“The support that I get is from this support group because when I have problems, I share with them and they give me advices”

"We get the support from this support group and nurses in the clinics"

"The support we get from our family members is very useful because if they do not support us we will have a serious depression and things will not go well at home. For example my child knows my status so other children fought with him but he told them my dad is better because he knows his status what about your dad? So it is nice to get family support"

"My family members are very supportive and sometimes they buy fruits for me and give money to support myself"

"Support from family members and community you get it if you have disclosed your status, then they will take care of you by buying fruits and vegetables. But if you did not disclose, no one will take you serious when you tell them that you are sick"

"Our family members help us through out because they will even remind you when it is time to take treatment and also with household chores like doing washing. Financially they can't because they do not have money themselves"

"They support with food, clothes and other things the family members do help. They have even taken my own child to take care of"

"Family members do assist a lot except where money is involved as they themselves do not have it. My brothers do help me a lot"

"I always get support from the support group because we share ideas, but our support group is no longer active. My brothers support me"

"The support the government is offering these days is useless because they give us a grant for only twelve months"

"The problem with money is there just like we mentioned in the beginning, money is needed, and especially when you are unemployed it is difficult to get the variety of food that is needed. It is not easy if the government is not helping us. It is difficult because these doctors will tell us that we did not qualify to get the grant money. There was a certain lady who died because she used to receive the money and they stopped it so she could not take care of herself, it is very bad"

Person 1: *"The 1st one is the issue of government considering taking our children to tertiary institution after matric because we do not have money to afford tertiary institution more so they have taken the grant away"*

Person 2: *"The 2nd most important I think we should be considered first when they allocate RDP houses"*

Person 3: *"The social grant is the 3rd one and it should be more than the aged pension grant so that when you have a family you are able to meet the needs because you are unable to work. We also have a problem with RDP houses and food parcels because ward counselors are the ones who allocate these houses and they do canvass for elections with them and people in need do not get them. They must be taken away from the ward counsellors"*

Person 4: *"The most difficult thing to get is the RDP houses"*

Person 5: *"The service that we easily get are ARV's and social grants"*

Person 6: *"I want to oppose that we get grants easily because some people get them earlier and some don't"*

Person 7: *"If it was me, I will rank them like this; the most easy to get are counselling, ARV's, grant and the most difficult to get are the RDP houses and followed by tertiary education for our children"*

Person 8: *"The most challenge that we face is that when you are supposed to get an RDP house, after you have filled the necessary forms, then Ward Councilors gives the houses to people who did not even fill the forms. There is a lot of discrimination"*

4.3 Discussion

This study identified factors that contribute to the HRQOL of PLWHA and the interrelationship between the factors as perceived by the study participants. The study focused on the factors that tended to most frequently and more severely compromise the HRQOL of PLWHA. This is on the basis that such information will inform the prioritization of the needs of PLWHA and the planning and management of appropriate care and support services. In the same context and in line with the objectives of this study, the identified factors were grouped into three categories (the physical, mental and external factors). The categorization was based on the level of occurrence of the factors. The physical factors were the physically observable manifestations of the disease; the mental factors were manifestations of HIV/AIDS and the responses to such manifestations and occurred in the mental/psychological domain; and the external factors were social elements impacting on the participants' response to the disease and health outcomes.

The above finding agrees with early research done by Murdaugh (1998), indicating that the HRQOL of PLWHA is dependent on physical elements, emotional factors, spiritual components, relationship with others and financial aspects. In further agreement with Murdaugh (1998), this study noted that HRQOL is a function of the interplay and balancing of all the factors involved. In a similar effort, Ferrans (1996) has described categories of determinants of HRQOL like the physical, psychological/spiritual, social, economic and family domains.

In this study, there was however less spiritual connection with the participants' level of resilience to the disease and a wider scope of social support elements for PLWHA. This may be attributed to better survival of PLWHA with the advent of ART, improved government support for PLWHA and their better acceptance and support from family members and health workers. This is the case for South Africa given its comprehensive ART programme and the provision of support grants during specific stages of HIV/AIDS related diseases.

The multifactorial nature of HRQOL determinants among PLWHA and their interrelatedness is again emphasized by the many studies that suggested the need for comprehensive treatment strategies that concurrently offer a combination of services like physical and mental rehabilitation and other support services (Handford et al., 2006). This is apparent in this study with the various physical and mental manifestations of HIV/AIDS aggravating each other's effect and thus creating a complex web of vicious circles. For instance, fatigue will perpetuate fatigue, poor adherence to treatment, poor health outcomes, job loss, weight loss, body image disturbance, social isolation, fear and worry, stigma (self, perceived and enacted) and vice versa.

In line with the above, South Africa has a comprehensive HIV/AIDS strategy that seeks to guide the provision of the multidimensional responses needed to address the needs of PLWHA. The participants of this study mostly praised the role of health services in the provision of ART, treatment of opportunistic infections and counselling services. Despite this, the accounts of the study participants raise questions about quality and comprehensiveness of the services offered. This can be seen in the very symptomatic management of the physical manifestations of HIV/AIDS and treatment side effect which were less holistic, not adequately multi-disciplinary in their approach and with little patient involvement. In the same context, social support services were noted to be less laudable by the participants. This is despite government's heavy spending on disability grants and other support initiatives for PLWHA. The participants noted that the HIV/AIDS support grant was difficult to access and was based on their CD4 count which they reported was often not a reflection of their ability to earn a living. Even if the CD4 counts can be used as a reliable proxy for HRQOL and ability to earn a living, loss of means of livelihood, assets and economic security were common prior to most marginal recovery. With this, socio-economic rehabilitation and reintegration was a major challenge for the study participants. In response, there were reports of people defaulting treatment in order to maintain a low CD4 count and high viral load and retain the support grant or get pregnant in order to secure the child support grant. The scale or authenticity of this report was beyond the scope of this study but presents an immense public health concern and needs to be further explored.

Furthermore, the many limitations of the studies that have explored the possibility of using biological markers as proxy for HRQOL further implicates the current dependence on CD4 counts and viral load as measures of HRQOL (Campsmith et al., 2003; Call et al., 2000). In addition, the discrimination of the eligibility of PLWHA to receive the support grant is also based on the subjective assessment of clinicians and thus raising ethical questions given the unreliability of such subjective assessments.

The participants remarked that the identified factors (Table 4.1) affected the ability to perform basic activities of living or remaining employed in their jobs. This finding is in agreement with other studies that have found strong associations between symptoms and role function (Hudson et al., 2004). In the same context, most of the participants were unemployed and often struggled with performing household functions like cooking, caring for their children and household cleaning and washing. In this regard, the ability to carry out such specific responsibilities should constitute the measurement of HRQOL. This is given the definition of HRQOL as “an individual’s perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO, 1993). The use of such measures is currently missing in most HIV specific HRQOL assessment instruments and may be useful in the South African context.

This study’s emphasis on symptoms as the main determinants of HRQOL concurs with studies that have demonstrated that an individual’s symptom status is the best predictor of their

HRQOL (Sousa et al., 1999). In addition, the symptom status of an individual and its impact on HRQOL is influenced by personal, intervening and modifying factors (Figure 4.1). These suppositions agree with Wilson and Cleary's (1995) *Measures of Patient Outcome in a Health-Related Quality of Life Conceptual Model*. In all, the interrelatedness between the various factors (Figure 4.1) identified by this study replicates the propositions of the HRQOL conceptual model (Wilson and Cleary, 1995) that incorporates physiological variables, symptom status and environmental, individual and nonmedical characteristics.

Stigma tended to be the main intervening factor influencing participants' response to the manifestation of HIV/AIDS in terms of seeking help or accessing the available support resources. The types of stigma reported were mostly perceived and enacted. In this regard, Zhou (2007) suggests that "stigma is not only the internalization of the AIDS stigma but also an effect of their interaction with others or actual experience with public attitude through which AIDS-related social standards are manifested". This was demonstrated in this study by the reported high rate of family acceptance of relatives that are HIV infected despite their fear of rejection. On the other hand, PLWHA were often not accepted or discriminated at the community level. This occurrence may be linked to the continued fear of the virus in communities as known HIV-infected persons were often not allowed to get involved in community cooking activities or using shared cooking or eating utensils at public events. This assertion is supported by the findings of Aggleton and Parker (2002,) indicating that stigma are often driven by the fear of being infected by the virus. These trends discourage PLWHA from disclosing their HIV status and thus deprive themselves of the support of their family members and other support networks. This fear also prevents the use of health and social support services for fear of being identified as HIV positive and thus discriminated against. These behaviours aggravate the manifestations of the virus in the absence or poor use of the appropriate treatment and support services.

Some participants displayed some inherent ability to better respond to stigma and discrimination while the support groups have helped most of their members to respond better to stigma and discrimination. The value of support groups has been reported by Liamputtong et al. (2009). In another study, Lyttelton et al., (2007) described support groups as “panacea of stigma and alienation”. This point emphasizes the importance of support groups in helping PLWH to respond appropriately to acts of stigma.

The individuals who were less affected by the fear of stigma and discrimination tended to be people with better education and with middle to high economic standing. Similar to other studies, this study also noted that the fear of stigma diminishes the level of perceived support and often results in psychological distress and social isolation (Mak et al., 2007). This scenario presents implications for the adherence to ART and is more likely to result in poor adherence to treatment (Mannheimer et al., 2005). In agreement with Thomas (2006), people’s ability to deal effectively with stigma either in the home or community affects their wellbeing, HRQOL and survival. This will in turn affect the ability to work and thus brings about significant economic hardship which perpetuates an already bad situation (UN, 2005).

It is however important to note that the high rate of acceptance and support of family members who are HIV positive observed in this study marks a shift from studies that have mostly reported a breakdown in family cohesion and social support network and increased intra-household tension as a result of an infected member (Thomas, 2006). Furthermore, Li et al., (2009) have found significant associations between the disclosure of HIV status to family members, family function and the quality of life of PLWHA. Family support is known to help improve the HRQOL of PLWHA as it helps improve their mental health and reduce psychological distress (Yen et al., 2004; Murphy et al., 2002; Lang 2000). Like this study findings, Chandra et al., (2003) itemized the family support resources to include information about treatment options, financial assistance, care in sickness, sharing feelings and reassurance that one is loved and valued. These factors have been noted to help buffer the effects of HIV related physical symptoms on depressive symptomatology (Hays et al., 1992). This is in consonance with the reports of the study participants who noted how they coped better with support from family, health workers and support group after disclosure.

The above points emphasize the importance of family and social support in responding to the manifestations and demands of living positively with HIV/AIDS. Despite these benefits, almost all the study participants indicated an initial reluctance to disclose their HIV status. In the past PLWHA have been known to be discriminated against, abandoned, abused and marginalized by their families and communities and the fear of these possible negative outcomes often discourages disclosure (Medly et al., 2004).

The high rate of HIV infection in South Africa together with improved survival of the HIV-infected due to advances in ART, better information on HIV prevention and care strategies and improved government support programmes may be responsible for the observed better acceptance of PLWHA by their family members and the more subtle discrimination at the community level. This assertion is on the basis that the fear of the virus and concerns about the burden of caring for PLWHA are among the major drivers of discrimination, rejection and stigmatisation of PLWHA and are ameliorated by the current state of the epidemic and its response programmes (Liamputtong et al., 2009; Li et al., 2008; Lyttleton, 2004).

The study participants also reported how their quality of life improved as the modifying factors increased over time (Figure 4.1). The time it takes to achieve the balancing effect of the modifying factors could not be established by this study but each of the modifying factors could be facilitated through appropriate interventions in order to ensure better quality of survival in the shortest possible time. This proposition is supported by Murdaugh's (1998) pathway to psychological adjustment among PLWHA. Murdaugh's (1998) pathway moves through four stages: disintegration (or mourning loss), re-normalizing, coming to terms and creating meaning.

In line with the above pathway, this study adds that PLWHA can move forwards and backwards along the stages depending on the state of equilibrium created by the balancing of intervening and modifying factors. Key among the factors are (1) increasing knowledge about the disease as a way to gain better control of the related symptoms and reduce the anxiety and unpredictability of living with the virus and (2) social support from various networks to provide psychological and financial resilience that buffers some of the negative effects of the mental, physical and external determinants of HRQOL (Table 4.1). Similar to other studies, this study also noted that the psychologically well adjusted participants seem to have come to terms with "their virus" and created new meanings of living with it as a coping mechanism and tended to have higher life satisfaction (Faber et al., 2010).

In all, the findings of this study highlight the combination of factors that influence quality of life of people living with HIV/AIDS. This study further proposes possible relationships between the various factors as shown in Figure 4.1 below.

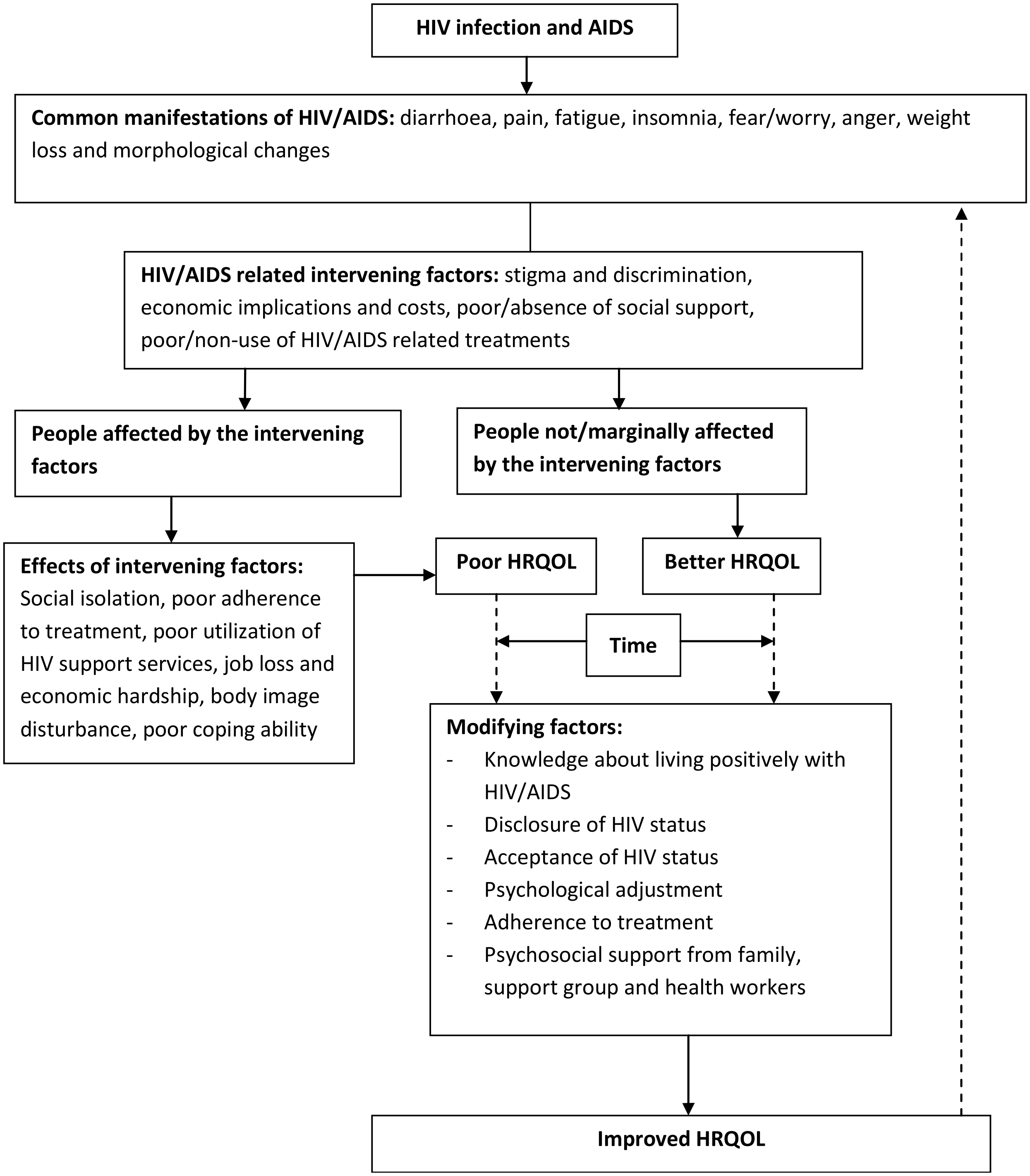


Figure 4.1: Factors affecting the HRQOL of PLWHA

In conclusion, the identified items are similar to those contained in the WHOQOL-HIV and MOS-HIV instruments. With this finding, it became unnecessary to develop a new instrument because the items identified have been covered by existing instruments. This was apparent through a direct matching of the subscales of the existing instruments with the items identified by this study’s participants. With this, Part B of Study I became unnecessary. The removal of items from the existing instruments envisaged in Study II remains important to promote the efficiency and convenience of their use without compromising their validity.

CHAPTER FIVE

FINDINGS AND DISCUSSION OF STUDY II: DESCRIPTION, VALIDATION AND SHORTENING OF THE WHOQOL-HIV AND MEASUREMENT OF CHANGES IN CD4 COUNTS, VIRAL LOAD, HRQOL OVER TIME

5.1 Introduction

This section of the study followed up a group of treatment naïve PLWHA from their time of treatment initiation over a twelve month period. The same group of participants was repeatedly interviewed at six monthly intervals (that is, baseline, six and twelve months respectively). This intention was, however, challenged by the logistical issues of conducting this research without disrupting the participants' use of health services. The pressure presented by this challenge made it difficult to keep accurate records of patient unique numbers on the questionnaires. This information gap made it difficult to accurately link the participants over time and hence limited the analysis in terms of linking the participants for a longitudinal analysis.

In view of this, the results presented in this chapter at best represent three different cohorts of PLWHA defined by their duration on treatment despite the fact that the same group of individuals was interviewed repeatedly. Efforts were, however, made by this analysis to avoid double counting or record duplication by the splitting of the database and results according to the time of data collection/duration on treatment. This measure was mainly aimed at ensuring that the study objective of monitoring the pattern of change over time is achieved (with regards to the HRQOL and biomedical markers).

Despite the challenge, and in order to maximize the opportunity that it presents, aggregate analyses of all the interviews conducted (regardless of time of interview) was also performed and mostly presented as appendixes to the study findings. These additional analyses were to augment the results of the changes observed over time. The interpretation of the aggregate analyses should be viewed against the backdrop that this study reported very high reliability scores and that the biomedical and HRQOL indicators of the participants was also subject to change over time. This assertion is given the assumed bio-psychosocial trajectory of HIV and AIDS (Gurunathan et al., 2009; Murdaugh, 1998). With this, each interview conducted at the different time points will measure different degrees of biomedical and HRQOL outcomes even if they are from the same group of individuals. It is hence hoped that the aggregate analyses will not directly translate to duplication of records if it is interpreted correctly.

With the above, this chapter presents the findings and discussion of Study II. The chapter is structured around the objectives of Study II which are to describe the quality of life of people living with HIV and AIDS; and establish the relationship between the biological markers and HRQOL measures and assess their change over time and finally to validate and shorten the WHOQOL-HIV instrument.

In line with the first objective, the results section describes the HRQOL of PLWHA in Limpopo Province. This description is mostly done along demographic characteristics and over time. In order to do this, the results section starts by providing demographic characteristics of the study participants at baseline and dropout rate over time, followed by a description of the level of reliability of the HRQOL instrument used in the study.

With the second objective, the relationships between the biological markers and HRQOL measures and their change over time were assessed and presented using Spearman correlation coefficient. The t-tests and ANOVA were further used to compare HRQOL scores across the different levels of the biological marker. For instance, the mean HRQOL scores were compared between people with suppressed viral load and those with unsuppressed viral load over time.

The third objective was omitted because an index instrument was not developed at the end of Study I. This was based on the conclusion that such an instrument will be unwarranted as its proposed items and domains are catered for by the WHOQOL-HIV instrument.

The fourth objective of validating the WHOQOL-HIV was achieved by using Pearson correlations and Limits of Agreement Plots to assess and present the convergent and discriminant validities of the WHOQOL-HIV instrument. The MOS-HIV instrument was used in this section to validate the measures provided by the WHOQOL-HIV instrument. The construct validities of each of the six domains were assessed using the rotated component matrix tables of the principal component analysis.

The fifth objective of item removal/shortening was done at each of the three times of data collection using the item-total correlation and Cronbach's Alpha if item is deleted.

The discussion section of this chapter followed the outline of the result as guided by the above objectives of Study II.

For reference and clearer understanding of the results, the list of the WHOQOL-HIV instrument domains and their respective subscales can be found in Appendix 2.1.

5.2 Results

THE DESCRIPTION OF THE HEALTH RELATED QUALITY OF LIFE OF PEOPLE LIVING WITH HIV AND AIDS IN LIMPOPO PROVINCE

5.2.1: Demographic characteristics of study participants

The demographic characteristics of the participants at baseline are presented in Table 5.1.

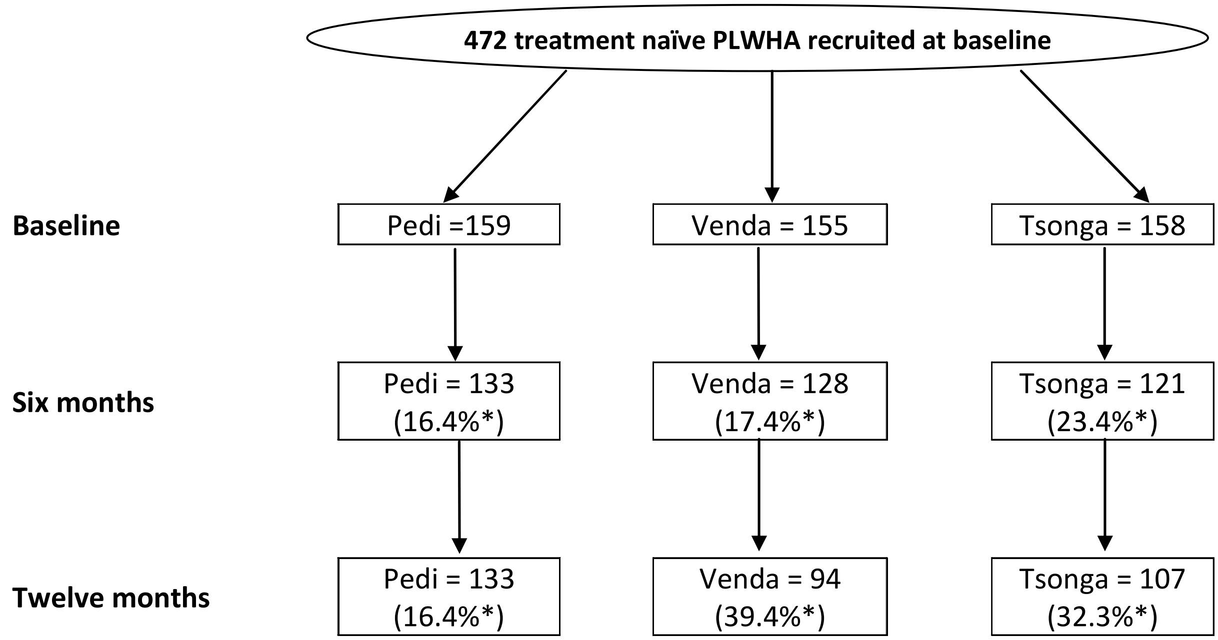
Table 5.1: Socio-demographic characteristics of study participants at baseline

Characteristics	Pedi (n = 159)	Venda (n = 155)	Tsonga (n = 158)
Sex n (%)			
Male	60 (37.7)	68 (43.9)	52 (33.1)
Female	99 (62.3)	87 (56.1)	105 (66.9)
Age group (years) n (%)			
18 – 25	15 (9.4)	11 (7.1)	5 (3.2)
26 – 35	55 (34.6)	44 (28.6)	46 (29.9)
36 – 45	52 (32.7)	56 (36.4)	63 (40.9)
46 +	37 (23.3)	43 (27.9)	40 (26.0)
Marital status n (%)			
Married	51 (34.0)	78 (56.6)	67 (45.3)
Never married	85 (56.7)	21 (13.6)	50 (33.8)
Divorced	4 (2.7)	18 (11.7)	6 (4.1)
Separated	7 (4.7)	23 (14.9)	10 (6.8)
Widowed	3 (2.0)	14 (9.1)	15 (10.1)
Children n (%)			
No	29 (19.1)	19 (12.9)	15 (10.8)
Yes	123 (80.9)	128 (87.1)	124 (89.2)
Education n (%)			
No education	25 (19.2)	27 (18.2)	48 (38.4)
Primary	70 (53.8)	65 (43.9)	37 (29.6)
Matric	29 (22.3)	44 (29.7)	36 (28.8)
Tertiary	6 (4.6)	12 (8.1)	4 (3.2)
Employment n (%)			
No	141 (89.2)	135 (87.7)	135 (90.6)
Yes	17 (10.8)	19 (12.3)	14 (9.4)
Support group n (%)			
No	24 (47.1%)	128 (89.5)	126 (89.4)
Yes	27 (52.9%)	15 (10.5)	15 (10.6)

The study cohort was drawn from three sites with each site, representing each of the target ethnic groups. The availability of biomedical patient data in each site was dependent on the site's policy on the timing of CD4 cell count and viral load testing. This means that some sites did not have the CD4 and viral load tests done at baseline and instead, relied on previous tests and presenting cardinal signs and symptoms of AIDS. Based on this, there were no baseline data for the Tsonga site and no six months data for the Venda site. Participants were, however, identified to participate at baseline in the Tsonga site even if there were no data for them.

Four hundred and seventy two participants were drawn from the three sites to participate in the study. The study cohort at baseline was mostly constituted by females, persons over 35 years old, married with children and unemployed. At baseline the ages of all the study participants ranged from 20 to 71 with an average age of 40.5 (s.d. = 9.90). The majority of the cohort had children, with each having an average of 3 children (s.d. = 1.71). The participants had disclosed their HIV status to an average of three people (s.d. = 2.32). The average household income was R565.98 (s.d. = R775.80).

This distribution of participants by ethnic group / study site and over time is illustrated in Figure 5.1 while the distribution of participants' demographic characteristics at baseline only is shown in Table 5.1. Given that same participants were followed from the day of treatment initiation to the 12th month (end of the follow up), the demographic characteristics varied over time due to deaths, loss to follow up and down referral of patients to feeder clinics outside the study sites for continued care. There was, however, no mechanism to establish the cause of patient attrition given that the study was conducted in very busy outpatient facilities in regional and super-speciality hospitals. The attrition pattern of participants due to the factors listed can be seen in the Figure 5.1 below.



* : Percentage dropout after baseline

Figure 5.1: Distribution of study participants by ethnic group and over the twelve months follow up period

From Figure 5.1 above, the lower dropout rated noted in the Pedi site in comparison to the Venda and Tsonga sites may be due to the fact that the Pedi site is a super-speciality hospital located in a high density area and in close proximity to its catchment population, unlike the other two sites which are regional hospitals in rural areas and servicing a widely dispersed catchment population.

The proportion of all participants joining support groups significantly increased with time (χ^2 = 66.78; p = .000; n = 765); 22% of the participants at baseline were in support groups, 33% and 57% of the participants were in support groups at six and twelve months, respectively. This was also the case for the proportion of people reporting CD4 count increase over time. All the participants CD4 cell counts were below 500 cells/µl at baseline while 5% and 15% of the participants had greater than 500 cells/µl at six and twelve months, respectively. While almost half of the participants still had a CD4 cell count of < 200 cells/µl at six months, about two-thirds of the participants had CD4 cell count of between 200 cells/µl and 500 cells/µl at twelve months (χ^2 = 336.71; p = .000; n = 882). The exact median CD4 cell counts at the different time points are presented later in this chapter in Figure 5.2. Similar to the observed changes in CD4 cell count, the proportion of people with suppressed viral load consistently increased with time ($\chi^2 = 80.60$; $p = .000$; $n = 560$). The proportion of participants with unsuppressed viral load reduced with time, giving 87%, 44% and 21% at baseline, six and twelve months, respectively.

5.2.2: Reliability of the WHOQOL-HIV

Table 5.2 shows the reliability values for each of the WHOQOL-HIV domains. The alpha scores presented in Table 5.2 are the aggregate scores over time and in all three languages.

Table 5.2: Reliability analysis for the WHOQOL HIV domains

Domain	**Cronbach's alpha**
Physical	.92
Psychological	.86
Level of Independence	.89
Social Relationship	.76
Environmental	.89
Spirituality/Religion/Personal Belief (SRPB)	.94
Overall quality of life and general health perceptions	.81

This study used the WHOQOL-HIV to measure the HRQOL of PLWHA in the three languages. The respective domains had very high combined reliability scores ranging from .79 with social relationship to .94 with the Spirituality/Religion/Personal Belief (SRPB) domain (Table 5.2). The overall quality of life and general health perception also has a high reliability (.81). Two subscales from the 29 subscales of the WHOQOL-HIV had low Cronbach's alpha scores (Appendix 5.1). The two subscales were physical environment and sexual activity at .43 and .53, respectively. In the 29 subscales, the highest reliabilities were recorded for death and dying and work capacity with Cronbach alphas of .96 each.

5.2.3 The health related quality of life of people living with HIV and AIDS in Limpopo Province

5.2.3.1 Health related quality of life score of the study cohort

Table 5.3 below shows mean HRQOL scores in the ethnic groups and over time. The study's inability to obtain baseline data in the Tsonga site and six months data in the Venda site is shown by the respective blank spaces in the table.

Table 5.3: Mean WHOQOL-HIV domain scores by ethnic group and over time

	Baseline					**Six Months**					**Twelve Months**				
	N	**Mean**	**SD**	**F**	**p value**	**n**	**Mean**	**SD**	**F**	**p value**	**N**	**Mean**	**SD**	**F**	**p value**
Physical Domain															
Pedi	144	10.47	1.72	12.59	.00	129	10.88	1.31	297.2	.00	126	9.93	1.13	294.11	.00
Venda	145	9.32	3.49			-	-	-			91	11.10	2.24		
Tsonga	-	-	-			109	15.46	2.66			94	16.06	2.37		
Psychological Domain															
Pedi	142	12.36	2.07	11.25	.00	129	12.78	1.60	53.21	.00	130	13.23	1.45	10.98	.00
Venda	139	11.38	2.77			-	-	-			91	13.36	2.48		
Tsonga	-	-	-			106	14.58	2.19			87	14.45	2.04		

Table 5.3 (continued): Mean WHOQOL-HIV domain scores by ethnic group and over time

	Baseline					Six Months					Twelve Months				
	N	Mean	SD	F	p value	n	Mean	SD	F	p value	N	Mean	SD	F	p value
Level of Independence Domain															
Pedi	138	10.54	1.35	102.2	.00	131	10.76	1.24	61.81	.00	128	9.66	.715	187.15	.00
Venda	146	7.95	2.71			-	-	-			92	11.48	1.80		
Tsonga	-	-	-			109	12.85	2.74			93	14.14	2.42		
Social Relationships Domain															
Pedi	141	11.60	1.33	7.072	.01	129	12.33	1.59	136.95	.00	131	11.29	1.15	140.32	.00
Venda	142	12.18	2.21			-	-	-			90	13.78	2.04		
Tsonga	-	-	-			114	15.17	2.18			91	15.42	2.38		
Environment Domain															
Pedi	130	11.45	1.05	1.39	.24	123	12.99	.86	17.12	.00	132	13.77	.94	5.37	.00
Venda	136	11.19	2.25			-	-	-			89	13.03	1.83		
Tsonga	-	-	-			106	13.91	2.27			90	13.54	2.21		

Table 5.3 above shows marked significant differences in quality of life scores between the three ethnic groups. Over time, the Tsongas consistently reported higher domain scores when compared to the scores of the Vendas and the Pedis. At baseline, the Pedis reported higher average domain scores when compared to the averaged scores of the Vendas. With the exception of the environmental domain, the observed differences between the Pedis and the Vendas at baseline were mostly significant.

On face value, the Tsongas and the Pedis had lower domain scores at twelve months in comparison to their domain scores at six months in some of the domains. In this regard, the Tsongas had lower average scores with the environmental and psychological domains at twelve months in comparison to the average score at six months. The Pedis, on the other hand, had lower average scores with the physical, level of dependence and social relationship domains at twelve months in comparison to the average score at six months. In general, the mean-differences between the average quality of life domain scores at six and twelve months were often small in comparison to the mean-differences between baseline and six and twelve months, respectively. The highest quality of life average domain score reported by the Tsongas was 16.06 (under physical domain at twelve months); for Vendas, it was 13.78 (under social relationship at twelve months); and for the Pedis it was 13.77 (under environmental domain at twelve months). A post hoc test comparing the three groups showed that differences observed between the three groups as shown in Table 5.3 were all significantly different ($p = 0.00$).

The above result was augmented by aggregate analyses of all the interviews conducted and is presented in Appendix 5.2. The analyses show significant differences in average scores of the ethnic groups in all 29 subscales and six domains (Appendix 5.2). Similarly, the Tsonga group consistently had higher HRQOL mean scores in almost all the 29 subscales and six domains of the WHOQOL-HIV. The mean difference between the Tsonga group and the other two groups was also very wide. Across the subscales, all the ethnic groups had the lowest scores with the subscales "dependence on treatment" and "financial resources". This observation is expected to be consistent in all the comparisons to follow.

The aggregate analysis in Appendix 5.2 further shows that when comparing the Pedi and Venda groups, the quality of life mean scores were in most cases higher among the Pedis. The few instances when the mean score was higher among the Venda group when compared to the Pedi group were with positive feelings, dependence on medication, social support, sexual activity, home environment, overall quality of life and general health perception and social support. The post hoc text in Appendix 5.3 further showed that the observed differences in mean HRQOL scores between the Pedi and Venda groups were often not statistically significant. Appendix 5.3 also shows that the differences observed between the Tsonga groups and each of the other two groups differed significantly in all subscales and domains.

5.2.3.2 Differences in quality of life scores by demographic characteristics

Table 5.4 below presents the HRQOL by sex and over time.

Table 5.4: Mean WHOQOL-HIV domain scores by sex and over time

	Baseline					Six Months					Twelve Months				
	N	Mean	SD	F	p value	n	Mean	SD	F	p value.	n	Mean	SD	F	p value
Physical Domain															
Male	118	9.87	2.69	.014	.90	76	12.88	3.44	.10	.75	109	12.17	3.30	.04	.85
Female	171	9.91	2.89			162	13.02	2.88			201	12.09	3.25		
Psychological Domain															
Male	115	12.33	2.40	6.49	.01	77	13.80	2.311	1.13	.29	110	13.57	2.06	.06	.81
Female	166	11.57	2.50			158	13.49	1.971			197	13.63	2.02		
Level of Independence Domain															
Male	121	8.73	2.54	7.76	.01	80	11.61	2.47	.21	.65	109	11.45	2.41	.15	.70
Female	163	9.56	2.44			160	11.76	2.23			204	11.56	2.58		

Table 5.4 (continued): Mean WHOQOL-HIV domain scores by sex and over time

	Baseline					Six Months					Twelve Months				
	N	Mean	SD	F	p value	n	Mean	SD	F	p value	n	Mean	SD	F	p value
Social Relationships Domain															
Male	116	12.12	1.60	3.08	.08	79	13.87	2.67	.97	.33	112	13.36	2.62	.67	.41
Female	167	11.73	2.0			164	13.55	2.20			199	13.11	2.49		
Environment Domain															
Male	111	11.64	1.62	6.37	.01	77	13.71	1.68	3.54	.06	109	13.51	1.53	.03	.87
Female	155	11.09	1.84			152	13.26	1.73			202	13.48	1.76		
Spirituality/Religion/ Personal Beliefs Domain															
Male	54	9.24	2.97	.13	.72	81	14.41	3.12	.00	1.00	73	13.58	3.12	.01	.92
Female	96	9.42	2.81			162	14.40	3.26			156	13.62	3.35		

Table 5.4 above shows the differences in quality of life domain scores when comparing males and females. The differences between males and females were mostly not significant at six and twelve months. The observed significant differences were at baseline and males had significantly higher scores with psychological and environmental domains. Females had significantly higher average score in the level of dependence domain. There was no significant difference between males and females in the physical domain, social relationship domain and the spirituality/religion/personal belief (SRPB) domain at six months.

On face value, males consistently had higher quality of life scores at six months when compared to their quality of life scores at twelve months. On the other hand, females recorded improved average quality of life domain scores in the psychological domain and environmental domains. Generally, the mean-differences between the six and twelve month scores were small in both males and females when comparing the average scores at six and 12 months with the average scores at baseline. The highest average domain scores for the males and females were under the SRPB and psychological domains at six months while their lowest scores were in the level of dependence domain at baseline.

An aggregate analysis of all the interviews conducted showed significant differences in average WHOQOL-HIV scores in seven out of the 35 subscales and domains of the WHOQOL-HIV. Males recoded significantly higher scores in three out of the seven components. The four subscales where males had higher mean scores were thinking, learning, memory and concentration (p = .01); home environment (p = 00.); and opportunity for acquiring new information and skills (p = .04). The females scored higher mean scores with activities of living (p = .03); dependence on medication or treatment (p = .04); work capacity (p = .01); and level of independence (p = .00). Both groups had notably lower mean scores with dependence on medication or treatment while the highest scores were reported for opportunity to acquire new information and skills. These findings are similar to the findings of the time specific analysis as the listed subscales constitutes the domains where such differences was observed earlier.

The table below shows the quality of life domain scores by marital status and over time. Three categories of marital status are considered as shown in the table. People not currently in a marriage are grouped together as divorced/separated/widowed.

Table 5.5: Mean WHOQOL-HIV domain scores by marital status and over time

	Baseline					Six Months					Twelve Months				
	n	Mean	SD	F	p value	n	Mean	SD	F	p value	n	Mean	SD	F	p value
Physical Domain (CD4 cell counts in cells/µl)															
Married	119	9.66	2.85	2.98	.05	93	13.28	3.19	22.32	.00	126	12.48	3.27	2.599	.07
Never married	99	10.42	2.42			99	11.77	2.55			95	11.49	2.95		
Divorced/Separated/Widowed	63	9.44	3.24			38	15.29	2.49			89	12.24	3.45		
Psychological Domain															
Married	113	11.76	2.64	1.21	.29	94	13.79	2.25	3.98	.02	123	13.66	2.12	1.505	.22
Never married	96	12.21	2.22			99	13.24	1.86			97	13.81	2.00		
Divorced/Separated/Widowed	63	11.66	2.60			34	14.31	1.90			87	13.31	1.91		

Table 5.5 (continued): Mean WHOQOL-HIV domain scores by marital status and over time

	Baseline					Six Months					Twelve Months				
	n	Mean	SD	F	p value	n	Mean	SD	F	p value	n	Mean	SD	F	p value
Level of Independence Domain															
Married	120	8.95	2.76	6.28	.00	94	11.99	2.26	5.58	.00	126	11.78	2.53	1.217	.29
Never married	91	9.93	1.78			103	11.25	2.08			96	11.39	2.19		
Divorced/Separated/Widowed	64	8.63	2.79			35	12.60	2.60			90	11.28	2.78		
Social Relationships Domain															
Married	115	11.88	2.08	.02	.98	93	14.18	2.32	17.07	.00	121	13.78	2.61	5.599	.00
Never married	98	11.93	1.41			103	12.76	2.16			100	12.97	2.45		
Divorced/Separated/Widowed	62	11.88	2.07			38	14.91	2.10			90	12.68	2.41		
Environment Domain															
Married	112	11.31	1.94	.01	.98	87	13.39	1.72	6.57	.00	123	13.48	1.63	.140	.86
Never married	91	11.30	1.37			99	13.19	1.37			99	13.45	2.08		
Divorced/Separated/Widowed	57	11.34	2.07			34	14.38	2.25			88	13.57	1.18		
Spirituality/Religion/ Personal Beliefs Domain															
Married	50	9.22	3.04	.18	.83	95	14.68	3.04	11.53	.00	71	14.41	3.28	4.160	.01
Never married	79	9.49	2.90			100	13.43	3.09			74	13.68	3.01		
Divorced/Separated/Widowed	14	9.64	2.62			39	16.10	2.96			84	12.90	3.38		

Table 5.5 above shows that the quality of life increased after treatment initiation. Regardless of marital status, the participants tended to have higher quality of life domain score at six and twelve months when compared to the baseline domain scores. On face value, scores sometimes declined at twelve months. Significant differences based on marital status were noted under the baseline level of dependence, social relationship and environmental domains and under the social relationship and SRPB domains at twelve months. In this regard, married people reported higher quality of life in comparison to the other two categories in instances where there were significant differences in domain scores at twelve months. All the quality of life domains at six months showed significant differences by marital status. Divorced/separated /widowed participants consistently had the highest quality of life domain scores followed by those who were married at six months. The highest scores were recorded for people who were divorced/separated /widowed at six months under the physical and SRPB domains, respectively

The aggregate analysis of all the interviews shown in Appendix 5.4 indicates that many of the domains and subscales differed significantly by marital status. People who were divorced/separated/widowed mostly recorded significantly higher mean scores in seven out of the twelve subscales and domains where the subscales and domain differed significantly. People who had never married had significantly higher scores with positive feelings and transport subscales while married people had significantly higher scores with sexual activity and social relationships subscales. The participants reported the lowest scores with financial resources and the highest scores with SRPB. Despite the reported difference in Appendix 5.4, Appendix 5.5 shows that differences between married and people who had never married was often not significantly different. Appendix 5.5 also shows the higher mean scores reported by persons who were divorced/separated/widowed often significantly differed from the mean scores of the other two groups (married and never married). In this regard, the findings of this aggregate analysis are also similar to the findings of the time specific analysis.

The WHOQOL-HIV domain scores are presented in Table 5.6 below showing a distribution of the scores across people with and without children. The presentation also displays the respective domain scores at different points in time.

Table 5.6: Mean WHOQOL-HIV domain scores by people with and without children and over time

	Baseline					Six Months					Twelve Months				
	n	Mean	SD	F	p value	n	Mean	SD	F	p value	n	Mean	SD	F	p value
Physical Domain															
With	233	10.08	2.86	3.48	.06	168	13.43	3.21	22.17	.00	217	12.87	3.42	52.03	.00
Without	45	9.22	2.59			56	11.30	1.82			85	10.08	1.55		
Psychological Domain															
With	224	12.04	2.44	1.69	.20	162	13.87	2.10	10.44	.00	211	13.77	2.13	4.61	.03
Without	46	11.51	2.70			59	12.88	1.75			89	13.22	1.80		
Level of Independence Domain															
With	229	9.24	2.52	.40	.53	166	12.07	2.30	19.79	.00	216	12.11	2.62	53.50	.00
Without	44	8.98	2.61			60	10.62	1.74			88	9.97	1.30		

Table 5.6 (continued): Mean WHOQOL-HIV domain scores by people with and without children and over time

	Baseline					Six Months					Twelve Months				
	N	Mean	SD	F	p value	n	Mean	SD	F	p value	n	Mean	SD	F	p value
Social Relationships Domain															
With	233	11.99	1.85	2.34	.13	171	13.90	2.34	16.11	.00	215	13.84	2.56	55.37	.00
Without	42	11.52	1.72			57	12.53	1.92			89	11.66	1.63		
Environment Domain															
With	219	11.36	1.75	.25	.62	163	13.52	1.84	2.46	.12	214	13.45	1.87	.36	.55
Without	40	11.51	1.61			57	13.11	1.19			88	13.58	1.21		
Spirituality/Religion/ Personal Beliefs Domain															
With	117	9.43	2.88	.03	.86	169	14.63	3.29	9.09	.00	145	14.68	3.24	58.41	.00
Without	26	9.54	2.98			60	13.22	2.55			78	11.58	2.09		

Table 5.6 shows that people with and without children had no significant differences at baseline. With the exception of the environmental domain, there were significant differences between their quality of life scores at six and twelve months. People with children consistently had significantly higher quality of life average domain scores when compared to people without children. The mean-differences in scores between six and twelve months were small when compared to their difference with baseline scores. For people with children, the highest scores were recorded under the spirituality domain followed by the social relationship domain. The highest score for those without children was recorded under the environmental domain. The lowest score for people with children was under level of dependence at baseline while for people without children it was the physical domain at baseline.

The aggregate analysis presented in Appendix 5.6 similarly showed that people with children consistently had higher scores in all the subscales and domains where there was significant difference between both groups. When compared to other demographic characteristics discussed earlier, more subscales and domains differed significantly when comparing the scores of participants with or without children. Like most other characteristics, mean scores in both groups was lowest with financial resources and highest with opportunity for acquiring new information and skill subscales. From the result, there was significant difference between both groups in all the six main domains except the environmental domain.

Table 5.7 below shows differences in HRQOL domain scores by employment status.

Table 5.7: Mean WHOQOL-HIV domain by employment status and over time

	Baseline					Six Months					Twelve Months				
	n	**Mean**	**SD**	**F**	p value	**n**	**Mean**	**SD**	**F**	p value	**n**	**Mean**	**SD**	**F**	p value
Physical Domain															
Employed	31	9.06	2.44	3.04	.08	10	16.00	3.86	10.25	.00	31	13.77	3.36	9.40	.00
Unemployed	257	9.99	2.84			208	12.88	2.96			271	11.91	3.19		
Psychological Domain															
Employed	29	11.61	2.31	.38	.54	8	14.70	2.53	2.07	.15	32	14.65	2.16	10.10	.00
Unemployed	251	11.91	2.51			206	13.62	2.07			267	13.47	1.97		
Level of Independence Domain															
Employed	32	8.88	2.74	.59	.44	10	13.60	3.10	7.02	.01	29	13.14	2.57	13.87	.00
Unemployed	251	9.24	2.49			209	11.63	2.25			275	11.35	2.44		
Social Relationships Domain															
Employed	29	12.16	1.44	.70	.41	10	15.03	2.24	3.44	.07	31	15.08	2.56	20.24	.00
Unemployed	253	11.86	1.89			214	13.63	2.32			272	12.99	2.43		

Table 5.7 (continued): Mean WHOQOL-HIV domain by employment status and over time

	Baseline					Six Months					Twelve Months				
	n	**Mean**	**SD**	**F**	**p value**	**n**	**Mean**	**SD**	**F**	**p value**	**n**	**Mean**	**SD**	**F**	**p value**
Environment Domain															
Employed	29	11.74	2.40	1.83	.18	9	13.72	1.79	.29	.59	29	14.38	1.98	9.16	.00
Unemployed	236	11.27	1.68			203	13.40	1.72			273	13.39	1.64		
Spirituality/Religion/ Personal Beliefs Domain															
Employed	16	8.88	3.52	.55	.46	10	15.80	2.94	1.90	.17	18	16.00	3.51	10.44	.00
Unemployed	133	9.44	2.78			212	14.39	3.19			203	13.44	3.19		

Table 5.7 shows that employed people had lower average domain scores when compared to the unemployed at baseline even if the differences were not significant. This pattern changed at six and twelve months with the employed people having higher quality of life scores at both times. Relative to the other demographic characteristics, employed people seem to have a much higher average score when compared to unemployed people. The highest average score among the employed people was 16.00 under the physical domain at six months and SRPB domain at 12 months. The highest quality of life scores for unemployed people were 13.62 under the psychological domain at six months and 14.39 under the SRPB domain at six months. The lowest score for employed people was 8.88 under level of dependence at baseline and 9.24 for unemployed under level of dependence at baseline.

Table 5.8 below presents the aggregate analysis of the HRQOL scores of only subscales and domains where there were significant differences between employed and unemployed people. In other words, the table does not include subscales and domains where there was no significant difference between both groups.

Table 5.8: Aggregate analysis of the mean WHOQOL-HIV subscale and domain scores showing significant difference by employment status

	N	Mean	SD	T	p value
Energy and fatigue	Yes	76	2.91	2.239	.03
	No	771	2.73		
Negative feelings	Yes	75	3.25	2.362	.02
	No	771	2.95		
Dependence on medication or treatments	Yes	76	1.95	2.758	.00
	No	768	1.70		
Social support	Yes	75	3.25	2.310	.02
	No	775	2.99		

Table 5.8 (continued): Aggregate analysis of the mean WHOQOL-HIV subscale and domain scores showing significant difference by employment status

	N	Mean	SD	T	p value
Sexual activity	Yes	75	3.11	3.511	.00
	No	768	2.77		
Financial resources	Yes	75	2.33	6.962	.00
	No	768	1.58		
Social Relationships	Yes	70	13.86	3.641	.00
	No	739	12.79	3.405	.00

The findings of the aggregate analysis shown in Table 5.8 above indicate that employed and unemployed people in the study differed in term of energy and fatigue, negative feelings, dependence on medication and treatments, social support, sexual activity, financial resources and social relationships. The reported means and t-test all show that employed people had significantly better quality of life in all the subscales and domains where significant differences were reported. While the table does not show all the subscales, on face value, the participants scores was lowest under dependence on medication or treatment and highest with social support subscales.

Table 5.9 below presents the quality of life domain scores by support group membership

Table 5.9: Mean WHOQOL-HIV domain scores by support group membership and over time

	Baseline					Six Months					Twelve Months				
	n	**Mean**	**SD**	**F**	**p value**	**n**	**Mean**	**SD**	**F**	**p value**	**n**	**Mean**	**SD**	**F**	**p value**
Physical Domain															
Member	38	10.55	2.28	3.61	.06	76	12.13	2.44	8.94	.00	170	11.11	2.58	44.39	.00
Nonmember	143	9.44	3.41			151	13.40	3.28			127	13.47	3.54		
Psychological Domain															
Member	33	11.52	1.90	.02	.88	78	13.45	1.93	.76	.37	171	13.38	1.70	5.37	.02
Nonmember	142	11.44	2.68			146	13.70	2.21			123	13.94	2.39		
Level of Independence Domain															
Member	38	10.16	1.52	17.62	.00	77	11.17	2.06	6.56	.01	171	10.64	2.05	54.02	.00
Nonmember	139	8.19	2.77			153	11.99	2.41			128	12.63	2.63		

Table 5.9 (continued): Mean WHOQOL-HIV domain scores by support group membership and over time

	Baseline					Six Months					Twelve Months				
	n	Mean	SD	F	p value	n	Mean	SD	F	p value	n	Mean	SD	F	p value
Social Relationships Domain															
Member	34	11.75	1.63	1.04	.31	77	12.93	2.00	13.61	.00	174	12.35	2.10	46.69	.00
Nonmember	140	12.15	2.13			156	14.10	2.43			124	14.23	2.63		
Environment Domain															
Member	36	10.71	1.16	2.93	.10	76	13.16	1.37	3.17	.08	176	13.65	1.20	3.81	.05
Nonmember	134	11.35	2.18			145	13.59	1.89			120	13.26	2.17		
Spirituality/Religion/ Personal Beliefs Domain															
Member	25	7.80	1.26	1.72	.20	79	13.66	3.13	6.95	.01	147	12.48	2.85	59.26	.00
Nonmember	23	8.74	3.33			154	14.82	3.23			77	15.64	3.01		

Table 5.9 shows that non members of support groups reported better quality of life in all the domains and consistently over time. On face value, people in support groups mostly reported lower average quality of life scores at twelve months when compared to their quality of life scores at six months while people not in support groups were more likely to have higher quality of life scores at twelve months when compared to their scores at six months. With the exception of the level of dependence domain at baseline, people not in support groups consistently had higher quality of life scores in instances where average scores between groups were significantly different. This was particularly the case at twelve months except for the environmental domain where there was no significant difference between both groups at twelve months. The highest average score among people not in support groups was 14.23 under the social relationship domain at twelve months and 15.64 under SRPB domain at twelve months. The lowest average score for people not in support groups was with level of dependence at baseline (8.19) while among people in support groups the lowest score was 10.16 under the level of dependence domain at baseline.

The aggregate analysis presented in Appendix 5.7 further indicates that many of the subscales and domains differed by the participants support group membership status. The aggregate analysis showed a slightly different trend in the pattern of difference in average scores reported by people in support groups and those not in support groups. Participants belonging to support groups reported significantly higher quality of life in some subscales and domain while the participants who did not belong to support groups had significantly higher quality of life scores in other instances. With regards to symptoms (p = 00.), pain and discomfort (p = .01) and energy and fatigue (p = .00), those not in support group reported a better quality of life while those in support group reported better quality of life on the subscale “overall quality of life” and general health perception” (p = .01). Another observation was that the participants in support groups had significantly high positive feeling score (p = .02) while the participants not in support groups had significantly lower negative feelings score (p = .00) and more social support (p = .00) and financial resources (p = .00).

The aggregate analysis in Appendix 5.7 further showed that people in support groups also had better self esteem (p = .02), body image appearance (p = .)02, opportunity to learn (p = .00), health care (p = .00) and environmental (p = .01) and psychological domain scores (p = .00). On the other hand, the same group had significantly less dependence on medication and treatments (p = .00), personal relationships (p = .00), social support (p = .00), sexual activity 00, financial resources (p = .00), social relationships (p = .00) and SRPB 00.

THE RELATIONSHIP BETWEEN CHANGES IN CD4 COUNT, VIRAL BURDEN AND HRQOL OVER TIME

5.2.4: Relationship between the biological markers HIV and AIDS and the HRQOL measure and their change over time

5.2.4.1 Change in biological markers over time

Figure 5.2 below shows the median CD4 cell count and viral load over time.

Figure 5.2: Median CD4 cell count and viral load over time

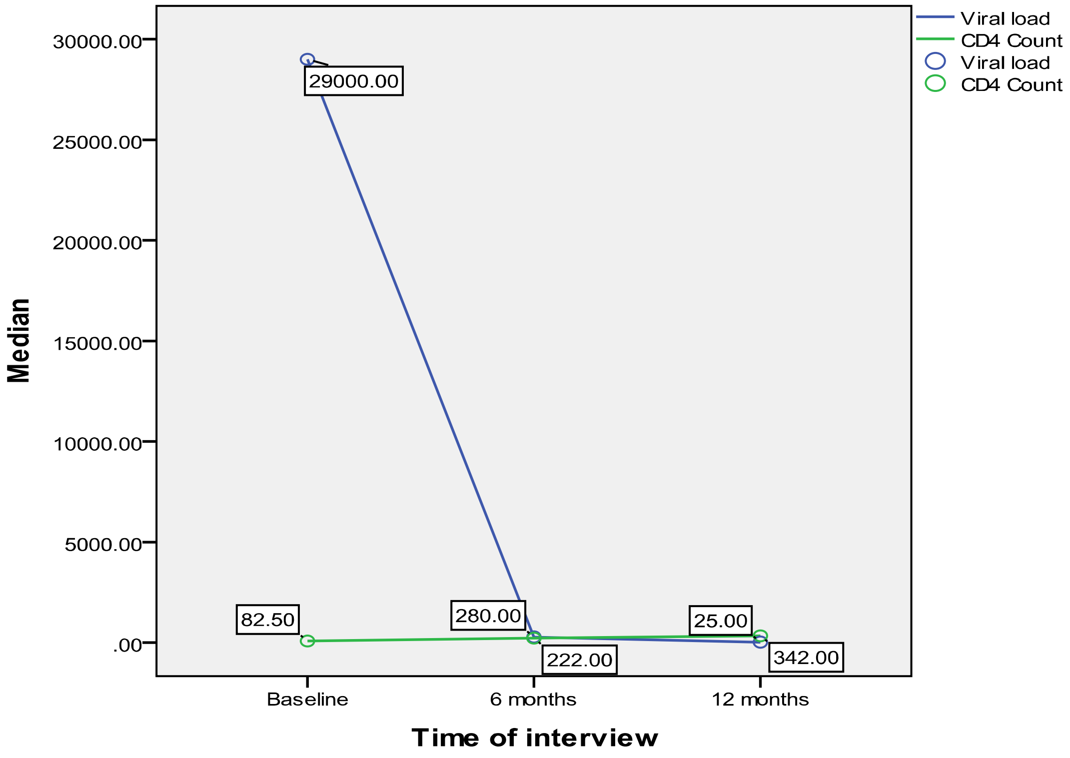


Figure 5.2 shows a marked decline in viral load six months after treatment initiation and a further reduction at 12 months. Similarly, the CD4 cell count increased over time. The lines for the viral load and CD4 cell counts both tended to plateau after six months with little changes at 12 months.

5.2.4.2 Change in HRQOL measures over time

Table 5.10 presents the average quality of life scores across the three points of data collection. Unlike the earlier tables, Table 5.10 is independent of demographic characteristics. Instead, it shows the pattern of change in each of domain scores over time.

Table 5.10: Comparison of the average WHOQOL-HIV domain scores at the three interview times

WHOQOL-HIV scales and domains	Interview time	n	Mean	SD	F	Sig.
Physical	Baseline	289	9.90	2.806	73.702	.000
	6 months	238	12.97	3.065		
	12 months	311	12.13	3.260		
Psychological	Baseline	281	11.88	2.484	56.359	.000
	6 months	235	13.59	2.089		
	12 months	308	13.61	2.031		
Level of Independence	Baseline	284	9.20	2.515	89.789	.000
	6 months	240	11.71	2.305		
	12 months	313	11.52	2.519		

Table 5.10 (continued): Comparison of the average WHOQOL-HIV domain scores at the three interview times

WHOQOL-HIV scales and domains	Interview time	n	Mean	SD	F	Sig.
Social Relationships	Baseline	283	11.89	1.850	44.426	.000
	6 months	243	13.66	2.360		
	12 months	312	13.21	2.543		
Environment	Baseline	266	11.32	1.769	137.594	.000
	6 months	229	13.41	1.725		
	12 months	311	13.49	1.681		
Spirituality/Religion/ Personal Beliefs	Baseline	150	9.35	2.859	128.508	.000
	6 months	243	14.40	3.207		
	12 months	230	13.63	3.281		

The mean scores for all quality of life scales and domains differed significantly over time. With the exception of the environmental domain, the mean scores tended to be higher at six months when compared to the mean scores at baseline and twelve months (Table 5.10). Six and twelve month scores had marked mean differences when compared to the baseline mean scores, respectively. As usual, the lowest means at baseline, six and twelve months were reported for financial resources while the highest mean scores were reported under the health care and opportunity for new information and skills domains. In both subscales, there was a significant and progressive increase with time.

Appendix 5.8, however, shows that the observed higher mean score at six months was not always significantly different from the mean scores at twelve months. For instance, the means at six and twelve months were not significantly different in terms of level of dependence (p = .38), environmental (p = .61) and psychological (p = 90.) domains.

5.2.4.3 Correlation and comparison of CD4 cell count, viral load and the HRQOL measures

The table below shows the correlation between the six quality of life domains and CD4 and viral load categories respectively, across the three points of data collection

Table 5.11: Correlation coefficients of CD4 cell count level, viral suppressions status and the WHO-QOL domains

		Baseline		**Six Months**		**Twelve Months**	
		CD4 cell count grouping	Viral load suppression status	CD4 cell count grouping	Viral load suppression status	CD4 cell count grouping	Viral load suppression status
Physical	Coefficient	-0.04	-0.21	.15[*]	0.12	-0.01	-0.12
	Sig. (2-tailed)	0.53	0.16	0.02	0.10	0.83	0.05
	n	279	48	237	204	302	270
Psychological	Coefficient	0.03	-0.07	.17[**]	0.02	0.08	-.17[**]
	Sig. (2-tailed)	0.62	0.66	0.01	0.74	0.15	0.01
	n	272	44	234	203	299	269
Level of Independence	Coefficient	-0.02	-.31[*]	0.04	0.09	0.00	-0.08
	Sig. (2-tailed)	0.77	0.04	0.54	0.21	0.98	0.17
	n	275	46	239	207	304	273

Table 5.11 (continued): Correlation coefficients of CD4 cell count level, viral suppressions status and the WHO-QOL domains

		Baseline		**Six Months**		**Twelve Months**	
		CD4 cell count grouping	Viral load suppression status	CD4 cell count grouping	Viral load suppression status	CD4 cell count grouping	Viral load suppression status
Social Relationships	Coefficient	0.06	0.23	-0.02	0.08	-0.07	-0.06
	Sig. (2-tailed)	0.36	0.12	0.73	0.23	0.23	0.34
	n	275	47	242	209	303	273
Environment	Coefficient	0.02	.40**	0.13	0.04	0.07	0.01
	Sig. (2-tailed)	0.82	0.01	0.06	0.63	0.21	0.86
	n	257	43	228	196	302	272
Spirituality/Religion/ Personal Beliefs	Coefficient	-0.11	.	0.07	0.05	-0.11	-0.01
	Sig. (2-tailed)	0.18	.	0.25	0.47	0.10	0.93
	n	146	0.00	242	207	228	220

For better clinical and statistical judgment, the viral load and CD4 cell count were grouped into categories. The viral load was classed as suppressed and unsuppressed by using 400 copies/ml as a cut-off point (DOH, 2003). The CD4 cell counts were, however, grouped into four (0 – 200 cell/µl; 201 – 349 cell/µl; 350 – 500 cell/µl; >500 cell/µl) (Peltzer et al., 2008). The correlation of these categories of biological markers with WHOQOL-HIV domains are shown in Table 5.11 which shows two notably low associations between viral load and level of dependence and environmental domains respectively at baseline. All the other correlations at the different times showed no associations.

Table 5.12 shows the aggregate analysis correlating the biomedical markers with HRQOL indicators.

Table 5.12: Aggregate Correlation coefficients of CD4 cell count level, viral suppressions status and the WHO-QOL domains

	CD4 cell count grouping:			**Viral load suppression status**		
	N	**r**	**p**	**N**	**r**	**p**
Physical	818	.20*	.00	522	-.08	.08
Psychological	805	.26*	.00	516	-.13*	.00
Level of Independence	818	.20*	.00	526	-.10*	.02
Social Relationships	820	.11*	.00	529	.03	.52
Environment	787	.37*	.00	511	-.04	.34
Spirituality/Religion/ Personal Beliefs	616	.21*	.00	427	.04	.37

The above table shows a slightly different pattern with CD4 cell count categories tending to correlate more with WHOQOL domains. The highest correlation coefficient observed was for the environment (r = .37, p = .000) and psychological domains (r = .26, p = .000). Despite this, all the correlations were too low to suggest any association (Sim and Wright, 2000).

Table 5.13 shows the average domain scores by viral load suppression status across the three data collection times

Table 5.13: WHOQOL-HIV domains scores by viral load suppression status over time

	Baseline					Six Months					Twelve Months				
	n	Mean	SD	t	p value	N	Mean	SD	t	p value	n	Mean	SD	T	p value
Physical Domain															
Suppressed	7	11.71	4.15	1.36	.18	113	12.21	2.81	-1.69	.09	212	12.39	3.37	1.76	.08
Unsuppressed	41	9.41	4.14			91	12.90	2.99			58	11.52	3.18		
Psychological Domain															
Suppressed	5	12.64	2.22	.44	.66	118	13.40	1.88	-.35	.73	215	13.87	1.97	2.60	.01
Unsuppressed	39	12.02	3.05			85	13.50	2.20			54	13.10	1.91		
Level of Independence Domain															
Suppressed	7	10.14	2.27	1.88	.07	117	11.42	2.03	-1.31	.19	218	11.68	2.64	1.60	.11
Unsuppressed	39	7.67	3.33			90	11.81	2.26			55	11.05	2.31		

Table 5.13 (continued): WHOQOL-HIV domains scores by viral load suppression status over time

	Baseline					Six Months					Twelve Months				
	N	Mean	SD	t	p value	N	Mean	SD	t	p value	n	Mean	SD	T	p value
Social Relationships Domain															
Suppressed	7	11.61	2.45	1.74	.09	120	13.35	2.38	-.93	.35	215	13.25	2.63	.84	.40
Unsuppressed	40	13.07	2.00			89	13.65	2.18			58	12.93	2.53		
Environment Domain															
Suppressed	5	9.70	1.82	2.86	.00	113	13.15	1.43	-1.19	.27	213	13.54	1.69	-.17	.87
Unsuppressed	38	12.43	2.03			83	13.42	1.63			59	13.58	1.41		
Spirituality/Religion/ Personal Beliefs Domain															
Suppressed						120	13.92	3.15	-.84	.40	174	13.59	3.24	.04	.97
Unsuppressed						87	14.29	3.08			46	13.57	3.64		

Like all the earlier analyses, Table 5.13 shows that the quality of life improved following treatment initiation. In other words, the quality of life at six and 12 months were higher than the quality of life at baseline among people with suppressed and unsuppressed viral load. On face value, people with suppressed viral load had a higher quality of life at twelve months in comparison to their reported quality of life at six months in all the six domains except the SRPB domain. Conversely, the mean quality of life of people with unsuppressed viral load tended to be lower at twelve months when compared to their score at six months. Despite this, significant differences in the quality of life score between people with suppressed and unsuppressed viral load were noted in two instances. People with suppressed viral load had higher environmental domain score at baseline and a higher psychological domain score at twelve months. The highest domain score was also noted among people with suppressed viral load under the psychological domain at twelve months. On the other hand, people with unsuppressed viral load reported the lowest quality of live domain average score under level of dependence at baseline.

Table 5.14 below shows results of the aggregate analysis of the average quality of life scores by viral load suppression status.

Table 5.14: Comparison of the aggregate average WHOQOL-HIV domains cores by viral load suppression status

	Viral load suppression status	**N**	**Mean**	**SD**	**T**	**p-value**
Physical	Suppressed	332	12.31	3.200	1.931	.05
	Unsuppressed	190	11.73	3.577	1.873	
Psychological	Suppressed	338	13.69	1.952	3.250	.00
	Unsuppressed	178	13.05	2.389	3.055	
Level of Independence	Suppressed	342	11.56	2.451	3.512	.00
	Unsuppressed	184	10.71	2.994	3.309	

Table 5.14 (continued): Comparison of the aggregate average WHOQOL-HIV domains cores by viral load suppression status

	Viral load suppression status	**N**	**Mean**	**SD**	**T**	**p-value**
Social Relationships	Suppressed	342	13.25	2.550	-.220	.83
	Unsuppressed	187	13.30	2.273	-.228	
Environment	Suppressed	331	13.35	1.678	.553	.58
	Unsuppressed	180	13.26	1.702	.550	
Spirituality/Religion/ Personal Beliefs	Suppressed	294	13.72	3.205	-.937	.35
	Unsuppressed	133	14.04	3.288	-.928	

(Suppressed viral load below 400 copies/ml; unsuppressed above 400 copies/ml)

The aggregate analysis in table 5.14 shows that the domain mean scores of the suppressed and unsuppressed participants differed significantly in two out of the six domains. The two domains were the psychological and level of dependence domains. With the exception of the SRPB domain, participants with suppressed viral loads had higher quality of life scores in the remaining five domains. The mean scores on level of dependence were relatively lower than the mean scores in the other five domains (Table 5.14). The highest mean scores were reported for the SRPB domain. Both the specific time and aggregate analyses show significant differences in the psychological domain.

Table 5.15 shows the average domain scores by CD4 cell count categories across the three data collection times

Table 5.15: WHOQOL-HIV domains scores by CD4 count level over time

	Baseline					**Six Months**					**Twelve Months**				
	n	**Mean**	**SD**	**F**	**p value**	**n**	**Mean**	**SD**	**F**	**p value**	**n**	**Mean**	**SD**	**F**	**p value**
Physical Domain (CD4 cell counts in cells/µl)															
0 - 200	254	9.95	2.87	.65	.52	105	12.60	2.95	2.65	.05	58	12.34	3.24	2.53	.06
201 - 349	23	9.43	2.40			84	12.83	2.91			97	12.53	3.54		
350 - 500	2	11.50	4.95			37	14.08	3.48			101	11.52	2.99		
> 500						11	14.00	3.29			46	12.89	3.07		
Psychological Domain															
0 - 200	247	11.92	2.53	.14	.86	101	13.30	2.20	2.50	.06	55	13.57	2.54	3.81	.01
201 - 349	23	12.17	1.94			84	13.57	2.03			98	13.53	1.91		
350 - 500	2	12.40	2.82			39	14.01	1.90			100	13.44	1.82		
> 500						10	14.88	1.65			46	14.57	1.75		
Level of Independence Domain															
0 - 200	251	9.21	2.55	.05	.94	100	11.69	2.11	1.94	.12	56	11.77	2.85	2.54	.06
201 - 349	22	9.05	2.17			86	11.35	2.270			99	11.71	2.69		
350 - 500	2	9.50	3.54			42	12.14	2.71			102	11.04	2.22		
> 500						11	12.73	2.24			47	12.15	2.38		

Table 5.15 (continued): WHOQOL-HIV domains scores by CD4 count level over time

	Baseline					Six Months					Twelve Months				
	n	Mean	SD	F	p value	n	Mean	SD	F	p value	n	Mean	SD	F	p value
Social Relationships Domain															
0 - 200	251	11.89	1.86	.30	.74	102	13.79	2.24	.84	.47	55	13.55	2.50	3.44	.01
201 - 349	22	12.15	1.50			86	13.34	2.41			101	13.54	2.70		
350 - 500	2	12.50	2.48			42	13.94	2.49			102	12.61	2.45		
> 500						12	13.48	2.39			45	13.74	2.35		
Environment Domain															
0 - 200	234	11.37	1.80	.21	.81	96	13.33	1.57	.85	.46	57	13.45	1.76	.87	.46
201 - 349	21	11.60	1.05			83	13.33	1.94			97	13.43	1.60		
350 - 500	2	11.00	3.54			39	13.81	1.66			101	13.54	1.67		
> 500						10	13.25	1.44			47	13.88	1.65		
Spirituality/Religion/ Personal Beliefs Domain															
0 - 200	129	9.45	2.90	2.27	.13	102	14.33	3.11	1.30	.27	38	14.34	3.50	5.37	.00
201 - 349	17	8.35	2.15			87	14.05	3.38			74	14.22	3.22		
350 - 500						41	14.88	2.84			86	12.58	2.98		
> 500						12	15.67	3.77			30	14.53	3.26		

Table 5.15 shows an increase in the quality of life with treatment even among people who had low CD4 cell counts at six and twelve months. On face value, the mean domain scores were lower at 12 months in all the CD4 cell count categories of the physical domain when compared to their mean scores at six months. Some CD4 cell count categories of the other five domains had higher mean scores at twelve months while others had lower scores when compared to their scores at six months. The significant differences in the mean scores of the various categories were only observed at 12 months in the psychological, social relationship and the SRPB domains. In these three domains, people with CD4 cell counts of over 500 cell/µl consistently had higher mean domain scores. The highest score was also reported under the psychological domain at six months (14.88) while the lowest score was reported under level of dependence domain at baseline (9.05).

Table 5.16 below shows the aggregate comparison of the quality of life domain scores by CD4 cell count categories.

Table 5.16: Comparison of the average WHOQOL-HIV domains scores by CD4 count level

		n	**Mean**	**SD**	**F**	**p value.**
Physical	0 - 200 cells/µl	417	10.95	3.193	14.406	.000
	201 - 349 cells/µl	204	12.30	3.329		
	350 - 500 cells/µl	140	12.20	3.320		
	> 500 cells/µl	57	13.11	3.115		
Psychological	0 - 200 cells/µl	403	12.49	2.555	21.570	.000
	201 - 349 cells/µl	205	13.40	2.001		
	350 - 500 cells/µl	141	13.58	1.860		
	> 500 cells/µl	56	14.63	1.724		

Table 5.16 (continued): Comparison of the average WHOQOL-HIV domains scores by CD4 count level

		n	Mean	SD	F	p value.
Level of Independence	0 - 200 cells/µl	407	10.17	2.772	17.863	.000
	201 - 349 cells/µl	207	11.28	2.582		
	350 - 500 cells/µl	146	11.34	2.425		
	> 500 cells/µl	58	12.26	2.344		
Social Relationships = 820)	0 - 200 cells/µl	408	12.59	2.233	6.671	.000
	201 - 349 cells/µl	209	13.31	2.506		
	350 - 500 cells/µl	146	12.99	2.517		
	> 500 cells/µl	57	13.69	2.341		
Environment	0 - 200 cells/µl	387	12.16	1.993	31.496	.000
	201 - 349 cells/µl	201	13.19	1.787		
	350 - 500 cells/µl	142	13.58	1.708		
	> 500 cells/µl	57	13.77	1.618		
Spirituality/Religion/ Personal Beliefs	0 - 200 cells/µl	269	11.99	3.912	12.182	.000
	201 - 349 cells/µl	178	13.57	3.626		
	350 - 500 cells/µl	127	13.32	3.119		
	> 500 cells/µl	42	14.86	3.404		

The aggregate analysis as presented in Table 5.15 also indicates that the average scores reported under each of the CD4 cell count categories tended to be higher in the psychology domain and lowest in the level of dependence domain. The lowest mean scores were under CD4 cell count of 0 – 200 cell/µl in the level of dependence (10.17) and physical (10.95) domains. On the other hand, the highest mean scores were noted under CD4 cell count of > 500 cell/µl under the psychology (14.63) and SRPB domains (14.86). On face value there was almost a chronological increase in the mean quality of life score with increase in CD4 cell count category in all the domains.

The post hoc test of the aggregate analysis as presented in Appendix 5.9 further shows the differences in the mean scores within the respective domains of the CD4 cell counts categories. The quality of life score tended to increase with increases in the CD4 cell count category. The differences between consecutive categories were mostly significant. There was, however, no clear and consistent pattern of difference between the scores under the 201 – 349 cells/µl and the 349 – 500 cells/µl categories in all the six domains. However, the differences observed between the two categories were not all significant. The mean scores recoded for 0 – 200 cell/µl under all the six domains were consistently significantly lower than all the other categories and had notably higher mean difference with all the categories.

VALIDATION THE WHOQOL-HIV IN THE PREDOMINANTLY SPOKEN LOCAL LANGUAGES IN LIMPOPO PROVINCE WHICH ARE NORTHERN SOTHO, TSHIVENDA AND XITSONGA

5.2.5 Validation of the WHOQOL-HIV instrument

5.2.5.1 Convergent and discriminant validity

Table 5.17 shows the correlations between the domains and scales of the MOS-HIV and WHOQOL-HIV.

Figure 5.17 shows the correlation coefficients of the domains of the WHOQOL-HIV and MOS-HIV instruments

Table 5.17: Correlation coefficients of WHOQOL-HIV and MOS-HIV domains

WHOQOL-HIV Domains							MOS-HIV Domains										
Name	Phy	Psych	LoD	SR	Env	SRPB	GHP	PF	RF	SF	CF	Pain	MH	E/F	HD	QoL	HT
Phy	1.00																
Psych	.65*	1.00															
LoD	.78*	.59*	1.00														
SR	.66*	.56*	.58*	1.00													
Env	.50*	.71*	.45*	.54*	1.00												
SRPB	.67*	.62*	.57*	.64*	.59*	1.00											
GHP	-.42*	-.23*	-.44*	-.15*	-.05	.01	1.00										
PF	.56*	.52*	.53*	.33*	.45*	.39*	-.24*	1.00									
RF	.48*	.42*	.55*	.33*	.24*	.13*	-.46*	.51*	1.00								
SF	.60*	.48*	.51*	.45*	.36*	.64*	-.06	.57*	.32*	1.00							
CF	.63*	.48*	.53*	.49*	.41*	.56*	-.05	.55*	.30*	.68*	1.00						
Pain	-.70*	-.56*	-.70*	-.46*	-.43*	-.50*	.42*	-.57*	-.49*	-.52*	-.52*	1.00					
MH	.57*	.40*	.45*	.44*	.39*	.57*	.06	.46*	.18*	.69*	.75*	-.468*	1.00				
E/F	.14*	.030	-.01	.18*	.06	.48*	.37*	.06	-.16*	.39*	.43*	.002	.5*	1.00			
HD	.67*	.49*	.53*	.47*	.43*	.62*	-.13*	.55*	.27*	.67*	.78*	-.545*	.75*	.41*	1.00		
QoL	-.52*	-.36*	-.58*	-.30*	-.21*	-.05	.61*	-.33*	-.51*	-.19*	-.20*	.539*	-.08*	.31*	-.26*	1.00	
HT	-.64*	-.43*	-.60*	-.44*	-.24*	-.32*	.56*	-.39*	-.50*	-.36*	-.38*	.61*	-.28*	.13*	-.43*	.71*	1.00

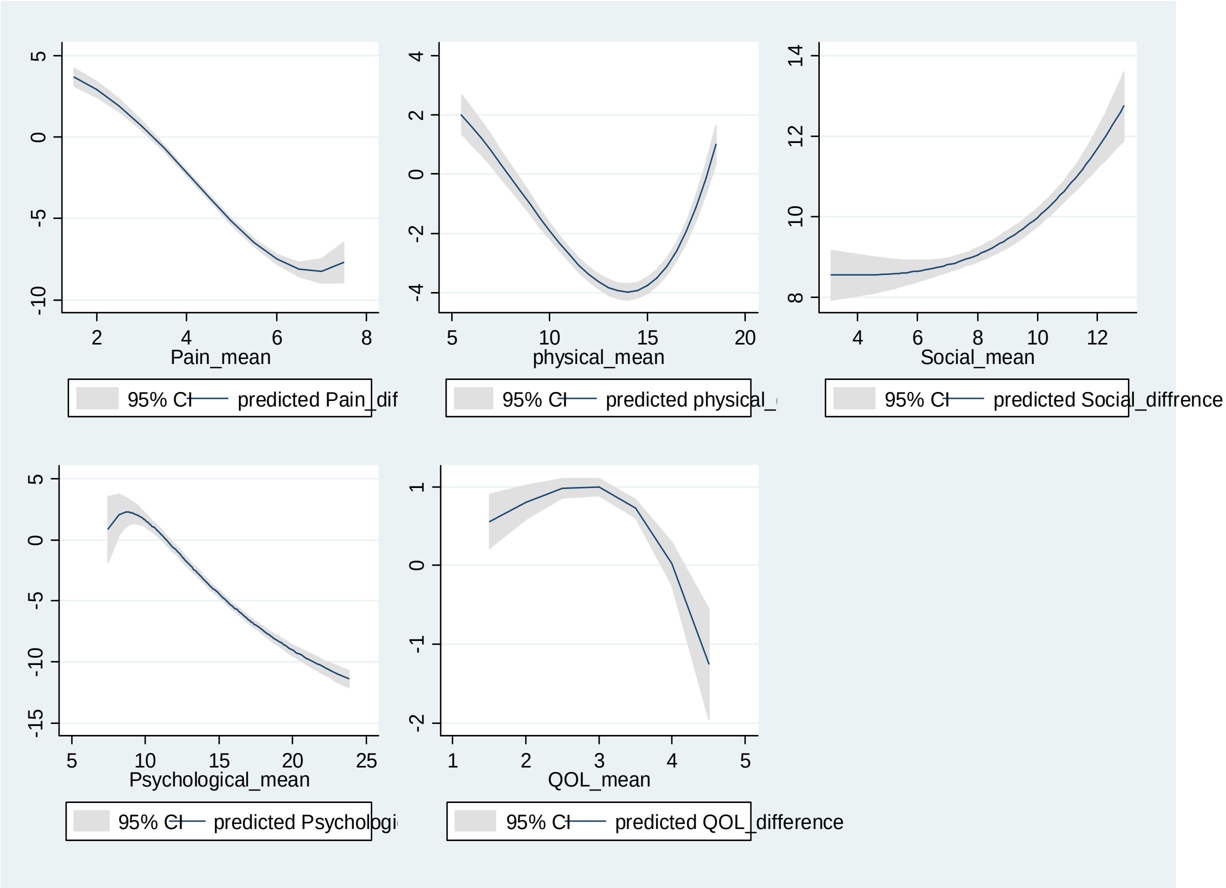
Green coded figures: WHOQOL vs WHOQOL; Red coded figures: WHOQOL vs MOS-HIV; Blue coded figures: MOS-HIV vs MOS-HIV;

Phy: physical; Psych: psychological; LoD: level of dependence; SR: social relationships; Env: environmental; SRPB: spirituality / religion / personal belief; GHP: general health perception; PF: physical functioning; RF: role functioning; SF: social functioning; CF: cognitive functioning; MH: mental health; E/F: energy/fatigue; HD: health distress; QOL: quality of life; HT: health transition s

The range of association between the WHOQOL-HIV domains ranged from 0.45 to 0.78 (p = 0.000). The strength of associations are from moderate to high. The highest correlation between WHOQOL-HIV domains and MOS-HIV scales was between the physical domain and the pain scale (0.70) followed by the level of dependence domain and the pain scale (0.70). A very poor correlation was found between the SRPB domain and the role functioning scale (0.13) followed by the physical domain and the energy/fatigue scale (0.14). In terms of the convergence of the WHOQOL-HIV and the MOS-HIV, the correlation of similar measures is as follows: physical domain and the physical function was 0.56; social relationship and social function was 0.45 and psychological domain and mental health was 0.40.

Table 5.17 also shows that there was no correlation between the energy/fatigue scale and the psychological, level of dependence and the environmental domains. In the correlation between the WHOQOL-HIV domains, the highest correlations were shown between the physical and the level of dependence domains (0.78; p = 0.00). On the other hand, the lowest correlation was between the environment and the level of dependence domains (0.45; p = 0.00).

Figure 5.3 further shows the confidence intervals of the difference between the scores on the respective scales. In all instances, the difference between the upper and lower limit was usually less than 1.



WHOQOL vs MOS-HIV scale	**Observations**	**Mean**	**95% CI**
Pain - Pain	862	3.14	3.36 - 2.92
Physical - Physical functioning	824	2.48	2.70 - 2.26
Social relationship - Social functioning	823	9.34	9.50 - 9.19
Psychology - Mental health	777	4.36	4.70 - 4.02
Overall QOL - QOL	865	0.83	0.92 - 0.74

Figure 5.3: Bland-Altman Plots on similar measures in the WHOQOL-HIV and MOS-HIV

Top left graph: pain (WHOQOL-HIV) and pain (MOS-HIV); top centre graph: physical domain (WHOQOL-HIV) and physical function (MOS-HIV); top right graph: social relationship (WHOQOL-HIV) and social function (MOS-HIV); bottom left graph: psychological domain (WHOQOL-HIV) and mental health (MOS-HIV); bottom right graph: overall quality of life and general health perception (WHOQOL-HIV) and quality of life (MOS-HIV).

5.2.5.2 Construct validity

5.2.5.2.1 Physical domain

The physical domain has 16 items with mean scores per item ranging from 3.97 (s.d. = ±1.27) with the item "how much do any sleep problems worry you" to 2.92 (s.d. = ±.99) with the item *"Do you have enough energy for everyday life"*. The factor analysis showed two factors with eigenvalues greater than 1.0. The two factors identified had a cumulative variance of about 65.2% even though the first factor contributed about 55.8% of the combined variance. The item with the highest loading in the first factor was "*to what extent do you feel that physical pain prevents you from doing what you need to do?"* at .814 and the highest loading in the second factor was *"how satisfied are you with your sleep"* at .843 (Table 5.18). Three items had a loading of less than .4 in the first factor. These three items had better loading in the second factor.

Table 5.18: Rotated component matrix for the physical domain items

Item	1st factor	2nd Factor
To what extent do you feel that (physical) pain prevents you from doing what you need to do?	.814	
How much are you bothered by fatigue?	.813	
Do you worry about your pain or discomfort?	.806	
To what extent are you bothered by fears of developing any physical problem?	.802	
How much are bothered by any unpleasant by any physical problems related to your HIV infection?	.791	
How difficult is it for you to handle any pain or discomfort?	.788	
How easily do you get tired?	.773	
Do you have any difficulties with sleeping?	.764	
To what extent do you fear possible future (physical) pain?	.742	

To what extent do you feel any unpleasant physical problems prevent you from doing things that are important to you?	.630	
How satisfied are you with your sleep?		.843
How satisfied are you with the energy that you have?		.824
How well do you sleep?		.756
How often do you suffer (physical) pain?	.438	.618
Do you have enough for everyday life?	-.460	-.587
How much do any sleep problems worry you?		.495

5.2.5.2.2 Psychological domain

The psychological domain has 20 items with mean scores ranging from 2.68 (s.d. = 1.22) with the item *"do you generally feel content?"* to 4.09 (s.d. = .869) with "*how satisfied are you with your ability to learn new information"*. The analysis showed that five factors had eigenvalues of over 1.0. The five factors had a combined variance of 67.9%. The first factor alone had a variance of about 32.6%. The item with the highest loading, the first factor was "*how satisfied are you with your ability to make decisions?"* (.789) and the highest loading in the second factor was *"how much do any feeing of depression bother you?"* (.908). In the third factor, the highest loading was with the item *"how positive do you feel about the future?"* and in the fourth factor it was *"do you feel inhibited by your looks?"* (.716). In the last factor, the highest loading was with the item *"are you able to accept your bodily appearance?"* (.781). The component matrix can be found in Table 5.19. Items with loading of less than .4 are not represented under the respective factors.

Table 5.19: Rotated component matrix for psychological domain items

	Factor				
	1st	2nd	3rd	4th	5th
How satisfied are you with your ability to make decisions?	.789				
How satisfied are you with your abilities?	.788				
How satisfied are you with your ability to learn new information?	.787				
How satisfied are you with yourself?	.749				
How satisfied are you with the way your body looks?	.588			.448	
How would you rate your memory?	.458				
How much do any feelings of depression bother you?		.908			
How much do any feelings of sadness or depression interfere with your everyday functioning?		.900			
How worried do you feel?		.844			
How often do you have negative feelings, such as blue mood, despair, anxiety, depression?		.661			
How positive do you feel about the future?			.783		
How much do you value yourself?			.776		
How much do you enjoy life?			.692		
How much confidence do you have in yourself?			.674		
How well are you able to concentrate			.550		
How much do you experience positive feelings in your life?			.504		.504
Do you feel inhibited by your looks?				.716	

Is there any part of your appearance which makes you feel uncomfortable?		.692	
Are you able to accept your bodily appearance?			.781
Do you generally feel content?			-.706

5.2.5.2.3 Level of dependence domain

The level of dependence domain has 16 items with mean scores ranging from *"how dependent are you on medications?"* at 1.56 (s.d. = .80) to *"how well are you able to get around?"* at 3.78 (s.d. = .98). Three factors had eigenvalues greater than 1.0. The three factors contributed about 66.6% to the observed variation and the first factor alone contributed about 43.0%. The highest loading in the first factor was "*how satisfied are you with your capacity to work*" at .884 (Table 5.20). The highest loading in the second factor was with *"how much do you need any medical treatment to function in your daily life"* (.819) and the highest loading in the third factor was with *"how much do any difficulties in your mobility bother you?"* (.901). Further information is provided in Table 5.20 below.

Table 5.20: Rotated component matrix for level of dependence domain items

	Factor		
	1st	2nd	3rd
How satisfied are you with your capacity to work?	.884		
How would you rate your ability to work?	.865		
Do you feel you are able to carry out your duties?	.859		
Are you able to work?	.857		
How satisfied are you with your ability to perform your daily living activities?	.789		
To what extent are you able to carry out your daily activities?	.720		
How well are you able to get around?	.705		

How satisfied are you with your ability to move around?	.600		
How much are you bothered by any limitations in performing everyday living activities?	.514	.423	.485
To what extent do you have difficulty in performing your routine activities?	.448		.422
How much do you need any medical treatment to function in your daily life?		.819	
How much do you need any medication to function in your daily life?		.816	
To what extent does your quality of life depend on the use of medical substances?		.787	
How dependent are you on medications?		.478	
How much do any difficulties in mobility bother you?			.901
To what extent do any difficulties in movement affect your way of life?			.899

5.2.5.2.4 Social relationship domain

The social relationship domain has 16 items with average scores ranging from 2.17 (s.d. = 1.21) with *"how well are your sexual needs fulfilled?"* to 4.34 (s.d. = .95) with *"how often do you feel you are discriminated against because of your health condition?"*. Four factors had eigenvalues greater than 1.0. The four factors contributed about 62.7% to the observed variation while the first factor alone contributed about 27.7%. The highest loading in the first factor was with the item *"do you feel happy about your relationship with your family members?"* at .795 (Table 5.21). The second factor's highest loading was with the item *"how would you rate your sex life?"* at .853, the third factor's highest loading was with *"to what extent can you count on your friends when you need them?"* at .865 and the highest loading in the fourth item was with *"how much do you feel alienated from those around you?"* at .758.

Table 5.21: Rotated component matrix for the social relationship domain items

	Factor			
	1	2	3	4
Do you feel happy about your relationship with your family members?	.795			
How satisfied are you with the support you get from your family?	.784			
How satisfied are you with your ability to provide for or support others?	.760			
To what extent do you feel accepted by the people you know?	.744			
To what extent do you feel accepted by your community?	.693			
Do you get the kind of support from others that you need?	.610			
How alone do you feel in your life?	.507			.434
How would you rate your sex life?		.853		
How satisfied are you with your sex life?		.804		
How satisfied are you with your personal relationships?		.651	.421	
How well are your sexual needs fulfilled?		.646		
To what extent can you count on your friends when you need them?			.865	
How satisfied are you with the support you get from your friends?		.404	.739	
How much do you feel alienated from those around you?				.758
Are you bothered by any difficulties in your sex life?				.753

How often do you feel you are discriminated against because of your health condition?

5.2.5.2.5 Environmental domain

The environmental domain has 32 items with average scores ranging from 1.71 (s.d. 1.10) with the item *"have you enough money to meet your needs?"* to 4.20 (s.d. = 1.13) with *"how concern are you with the noise in the area where you live in?"*. Six factors had eigenvalues greater than 1.0. The highest loading in the first factor was *"how satisfied are you with opportunities to learn new information?"* (.817), the highest loading in the second factor was *"how much do you like where you live?"* (.786) and the highest loading in the third factor was *"to what extent do you have problems with transport?" (*Table5.22). In the fourth factor, the highest loading was observed with *"do you have financial difficulties?"* (.875); in the fifth factor the highest loading was with *"How satisfied are you with your physical environment (e.g. pollution, climate, noise, attractiveness?"* (.637) and in the sixth factor, the highest loading was observed under the item *"to what extent do you have opportunities for leisure activities?"* (.565). All six factors contributed about 61.88% to the observed variation with the first factor only contributing about 29.00%.

Table 5.22: Rotated component for the environmental domain items

	Factor					
	1st	2nd	3rd	4th	5th	6th
How satisfied are you with your opportunities to learn new information?	.817					
How satisfied are you with your opportunities for acquiring new skills?	.807					
How satisfied are you with your physical safety and security?	.715					
How satisfied are you with the way you spend your spare time?	.713					
How satisfied are you with your access to health services?	.671		.417			
How satisfied are you with the social care services?	.664					
How satisfied are you with the conditions of your living place?	.636	.412				
How satisfied are you with the climate of the place where you live?	.611					
How would you rate the quality of social services available to you?	.527					
How much are you able to relax and enjoy yourself?	.416					
How much do you like it where you live?		.786				
How comfortable is the place where you live?		.785				
Do you feel you are living in a safe and secure environment?		.707				
How much do you enjoy your free time?		.622				
How safe do you feel in your daily life?	.419	.617				

How healthy is your physical environment?	.587				
To what extent do you have problems with transport?		.823			
How much do difficulties with transport restrict your life?		.787			
To what extent do you have adequate means of transport?		.671			
How easily are you able to get good medical care?		.616			
How satisfied are you with your transport?		.570			
To what extent do you have opportunities for acquiring the information that you feel you need?		.467			.404
Have available to you is the information that you need in your day-to-day life?		.466			.456
Do you have financial difficulties?			.875		
How much do you worry about money?			.868		
Have you enough money to meet your needs?			.756		
How satisfied are you with your financial situation?			.676		
How satisfied are you with your physical environment (e.g. pollution, climate, noise, attractiveness)?				.637	
How much do you worry about your safety and security?				.604	
How concerned are you with the noise in the area you live in?					-.582
To what extent do you have the opportunities for leisure activities?				.510	.565
To what degree does the quality of your home meet your needs?	.404				.454

5.2.5.2.6 Spirituality/religion/personal belief (SRPB) domain

The SRPB domain has 15 items and the mean scores on the items ranged from 2.61 (s.d. = 1.24) with the item *"to what extent do any feelings you are suffering from a fate or destiny that bothers you?"* to 4.05 (s.d. = .84) with the item *"do your personal belief give meaning to your life?".* Two factors had eigenvalues greater than 1.0. The two factors contributed about 70% to the observed variations with the first factor alone contributing about 57%. The highest loading in the first factor was by the item *"how concerned are you about how you will die?"* (.904) while the highest item in the second factor was "*to what extent do your personal beliefs give you the strength to face difficulties?"* at .838 (Table 5.23).

Table 5.23: Rotated component matrix for the spirituality/religion/personal belief domain items

	Factor	
	1st	2nd
How concerned are you about how where you will die?	.904	
How bothered are you by the thought of not being able to die the way you would want to?	.896	
How much do you blame yourself for your HIV infection?	.887	
How guilty do you feel about being HIV positive?	.875	
To what extent are you concerned about how people will remember you when you are dead?	.872	
How much do you worry about death?	.868	
How much preoccupied are you about suffering before dying?	.852	
To what extent are you concerned about your HIV status breaking your family line and your future generations?	.847	
To what extent are you bothered by people blaming you for your HIV status?	.847	

To what extent do you feel guilty when you need the help and care of others?	.816	
How much do you fear the future?	.755	
To what extent do any feelings you are suffering from fate or destiny bother you?	.627	
To what extent do your personal beliefs give you the strength to face difficulties?		.838
To what extent do your personal beliefs help you to understand difficulties in life?		.811
Do your personal beliefs give meaning to your life?		.691

THE DEVELOPMENT OF A SHORTER VERSION OF THE WHOQOL-HIV THAT ADEQUATELY REPLICATES THE DOMAINS OF THE LONG VERSIONS OF THE WHOQOL-HIV THROUGH ITEM REMOVAL TECHNIQUES

5.2.6 Shortening of the WHOQOL-HIV instrument

Item analysis was done by calculating the corrected item – total correlation and Cronbach's Alpha if item deleted. Given the transient nature of the HIV and AIDS, the analysis was done by duration on treatment which has been shown to be linked to wellbeing in terms of immune reconstruction. With this, the analysis was done separately for baseline, six and 12 months respectively, for each of the six domains. The result of the analysis can be found in Appendixes 5.10 to 5.15. The results consistently showed that the items that had higher correlation with the rest of the items in each of the respective domains varied with time. The best two items in terms of the correlation coefficients were in some instances common across the three measurement times. Extracts of the best two items with the highest corrected item – total correlation coefficient are presented in Table 5.24.

Bearing in mind that each domain is made up of many subscales, it was notable that the best two items under each domain were more likely to come from specific subscales. This was often the case for the six and 12 months analysis, respectively. The items (questions) may not be the same but fell under the same subscale in the respective domains.

For instance, under the physical domain, the best two items for the baseline analysis were from the sleep and pain subscales, six months best two were from fatigue while the 12 months best two were from fatigue and pain, respectively. The item *"how bothered are you by fatigue"* was common at six and 12 months. Under the psychological domain, the best two items for the baseline analysis were from self esteem and negative feeling, the six months best two items fell under body image and self esteem while the 12 months best two items fell under body image and negative feeling. The item *"how much do any negative feeling of sadness or depression interfere with your everyday functioning"* featured in baseline and 12 months while the item "how satisfied are you with the way your body looks" featured in the six and 12 months analyses.

In the level of dependence domain, the best two items were from the work subscale at baseline and at six and 12 months the best items were from the work and activity of daily living subscales respectively. The item "how would you rate your ability to work" was common to the baseline and 12 months analyses.

Under the social relationship domain, the item *"how satisfied are you with your personal relationship"* featured in all three analyses (baseline, six and 12 months). In addition, an item from sex featured at baseline, an item from inclusion featured at six months while an item from support featured at 12 months. In the environmental domain, all three analyses had different items from the environmental subscale, the baseline data had an item from information, the six month analysis had a item from the leisure subscale while the 12 months analysis had an item from the safety subscale. Lastly, SRPB domain had best two items falling under the death subscale for the baseline and six months analysis respectively, even if the items were not always the same, but the item “how bothered are you by the thoughts of not being able to die the way you would want to”. On the other hand the 12 month analysis under the SRPB domain had its best two items from the forgiveness and future subscales.

Table 5.24: Items with the highest corrected item – total correlation coefficient by WHOQOL-HIV domain and time of interview/duration on treatment

Physical domain	
	Baseline
	To what extent do you feel that (physical) pain prevents you from doing what you need to do?
	Do you have any difficulties with sleeping?
	6 months
	How much are you bothered by fatigue?
	How easily do you get tired?
	12 months
	How much are you bothered by fatigue?
	Do you worry about your pain or discomfort?
Psychological domain	
	Baseline
	How much do you value yourself?
	How much do any feelings of sadness or depression interfere with your everyday functioning?
	6 months
	How satisfied are you with the way your body looks?
	How satisfied are you with yourself?
	12 months
	How satisfied are you with the way your body looks?
	How much do any feelings of sadness or depression interfere with your everyday functioning?
Level of dependence domain	
	Baseline
	Are you able to work?
	How would you rate your ability to work?
	6 months
	How satisfied are you with your capacity to work?
	Do you feel able to carry out your duties?
	12 months
	How would you rate your ability to work?
	Do you feel able to carry out your duties?

Table 5.24 (continued): Items with the highest corrected item – total correlation coefficient by WHOQOL-HIV domain and time of interview/duration on treatment

Social relationship domain	
	Baseline
	How satisfied are you with your sex life?
	How satisfied are you with your personal relationships?
	6 months
	How satisfied are you with your personal relationships?
	To what extent do you feel accepted by the people you know?
	12 months
	How satisfied are you with the support you get from your friends?
	How satisfied are you with your personal relationships?
Environmental domain	
	Baseline
	How comfortable is the place where you live?
	How satisfied are you with your opportunities to learn new information?
	6 months
	How satisfied are you with the conditions of your living place?
	How satisfied are you with the way you spend your spare time?
	12 months
	Do you feel you are living in a safe and secure environment?
	How healthy is your physical environment?
SRPB domain	
	Baseline
	How bothered are you by the thought of not being able to die the way you would want to?
	How concerned are you about how where you will die?
	6 months
	How much do you worry about death?
	How bothered are you by the thought of not being able to die the way you would want to?
	12 months
	How guilty do you feel about being HIV positive?
	To what extent are you concerned about how people will remember you when you are dead?

5.3 Discussion

5.3.1 The health related quality of life of people living with HIV and AIDS in Limpopo Province

This chapter started by describing the socio-demographic characteristics of this study's participants given that an individual's perceived quality of life is determined by their socio-cultural and demographic characteristics (Spring et al., 2005; WHO, 1983). This assertion was demonstrated in this study through the observed differences in the participants' quality of life based on their socio-cultural and demographic characteristics. Most of the participants were females who were married with children and unemployed. This trend was observed in Table 5.1.

The above group does not only characterize the typical AIDS survivals on treatment but also reflects a group that may be socio-economically less able to cope with living with the virus (Venter et al., 2009). In terms of the disease prevalence, females are at a higher risk of HIV infection when compared to males (UNAIDS, 2004). Some of this higher risk can be linked to the biological make up of women. The vulnerability of females to HIV and AIDS is also linked to their reduced power in relationships given their gender-linked socio-cultural and economic dependence on their male partners. This also means that they have less access to household and community resources which may include HIV and AIDS treatment and related social support services (Taylor, 1996). This phenomenon is expected to be exacerbated by the high poverty and unemployment noted by this study. Research studies have for instance noted that food insecurity and hunger is higher among HIV positive individuals. One study noted that this risk was 17 times more among PLWH when compared to the general population (Normen et al., 2005;) Poverty is also known to be a major obstacle to treatment and care (Simwaka et al., 2006). The effect of unemployment and poverty may be perpetuated by the need for frequent and repeated visits to health facilities for treatment and care. This trend has implications for the affordability of other household necessities like food, water, electricity, education and clothing (Collins et al., 2007). This creates a vicious cycle and has implications for health, wellbeing, quality of life and survival of people living with AIDS. Tables 5.4 and 5.5 show the differences between the quality of life of males and females and support the proposition that males performed better in terms of financial resources and the psychological domain components.

In the context of the above, there were notable significant differences in the perceived health related quality of life of employed and unemployed people as illustrated in Tables 5.7 and 5.8. This study showed that unemployed people perceived themselves to be having less social support and fewer social relationships. This observation is despite their benefits in the face of unemployment. This study also noted that negative feeling was reported to be more profound among the unemployed. This observation is equally worrying given its role in psychological adjustment, acceptance of the virus, use of health and social services and improved chance of recovery. The deleterious effect of negative feeling has been underscored by the finding of Study I and the theoretical model on “achieving a balance” in HIV and AIDS by Murdaugh (1998).

Various analyses in this study also suggest strong links between the environmental domain and its financial resource subscale and the biological markers of HIV and AIDS. Similarly, unemployed people perceived themselves to be worse in terms of their “dependence on medication or treatment”. This may translate to mean that unemployed people are more likely to have undesirable health outcomes. This assertion is in consonance with the suggestions that greater burden of AIDS symptoms are experienced by economically more disadvantaged groups. As well, this study finding indicates that unemployed people had significantly lower scores in subscales that fall under the physical domain (Makoae, 2005). In this regard, Ruutel et al. (2009) have described employment status as one of the most influential contributors to HRQOL while Worthington and Krentz (2005) noted that employment and higher income are related to better quality of life among PLWH. Ruutel et al., (2009) added that employment does not only provide financial resources but also a source of structure, social support, role identity and meaning.

The study also showed that females were more likely to report better perceptions of “level of dependence”, “work capacity” and ‘activity of daily living”. These elements may be reflective of better health and activity tolerance among females when compared to males. This finding is in agreement with the findings of the original instrument validation study by the WHOQOL-HIV Group (2004). In the same context, the study’s data showed that females were more likely to have a suppressed viral load and CD4 count greater than 500 cells/µl over time when compared to males. This finding agrees with studies that have shown greater benefits of ART over time in females when compared to males (Moore et al., 2001). Other studies have further shown that females are more likely to have a lower viral load when the CD4 cell count was greater than 350 cells/µl (Donnelly et al., 2005).

Many of the health related quality of life subscales and domains varied significantly by marital status. These differences are presented in Table 5.5 and Appendix 5.4. These differences were inconsistent but highlight the fundamental contribution of the presence or absence of a partner in shaping the quality of life of people living with HIV and AIDS. The married participants had significantly higher average scores on social support, financial resources and social relationships. These observations are in consonance with the findings of Jatoi et al (2007) that have linked marriage with longer and better quality of life (Rohrbaugh et al., 2005; Gore et al., 2006). This phenomenon has also been associated with the fact that marriage may provide better social support and financial resource needed to better access the relevant health service (Denberg et al., 2005; Iwashyna and Christakis, 2003). All the other instances where divorced/separated/widowed women may have performed better than married women may be linked to their autonomy and ability to cater for themselves.

Based on the observed differences in quality of life domain and subscale scores by support group membership seen in Table 5.9 and Appendix 5.7, it may be concluded that support groups attracted people with lower financial standing and with less social support and relationships. The tendency of support groups to attract people requiring more professional attention and support have also been noted by a similar study (Buck et al., 1999). The finding of this study and the reviewed literature further suggest that such people (with lower financial standing and with less social support) are more likely to be in a poorer state of health and experience more HIV related symptoms. The ability of support groups to attract such people is important given its established gains for such individuals. In line with the findings of Study I, other studies have shown that support groups help to reduce isolation and improve quality of life (Crook et al., 2005). Support group service should hence form part of the essential services for people living with HIV and AIDS given the chronic nature of the disease and their many unmet needs. The findings of this study suggest that support groups help to facilitate psychological adjustment to the disease. This observation is premised on the fact that the aggregated analysis in Appendix 5.7 showed that people in support groups had significantly higher scores of self-esteem, body image, psychological standing and positive feeling scores when compared to those people not in support groups.

Similarly, other studies have demonstrated that support groups help deal with the manifestations of poor adjustment such persistent denial and behavioral disengagement that avoid dealing with change (Tunner-Cobb et al., 2002). Poor coping and adjustment have been linked by other studies to immunological deterioration (Freeman, 2004). This is important as support groups could help augment the negative effect of the observed lower scores on the symptoms and financial resources subscales among its members. This assertion is based on the fact that these factors are known predictors of poor quality of life and poor immunity (Preeze and Peltzer, 2009).

In agreement with the literature review section of this report, the above variations in HRQOL based on socio-demographic characteristics further demonstrate the complexity of defining quality of life (Tyrrell et al., 2005; Kimmel, 2000; Ferrans and Power, 1992). This variation was again seen in the differences observed between the three cultural groups. While it is beyond the scope of this study to describe the reason for such cultural variations, other studies have among other factors attributed the observed differences to societal attitudes and inherent outlooks and expectations in respective cultures (Buck et al., 1999). In the same context, such cultural differences in disease expression have been documented and described by Guillemin et al. (1993). Buck et al., (1999) add that different cultural groups may not give the same weighting to certain health related parameters. In this regard, Dodrill et al., (1984) suggest that some cultural groups have lesser likelihood of acknowledging the presence of psychosocial problems. The knowledge of this variation is important in planning care and support that is meaningful and responsive to the needs of recipients based on their expectations. Hence, achieving one of the cardinal objectives of quality of life assessment of allowing individuals to gauge their health will not be achieved if cultural interpretations of such assessments are not considered.

5.3.2 Relationship between the biological markers HIV and AIDS and the HRQOL measure and their change over time

The correlation was weak between CD4 counts and the overall quality of life domains. Similarly, viral load suppression status (Tables 5.11 and 5.12) had very low correlation coefficients with overall quality of life. Despite this, the findings corroborate the outcomes of studies that have shown that the economic standing and psychological state of an individual impact on their immune status and HIV disease progression (Freeman, 2004). Another study conducted among another cultural group in South Africa reported similar correlations between quality of life domains and CD4 cell counts (Venter et al., 2009). Jia et al., (2007) further demonstrated a significant positive longitudinal association between CD4 cell count and emotional status of people living with HIV and AIDS. The reported correlations were, however, too low for quality of life measures to become direct predictors of CD4 cell count and viral load. This observation may be linked to the highly subjective nature of the quality of life measure and the many socio-cultural and demographic factors that influence their variation. Such variations may be profound even in the most homogenous populations given the expected differences based on age, sex, religious beliefs, ethnic group, marital status, economic standing and the extent of social support and access to treatment and other health services. This assertion draws on the finding of this and other studies that have shown marked differences based on these variables (Preez and Peltzer., 2009; Peltzer and Phaswana-Mafuya, 2008; WHOQOL-HIV Group, 2004).

The study by Venter et al., (2009) for instance, showed marked differences in correlation coefficient across the various quality of life domains and CD4 cell count by simply splitting their study population by sex. The general prominence of the psychological, environmental and level of dependence domains noted in this and related studies may require a further analysis to explore the link between the individual items on scales and the biological markers (CD4 cell count and viral load).

The study also noted marked differences in quality of life between the baseline and the other points of data collection following treatment initiation. This finding agrees with studies that have shown such improvements in the perceived quality of life over time (Saunders and Burgonye, 2002; Solomon et al., 2009). This observation highlights the benefits of treatment in improving the health and health related quality of life of people living with HIV and AIDS. Similarly, other studies have demonstrated significant improvements in the quality of life of people with advanced HIV following treatment initiation (Nieuwkerk et al., 2001; Cohen et al., 1998). Furthermore, this study found that the quality of life of people with low CD4 cell counts and unsupressed viral load also increased with treatment initiation. There was no significant difference between the six and 12 month scores in three domains (psychological, level of dependence and the environmental domains). This may suggests that the study cohort did not improve in these domains between the sixth and 12th month post treatment initiation or the improvements were too negligible for the participants to notice when compared to the improvement they may have noted in the first six months. The participants however, had a significantly higher score in the physical, social relationships and the SRPB domains at six months when compared to their score at 12 months. This finding agrees with the findings of Solomon et al. (2009) which showed high improvements in the quality of life in the first six months and this improvement diminished over time. This observation should be read against the backdrop of the subjective nature of the assessment and the marked improvement in clinical symptoms at six months and stabilization over the following six months.

5.3.3: Validation and shortening of the WHOQOL-HIV instrument

All the six WHOQOL-HIV domains reported very high reliabilities even though two (physical environment and sexual activity) of their 29 subscales reported relatively low Cronbach's Alpha. The reliability values noted in this study are similar to those found in the original field test of the WHOQOL-HIV instrument (WHOQOL-HIV Group, 2003). The original field study also reported some relatively low Cronbach's Alpha in specific subscales in the environmental and SRPB domains.

Bearing in mind the high reliability noted in the respective domains, the factor analysis showed that each domain had multiple dimensions. This finding is in line with the original instrument design as each domain is made up of multiple subscales or facets (WHOQOL – HIV Group, 2004, 2003). The factors identified in this study almost replicate those suggested in the original instrument.

Convergent validity of this instrument was established by comparing the upper and lower confidence limits of the differences in scores of similar domains and subscales of the WHOQOL-HIV instrument and the MOS-HIV instrument (Figure 5.3). This comparison is clinical rather than statistical and is based on the Bland-Altman Limits of Agreement (Bland and Altman, 1986, 1991). The plots generally showed agreements between both instruments with differences in confidence interval of less than 1.0 in the various domains. Furthermore, Pearson Correlations of the similar domain and items (in the MOS-HIV and WHOQOL-HIV) in Table 5.17 showed moderate correlations between the respective subscales/domain. This indicates that the measures are related but each instrument still has its unique value over the other. The review by Pesudovs et al., (2007) indicates that moderate correlations (>.3 and <.9) should be ideal for any meaningful convergent validity.

The literature review of this report underscored the importance of considering target population characteristics in instrument development and selection. This consideration was apparent in this study as efforts to reduce the items through item-total correlation did not yield similar results at the three times of data collection. This assertion supports the finding of Study I which indicated that the clinical concerns and psychosocial needs of people living with HIV and AIDS vary greatly with time and treatment. A similar study for instance showed that the same quality of life instrument cannot be used for individuals with glaucoma and those with low vision (Lamoureux et al., 2007). Given the very transient nature of HIV and AIDS symptoms across the different biological (Gurunathan et al., 2009) and psychological (Murdaugh, 1998) stages of the disease, an instrument that considers all the stages in item selection will be most appropriate. This is against the consideration that an instrument that specifically targets newly diagnosed individuals with no symptoms may not be suitable for individuals with AIDS.

In all, this section of the study was able to describe the HRQOL of PLWH in Limpopo Province over time and noted the weak to no association between HRQOL indicators and the biomedical markers of HIV/AIDS. The study mostly underscores the multiple factors that affect the natural history of HIV/AIDS. Some of such factors are time, treatment and the socio-demographic characteristics of the individual. This proposition is also predicated on the observation that an individual's perceived quality of life and wellbeing is also defined by their cultural and religious beliefs and will hence vary by cultural groups. With all the variations observed in the study, including the differences in the findings of the time specific and aggregate analyses, one can say that PLWH are highly heterogeneous and should only be grouped together with caution in research studies and intervention programmes. This observation made it impossible to create a universal and shorter HRQOL instrument from the existing WHOQOL-HIV instruments.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

The main objective of this study was firstly to explore the HRQOL and the experiences of PLWH in seeking care and support services and secondly, to validate the ability of the WHOQOL-HIV instrument to measure the health related quality of life of PLWH among the three cultural groups in Limpopo Province over time. With this objective, the study followed various research methods with literature support leading to key qualitative and quantitative findings. Following this process, the conclusions below can be jointly made about the qualitative and quantitative components of this study.

There are a variety of factors that impact on the HRQOL of PLWH in Limpopo Province. These factors can be categorized as physical, mental and external. The physical factors are the biological problems; the mental factors include the psychological problems, fears and concerns; and the external factors are environmental issues that are largely beyond the control of the individual. The extent to which the factors affect quality of life is predicated by their frequency of occurrence and severity, which is in turn, dependent on the individual's duration on treatment, membership of a HIV support group, disclosure of their HIV status as well as their socio-demographic and economic standing. In this regard, individuals who are on treatment for a longer time have disclosed their HIV status (to at least their family members), and belong to a support group. Individuals with better socio-demographic and economic status are more likely to have a better quality of life and better ability to live with the virus.

Among other things, the above proposition highlights the benefit of ART and support groups as they help to restore health and hope to individuals who often get despondent about life, survival and the future following a positive HIV diagnosis and AIDS. On a positive note, the participants of this study had good access to health service, particularly ART, but deplored the quality of social support services such as disability grants and access to housing.

ART was generally rated and notably useful in improving the quality of life of the participants, including those who maintained an unsuppressed viral load and with low CD4 cell counts over time. Most patients indicated that they will continue to adhere to treatment despite its associated morphological changes and other side effects. This position was also confirmed by the quantitative study, with the generally improved quality of life and immune reconstruction following treatment initiation.

A notable obstacle to commencing treatment and the utilization of support services were late HIV diagnosis and the nondisclosure of HIV status. On this premise, the study participants often recounted how their lives changed for the best following their serostatus disclosure. This study noted that none and late disclosure of HIV status was often driven by the fear of rejection and reprisal from their families and the community.

The above fear was mostly untrue particularly at family level, with family members accepting and supporting HIV positive family members. In most cases, the family turned out to be the strongest source of financial and psychological support for the participants. Health care workers also provide similar kinds of support to known PLWH. Elements of stigma still exist at community level and are driven by fear of HIV infection. The common places where PLWH get stigmatized are socio-cultural and religious gatherings like funerals, weddings and churches.

In the same context, social support from family members, HIV support groups and health workers tended to facilitate psychological adjustment to living with the virus and creating new personal meaning of living with HIV and AIDS. Psychosocial support does not only buffer the effect of the physical factors but also alleviates some of the devastating fears of living with the virus. It provides hope for the future and reasons to live.

Psychological adjustment to living with the virus has positive consequences for the use of health and social support services and the optimization of health and recovery.

While diarrhoea, pain and fatigue were the most commonly cited physical problems, the study noted that all the 14 core factors affecting the quality of life of PLWH are interlinked in a vicious circle where one factor perpetuates the effect of another factor. For instance, fatigue will result in insomnia and vice versa. The link between these factors has the propensity to negatively trigger all the other factors identified by this study. This point emphasizes the benefits of the comprehensive management of HIV/AIDS and that suboptimal management of any of the factors has a strong negative bearing on the other factors.

Furthermore, the observed improvement in HRQOL and biomedical markers over time may largely be attributed to the cumulative effect of treatment and recovery through the gradual immune reconstruction process, but psychological adjustment through the passage of time is equally important. In this regard, efforts to facilitate the treatment and rehabilitation of the physical, mental and external domains are essential given the strong interplay between them.

It was also not surprising that financial worry ranked among the highest concern of PLWH in both the qualitative and quantitative studies. This assertion should be read against the backdrop that the debilitating effect of AIDS often leads to job loss and the liquidation of other forms of financial security. In this regard, the reported needs of PLWH anchor on financial insecurity including matters of housing and tertiary education for children and aggravated by the poor and limited access to the disability grant.

What is clear from the qualitative and quantitative studies is that recovery from AIDS to living as normally as possible with the virus is achievable if all modifying factors are harnessed. This process can be further improved by programmes that facilitate socio-economic rehabilitation. This proposition is further supported by the marked differences in the quality of life and the extent of immune reconstruction of people with and without formal employment and how social isolation perpetuates poor quality of life and recovery.

This study also predominantly showed weak to no association between the biomedical markers of HIV/AIDS and the HRQOL indicators. The biomedical markers are therefore not accurate predictors of the HRQOL of an individual. In this regard, an individual may experience significant improvement in their biological markers but still be unfit to cope with living as normally as possible, including earning a living. While the quantitative study showed significant improvements in HRQOL over time, the mean differences between the six and 12 months were often very small and not significant.

The two paragraphs above discourage reliance on CD4 cell count and viral load as valid criteria for eligibility for disability grants and reemphasize the need for further socio-economic rehabilitation and support of PLWH following immune reconstruction.

Much value was placed on physical symptoms as determinants of quality of life. A HRQOL instrument that is mostly constituted by measures of AIDS specific symptoms may provide a better link between HRQOL and the biomedical markers. This assertion may contradict the notion that HRQOL is multifaceted but should be read against the backdrop that the determinants of HRQOL among PLWH are interlinked and interrelated. This suggestion is further supported by the high correlations between the various domains of the WHOQOL-HIV instrument. This point does not undermine the value of a multifaceted instrument as it provides a detailed and holistic overview of the impact of HIV/AIDS on the individual. However, a symptom centered instrument exploring the frequency and severity of incidences can be used to form a brief and concise instrument that can be used routinely to predict the state of the other dimensions of quality of life and biomedical markers and thus make recommendations in routine care of PLWH.

Despite the above suggestion, the WHOQOL-HIV instrument was noted to be reliable and valid in measuring the HRQOL in the three languages. The study also showed the multidimensional nature of the instrument. This point corroborates the multiple determinants of quality of life identified in the qualitative study and the socio-economic and demographic variations within each category of determinants.

The shortening of the WHOQOL-HIV is highly discouraged by this study. This is based on the fact that PLWH are highly heterogeneous given the bio-psychosocial trajectory of the disease which can be cyclic depending on the balance between the modifying and intervening factors. A simple analogy to this is that the needs and concerns of a newly HIV infected and undiagnosed individual are different from those of a person with full blown AIDS who is not on treatment as well as those of a psychologically well adjusted individual on treatment with stable biological markers of HIV. This position is well supported by the findings of the qualitative and quantitative components of this study.

In all, ethnicity was a major determinant of quality of life with significant variations observed along its divide. This observation underscores the role of the socio-demographic characteristics of an individual in shaping their perceived position in life in relation to their goals, expectations, standards and concerns.

6.2 Recommendations

In view of the study findings and conclusions of the qualitative and quantitative components of this study, the following recommendations are proposed:

- Multidisciplinary teams should be constituted and actively involved in care, treatment and support of all PLWH to ensure that appropriate attention is given to the physical, mental and external factors affecting the quality of life.
- Community awareness focusing on how to live with HIV/AIDS and/or individuals with HIV/AIDS is needed to address the issues of stigma that mostly stem from the fear of infection. Such programmes should target religious and cultural leaders and groups, given that a lot of the stigmatization was noted to occur mostly at these places.
- Tools to profile the physical, mental and external needs of PLWH should be developed and used given variations in such needs across the different categories of PLWH.

- PLWH and their family members should be educated about basic self care and self help measures to deal with the common signs and symptoms of HIV/AIDS like pain, diarrhoea, fatigue, cough, dermatological problems and insomnia
- The above recommendation should include non-pharmacological approaches like hygiene practices, dietary adjustments that are feasible, appropriate exercise programmes, relaxation techniques and other plausible indigenous approaches. These will help limit undue reliance on medications and their consequences and hopefully increase self determination and self care.
- Factors to promote psychological adjustment (like disclosure of HIV status, family support, support group membership) should be facilitated given their importance in determining the natural history of the disease, use of health and social support services, recovery and the quality of survival of PLWH.
- CD4 cell count and viral load should not be used as a measure of the overall wellness of people living with HIV/AIDS.
- CD4 cell count and viral load should not be used as eligibility criteria for accessing disability grants
- There is a need to explore ways of developing a brief and universal quality of life tool that replicates the existing quality of life tools and correlates with biomedical markers of HIV/AIDS. A symptom focused tool that measures the severity and frequency of commonly HIV/AIDS related symptoms may serve this purpose.
- Programmes to help PLWH who may have lost their jobs as a result of illness to get back to work or to continue to financially support PLWH till they are able to support themselves should be considered.
- The potentials of support groups of PLWH needs to be fully explored and harnessed given their benefits particularly among the most vulnerable of PLWH.
- More research to further understand and link the bio-psychosocial trajectory of HIV/AIDS is required to better delineate the different categories of PLWH and guide the precision and responsiveness of intervention programmes to suit the different categories.

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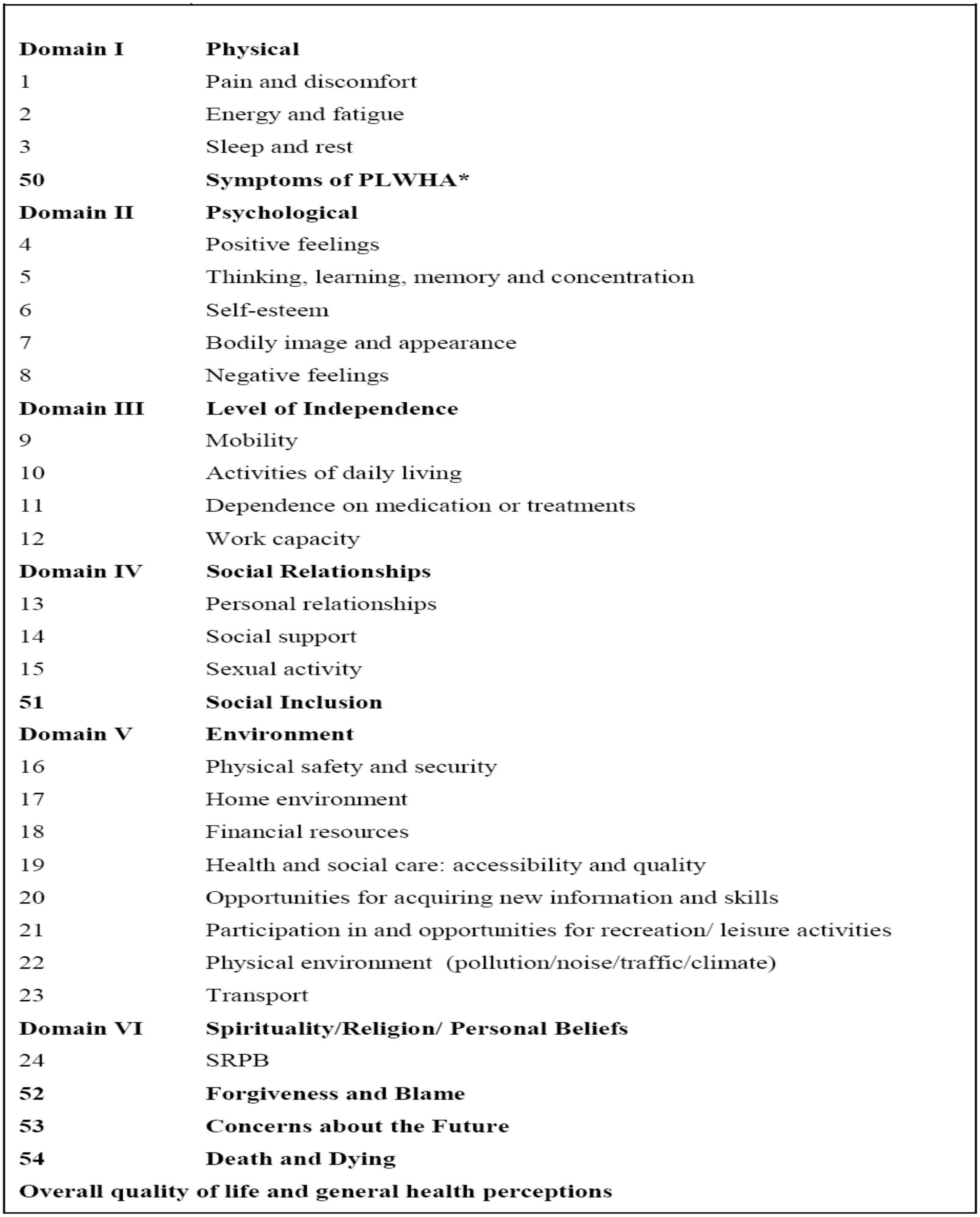
Appendix 2.1: WHOQOL-HIV domains and subscales



Domain I	**Physical**
1	Pain and discomfort
2	Energy and fatigue
3	Sleep and rest
50	**Symptoms of PLWHA***
Domain II	**Psychological**
4	Positive feelings
5	Thinking, learning, memory and concentration
6	Self-esteem
7	Bodily image and appearance
8	Negative feelings
Domain III	**Level of Independence**
9	Mobility
10	Activities of daily living
11	Dependence on medication or treatments
12	Work capacity
Domain IV	**Social Relationships**
13	Personal relationships
14	Social support
15	Sexual activity
51	**Social Inclusion**
Domain V	**Environment**
16	Physical safety and security
17	Home environment
18	Financial resources
19	Health and social care: accessibility and quality
20	Opportunities for acquiring new information and skills
21	Participation in and opportunities for recreation/ leisure activities
22	Physical environment (pollution/noise/traffic/climate)
23	Transport
Domain VI	**Spirituality/Religion/ Personal Beliefs**
24	SRPB
52	**Forgiveness and Blame**
53	**Concerns about the Future**
54	**Death and Dying**
Overall quality of life and general health perceptions	

Appendix 3.1: Study I information sheet and consent form (Pedi, Tsonga and Venda translations were provided).

Validation and Longitudinal Application of the WHOQOL-HIV Questionnaire among People Living With HIV and AIDS in Limpopo Province, South Africa

Introduction

Good morning/afternoon. I am Mr. Jude Igumbor, a doctoral student at the University of the Witwatersrand. I am is gathering information about the health related quality of life and the experiences of PLWH with health and social services through this research study. I would be grateful if you would be willing to assist by responding to questions related to this research. You will be interviewed as a group with your support group members and it takes about 45 minutes of your time.

Purpose of the Study

The aim of this study is to describe how you perceive your quality of life and your experiences in seeking care and support services. We started this study because we have seen the importance of involving you to help health care providers to better understanding your health and things that affect it. The Research Ethics Committee of the University of the Witwatersrand has approved the study protocol. This research is being conducted in hospitals based support groups across Limpopo Province including yours.

Procedures

We will interview you about your overall health, wellbeing and experience with health and social services. You will be asked to identify key issues influencing these things. To make sure that we properly capture what you have told us, we will like to record what the group says using a tape recorder. We will also like to make sure that your personal information is not captured in the recording by asking that you do not mention names during the discussion instead would like to give each other numbers that we can refer to each other in.

Your responses will remain confidential. Your personal information like your name or address will not be included in our data and report. The information that you will give us might also be inspected by the University of Witwatersrand, Human Research Ethics Committee (HREC) or other persons appointed by the HREC. Their involvement will be to make sure that your right and dignity is being protected by this research study. Your taking part in this study will not benefit you directly, but it may benefit others in the future.

Right to Refuse or Withdraw

Your participation in this study is voluntary. If at any time you do not want to answer an interview question, you may skip that question. Your decision to take part or not to take part in the interview or your decision not to answer any question will have no impact on your care in this hospital.

The researcher will only interview you after you have agreed to participate and have signed this consent form. You are free to ask questions before agreeing to participate

Contact Numbers

You are free to ask questions before agreeing to participate. In case you have any questions you may contact Mr Jude Igumbor 011 717 5459 or 072 320 2155.

This research has been approved protocol by the University of the Witwatersrand, Human Research Ethics Committee (HREC). This study has been structured in accordance with the Declaration of Helsinki (last updated: October, 2000) which deals with the recommendations guiding health researchers involving human beings. If you want any information regarding your rights as a research participant, or complaints regarding this research study you may also contact the Chairperson of the HREC, which is an independent committee established to help protect rights of research participants at (011) 717 2229

I would like to invite you to consider participating in this research study, entitled: "*Measures of Quality of Life and Experiences with Care and Support Services among Persons Living with HIV Infection in Limpopo Province, South Africa*".

Consent (Pedi, Tsonga and Venda translations were provided).

We will require your approval by writing your name and signing in the space provided below:

I …………………………………… certify that the consent form has been read out to me and any questions I had, have been answered. I give my consent and agree to participate in this study about the health related quality of life and experiences with health and social services among PLWH in Limpopo Province.

Name of Hospital …………………. ………………………………………………………..

Signature of Participant……………………… Date…………………………….......

Signature of interviewer …………….. Date…………………………….......

Consent to audio tape the focus group discussion

(Pedi, Tsonga and Venda translations were provided).

The discussions regarding the research described above will be audio-taped to allow for an accurate recording of your responses to the questions.

I …………………………………………………….. certify that the consent form and information sheet of the study has been read out to me and any questions I had, have been answered. I hereby give my consent to be audio-taped in this study about the health related quality of life and experiences with health and social services among people living with HIV and AIDS in Limpopo Province and I have been given a copy of this consent form.

Signature of Participant……………………… Date…………………………………..

Signature of interviewer ……………… Date…………………………………..

Appendix 3.4: Health and demographic data of Study II participants

Interviews Schedule for Quality of Life and Access to Services

Code number: ☐☐☐☐☐☐

Demographic Information

1. What is your age in years? ______________________yrs.

2. What is your sex Male ☐ Female ☐

3. What is your marital status?

Married ☐ Never married ☐ Divorced ☐

Separated ☐ Widowed ☐

4. Do have children Yes ☐ No ☐

5. How many children do you have? ______________________

6. What is the highest level of education you have attained?

No education ☐ Primary certificate ☐ Matric ☐

Tertiary certificate ☐

7. Are your currently employed? Yes ☐ No ☐

8. Where do you live (please ask for name of town\village and leave the name of location in the bracket only)? ____
(____________________________________)
9. The accommodation you live in is? owned by your family rented by your family sharing with another family
10. The accommodation you live in is a? shack roundavel formal
11. What is your occupation?
____
12. What was your last occupation?
____
13. What is your source of income and financial support?
____
14. Do have medical aid? ____
15. Does your medical aid pay for all your medical expenses? __________________________
16. What is your monthly household income?
R____

17. Have you disclosed your HIV status to anyone ? Yes ☐ No ☐

18. How many people have you disclosed your HIV status to: _____________________

19. If you have not disclosed your HIV status, are you planning to disclose soon? Yes ☐ No ☐

20. Do you belong to a support group? Yes ☐ No ☐

21. When were you diagnosed with HIV?__________________________________(years/months/weeks/days)

22. How long have been on treatment__________________________________(years/months/weeks/days)

23. What is your viral load: _____________________________________

24. What is your CD4 count: _____________________________________

25. Did you experience any side effect since you started treatment?

Yes ☐ No ☐

26. Have the side(s) effects been resolved?

I have not experienced any side effects ☐
No the side effect has not been resolved ☐
Yes the side effects have been resolved ☐

27. If you experienced any side effect since you started treatment, kindly list the kind of side effect starting from the most serious to the least serious

____

____

____

28. In the last two weeks have you ever been to the hospital or clinic because you were sick and how many times?_________________________

29. In the last two weeks have you ever been admitted to the hospital or clinic because you were sick and how many times? _________________________

30. Do you experience any health problem?

Yes ☐ No ☐

31. If you experience health problems, what are the common health problems that you experience?

____

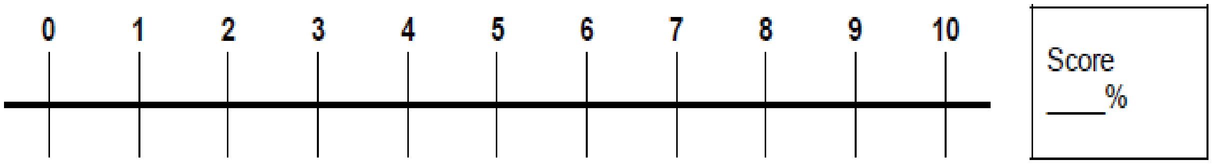
____

____

	Yes	No
32. Do you sometimes find it difficult to remember to take your medicine?	☐	☐
33. When you feel better, do you sometimes stop taking your medicine?	☐	☐
34. Thinking back over the past four days, have you missed any of your doses?	☐	☐
35. Sometimes if you feel worse when you take the medicine, do you stop taking it?	☐	☐

36. Ask the client to think back over the past four days and identify the times when he or she either missed a dose or took it at the wrong time. Show the client a copy of this visual

analogue scale, or an unmarked enlarged version. While placing your finger on the appropriate place, tell the client that if he or she had taken all medicine doses to point to 10. If the client missed all the doses, he or she would point to 0—in the meantime, you move your finger to 0. Now give the client an opportunity to point out their level of adherence. The health care worker then marks the visual analogue scale. If the scale is marked off at 4, then the percentage adherence would be 40 percent.



37. In the last few months have you ever come for treatment and were unable to get treatment?

Yes ☐ No ☐

38. If yes give reason: ____

39. Did you ever miss getting your treatment in the last four months because of the doctor’s strike?

Yes ☐ No ☐

40. When was the last time the patient was given treatment? _________________ (dd/mm/yyyy)

41. How many tablets was the patient given during his/her last visit to the clinic for the different medications?

_____________________________ _______________________

____________________________ _______________________

_____________________________ _______________________

_____________________________ _______________________

_____________________________ _______________________

42. Did the patient return any treatment today and how many did they return for the different medications?

_____________________________ _______________________

____________________________ _______________________

_____________________________ _______________________

_____________________________ _______________________

_____________________________ _______________________

43. Has the patient’s treatment regimen been changed in the last four months?

Yes ☐ No ☐

44. What is the patient’s old treatment regimen if they have changed?

45. What is the patient’s new treatment regimen if they have changed?

Appendix 3.5: Study II information sheet and consent form

Validation and Longitudinal Application of the WHOQOL-HIV Questionnaire among People Living With HIV and AIDS in Limpopo Province, South Africa

Introduction

Good morning/afternoon. I am Mr. Jude Igumbor, a student at the University of the Witwatersrand. I am gathering information on the wellbeing and the experiences of people living with HIV (PLWH). I would be grateful if you would be willing to assist by responding to questions related to this issue. The interview will take about 30 minutes of your time.

Purpose of the Study

The study aims to describe the general wellbeing and experiences of people living with HIV and AIDS. This study is driven by the need to generate the necessary information to help improve the health related quality of life of people living with HIV and AIDS and their access to needed services.

The study will follow up patients who have just started receiving ART for a period of one year. The patient that will take part in this study will be interviewed three times during the one year period. The interviews will be conducted at 6 monthly intervals and will include the first one at the beginning of treatment, the one at six months after treatment initiation and the last one at 12 months.

Your responses to this study will be confidential. The information you are going to provide will not have any personal information linked to it, that is, no information such as your name or address will be reported with the data and the information might also be inspected by the University of Witwatersrand, Human Research Ethics Committee, auditors/ authorised persons.

Your taking part in this study will not benefit you directly, but it may benefit others in the future. This information will be used to find ways to improve the access to health and support services and the health related quality of life of people living with HIV and AIDS. You will not receive payment for taking part in this study.

Right to Refuse or Withdraw

Your participation in this study is voluntary. If at any time you do not want to answer an interview question, you may skip that question. Your decision to take part or not to take part in the interview or your decision not to answer any question will have no impact on your care in this hospital.

The researcher will only interview you after you have agreed to participate and have signed this consent form. You are free to ask questions before agreeing to participate.

Contact Numbers

You are free to ask questions before agreeing to participate. In case you have any questions you may contact Jude Igumbor on 072 320 2155 or his supervisor Professor A. Stewart on 011 717 3718.

This study protocol has been submitted to the University of the Witwatersrand, Human Research Ethics Committee and has been approved. This study has been structured in accordance with the Declaration of Helsinki (last updated: October, 2000) which deals with the recommendations guiding health research involving human beings. If you want any information regarding your rights as a research participant, or complaints regarding this research study, you may also contact the Chairperson of the Human Research Ethic Committee, which is an independent committee established to help protect rights of research participants at (011) 717 2229.

I would like to invite you to consider participating in this research study, entitled: “*Measures of Quality of Life and Experiences with Care and Support Services among Persons Living with HIV Infection in Limpopo Province, South Africa*”.

Consent form

We will require your approval by writing your name and signing in the space provided below:

I ………………………………………................... certify that the information sheet form has been read out to me and any questions I had, have been answered. I give my consent and agree to participate in this study about the health related quality of life and experiences with health and social services among people living with HIV and AIDS in Limpopo Province and I have been given a copy of this consent form and information sheet.

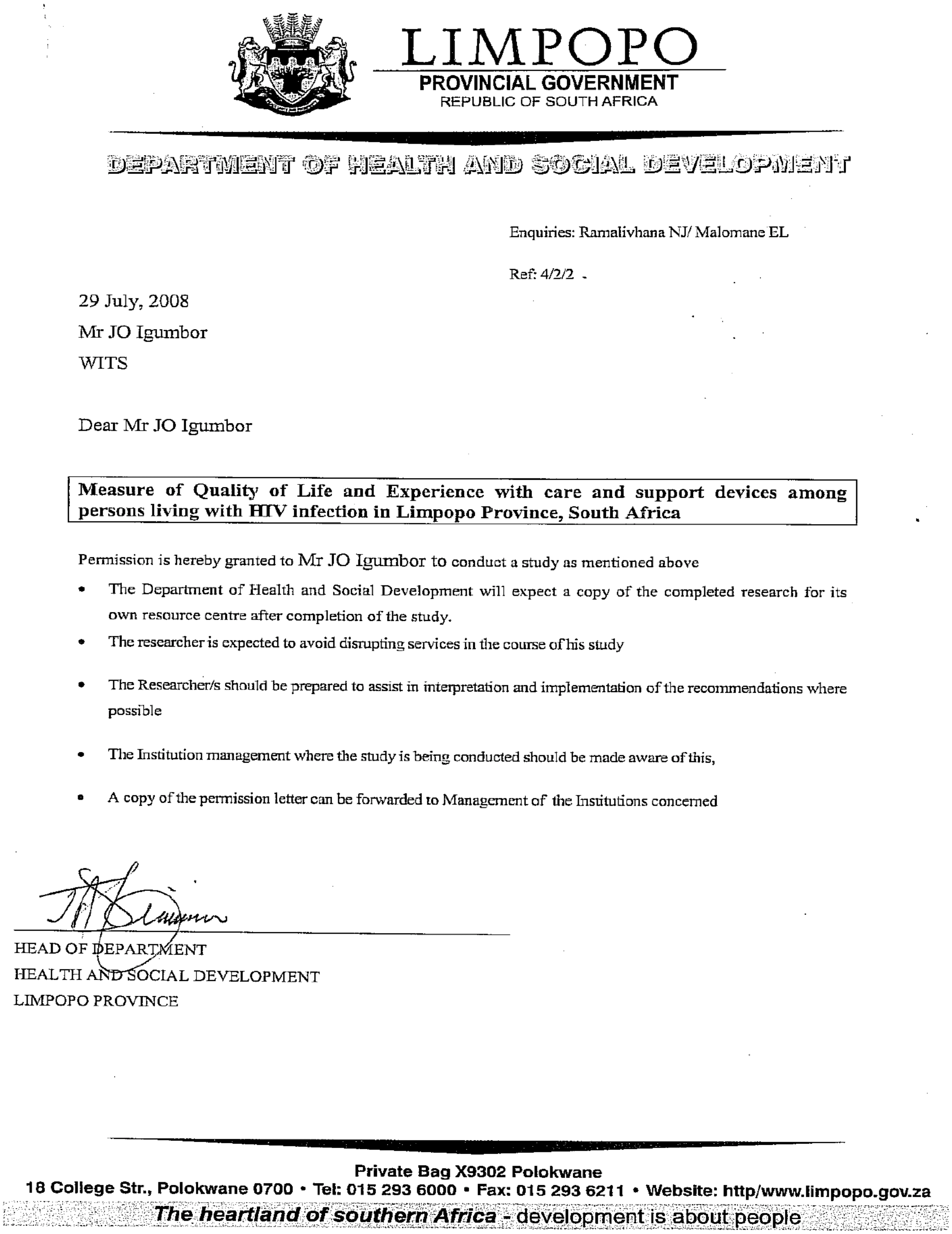
Signature of Participant………………………………………….

Name of interviewer…………………….................................

Signature of interviewer ………………………………………..

Date……………………………………………………………………..

Appendix 3.6: Permission to conduct research: Limpopo Provincial Department of Health



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH AND SOCIAL DEVELOPMENT

Enquiries: Ramalivhana NJ/ Malomane EL

Ref: 4/2/2

29 July, 2008
Mr JO Igumbor
WITS

Dear Mr JO Igumbor

Measure of Quality of Life and Experience with care and support devices among persons living with HIV infection in Limpopo Province, South Africa

Permission is hereby granted to Mr JO Igumbor to conduct a study as mentioned above

- The Department of Health and Social Development will expect a copy of the completed research for its own resource centre after completion of the study.
- The researcher is expected to avoid disrupting services in the course of his study
- The Researcher/s should be prepared to assist in interpretation and implementation of the recommendations where possible
- The Institution management where the study is being conducted should be made aware of this,
- A copy of the permission letter can be forwarded to Management of the Institutions concerned

HEAD OF DEPARTMENT
HEALTH AND SOCIAL DEVELOPMENT
LIMPOPO PROVINCE

Private Bag X9302 Polokwane
18 College Str., Polokwane 0700 • Tel: 015 293 6000 • Fax: 015 293 6211 • Website: http/www.limpopo.gov.za
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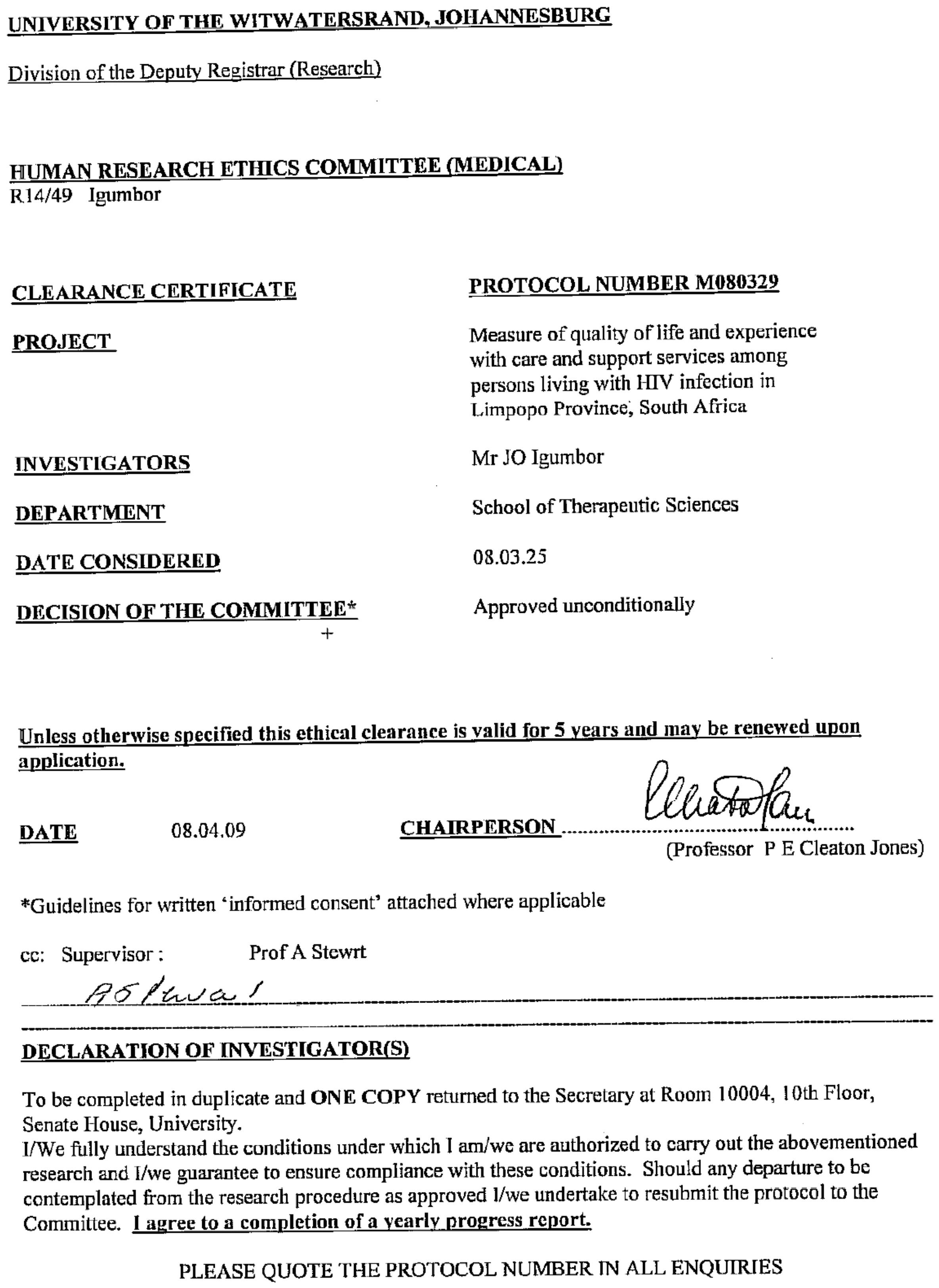
Appendix 3.7: Ethical approval for the study



UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Igumbor

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER M080329**
PROJECT	Measure of quality of life and experience with care and support services among persons living with HIV infection in Limpopo Province, South Africa
INVESTIGATORS	Mr JO Igumbor
DEPARTMENT	School of Therapeutic Sciences
DATE CONSIDERED	08.03.25
DECISION OF THE COMMITTEE*	Approved unconditionally

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

DATE 08.04.09 **CHAIRPERSON** ....
(Professor P E Cleaton Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Prof A Stewrt

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix 5.1: Reliability analysis for the WHOQOL HIV domains

Item	Cronbach's alpha
Physical Domain	**.92**
Pain and discomfort	.87
Energy and fatigue	.84
Sleep and rest	.75
Symptoms of PLWH	.86
Psychological Domain	**.86**
Positive feelings	.57
Thinking, learning, memory and concentration	.67
Self-esteem	.72
Bodily image and appearance	.66
Negative feelings	.90
Level of Independence Domain	**.89**
Mobility	.65
Activities of daily living	.79
Dependence on medication or treatments	.76
Work capacity	.96
Social Relationship Domain	**.76**
Personal relationships	.61
Social support	.66
Sexual activity	.53
Social Inclusion	.68
Environmental Domain	**.89**
Physical safety and security	.67
Home environment	.69
Financial resources	.82
Health and social care: accessibility and quality	.74
Opportunities for acquiring new information and skills	.84
Participation in and opportunities for recreation/ leisure activities	.61
Physical environment (pollution/noise/traffic/climate)	.43
Transport	.81

Spirituality/Religion/Personal Belief (SRPB) Domain	**.94**
SRPB	.70
Forgiveness and Blame	.92
Concerns about the Future	.84
Death and Dying	.96
Overall quality of life and general health perceptions	**.81**

Appendix 5.2: Mean WHOQOL-HIV scale and domain scores by ethnic group

WHOQOL-HIV scales and domains	Ethnic group	n	Mean	SD	F	Sig.
Pain and discomfort	Pedi	414	2.44	.586	342.845	.000
	Venda	241	2.27	1.004		
	Tsonga	218	4.03	.933		
Energy and fatigue	Pedi	421	2.56	.525	178.944	.000
	Venda	242	2.52	.606		
	Tsonga	216	3.40	.639		
Sleep and rest	Pedi	416	2.99	.422	244.174	.000
	Venda	239	2.89	1.060		
	Tsonga	216	4.21	.733		
Symptoms of PLWH	Pedi	422	2.45	.609	349.217	.000
	Venda	243	2.34	.976		
	Tsonga	219	4.06	.914		
Positive feelings	Pedi	419	2.93	.735	22.016	.000
	Venda	240	3.05	.849		
	Tsonga	218	2.59	.794		
Thinking, learning, memory and concentration	Pedi	421	3.48	.596	18.599	.000
	Venda	240	3.32	.848		
	Tsonga	216	3.71	.656		
Self-esteem	Pedi	416	3.47	.604	6.292	.002
	Venda	240	3.41	1.117		
	Tsonga	215	3.67	.730		
Bodily image and appearance	Pedi	420	3.30	.739	168.114	.000
	Venda	242	2.91	.587		
	Tsonga	210	4.15	.856		
Negative feelings	Pedi	420	2.76	.787	174.277	.000
	Venda	237	2.46	1.148		
	Tsonga	220	3.94	.834		
Mobility	Pedi	422	3.14	.647	82.457	.000
	Venda	242	2.68	.876		

	Tsonga	223	3.57	.768		
Activities of daily living	Pedi	415	2.75	.496	184.056	.000
	Venda	241	2.57	.994		
	Tsonga	211	3.87	.972		
Dependence on medication or treatments	Pedi	416	1.48	.658	90.961	.000
	Venda	242	1.67	.635		
	Tsonga	217	2.26	.828		
Work capacity	Pedi	423	2.95	.459	120.516	.000
	Venda	243	2.39	1.135		
	Tsonga	220	3.67	1.152		
Personal relationships	Pedi	422	3.30	.551	176.869	.000
	Venda	241	3.32	.782		
	Tsonga	219	4.29	.752		
Social support	Pedi	423	2.51	.674	174.666	.000
	Venda	242	3.37	.921		
	Tsonga	217	3.63	.873		
Sexual activity	Pedi	417	2.60	.752	38.393	.000
	Venda	237	2.79	.726		
	Tsonga	220	3.18	.912		
Social Inclusion	Pedi	415	3.34	.721	126.273	.000
	Venda	240	3.28	.654		
	Tsonga	218	4.21	.773		
Physical safety and security	Pedi	423	3.31	.606	24.894	.000
	Venda	241	3.16	.887		
	Tsonga	221	3.63	.773		
Home environment	Pedi	417	3.26	.514	7.465	.001
	Venda	243	3.47	.864		
	Tsonga	216	3.31	.767		
Financial resources	Pedi	419	1.37	.704	135.466	.000
	Venda	237	1.44	.782		
	Tsonga	218	2.43	1.006		
Health and social care:	Pedi	418	3.51	.935	12.799	.000

accessibility and quality	Venda	239	3.48	.814		
	Tsonga	220	3.83	.674		
Opportunities for acquiring new information and skills	Pedi	426	3.85	.715	11.870	.000
	Venda	241	3.55	.921		
	Tsonga	218	3.85	.831		
Participation in and opportunities for recreation/ leisure activities	Pedi	416	3.17	.520	16.306	.000
	Venda	241	3.00	.849		
	Tsonga	217	3.36	.739		
Physical environment (pollution/noise/traffic/climate)	Pedi	421	3.45	.618	16.909	.000
	Venda	238	3.19	.640		
	Tsonga	219	3.53	.791		
Transport	Pedi	421	3.38	.860	100.281	.000
	Venda	242	2.44	.793		
	Tsonga	217	3.38	1.003		
SRPB	Pedi	415	3.68	.699	21.440	.000
	Venda	0	.	.		
	Tsonga	224	3.94	.636		
Forgiveness and Blame	Pedi	424	2.54	1.089	391.297	.000
	Venda	238	2.00	1.006		
	Tsonga	221	4.48	.856		
Concerns about the Future	Pedi	426	2.49	1.032	251.702	.000
	Venda	237	1.82	.845		
	Tsonga	220	3.77	.872		
Death and Dying	Pedi	426	2.50	1.098	168.386	.000
	Venda	240	2.21	1.161		
	Tsonga	222	3.99	1.175		
Overall quality of life and general health perceptions	Pedi	423	3.30	.629	18.829	.000
	Venda	239	3.39	.998		
	Tsonga	219	3.69	.762		
Physical	Pedi	399	10.43	1.468	424.807	.000
	Venda	236	10.01	3.181		
	Tsonga	203	15.74	2.542		

Psychological	Pedi	401	12.78	1.773	65.156	.000
	Venda	230	12.17	2.823		
	Tsonga	193	14.52	2.116		
Level of Independence	Pedi	397	10.32	1.230	206.873	.000
	Venda	238	9.31	2.952		
	Tsonga	202	13.45	2.667		
Social Relationships	Pedi	401	11.73	1.427	232.618	.000
	Venda	232	12.80	2.284		
	Tsonga	205	15.28	2.271		
Environment	Pedi	385	12.74	1.363	48.847	.000
	Venda	225	11.92	2.274		
	Tsonga	196	13.74	2.243		
Spirituality/Religion/ Personal Beliefs	Pedi	410	11.18	2.975	424.345	.000
	Venda	0	.	.		
	Tsonga	213	16.21	2.719		

Appendix 5.3: LSD post hoc comparison of the mean WHOQOL-HIV scale and domain scores by ethnic group

Scale and domains	(I) Ethnic group	(J) Ethnic group	Mean Difference (I-J)	Sig.
Pain and discomfort	Pedi	Venda	.166*	.012
		Tsonga	-1.592*	.000
	Venda	Pedi	-.166*	.012
		Tsonga	-1.758*	.000
Energy and fatigue	Pedi	Venda	.035	.451
		Tsonga	-.842*	.000
	Venda	Pedi	-.035	.451
		Tsonga	-.877*	.000
Sleep and rest	Pedi	Venda	.099	.092
		Tsonga	-1.218*	.000
	Venda	Pedi	-.099	.092
		Tsonga	-1.317*	.000
Symptoms of PLWH	Pedi	Venda	.104	.109
		Tsonga	-1.614*	.000
	Venda	Pedi	-.104	.109
		Tsonga	-1.718*	.000
Positive feelings	Pedi	Venda	-.126*	.047
		Tsonga	.341*	.000
	Venda	Pedi	.126*	.047
		Tsonga	.467*	.000
Thinking, learning, memory and concentration	Pedi	Venda	.158*	.005
		Tsonga	-.233*	.000
	Venda	Pedi	-.158*	.005
		Tsonga	-.392*	.000
Self-esteem	Pedi	Venda	.054	.410
		Tsonga	-.199*	.003
	Venda	Pedi	-.054	.410

		Tsonga	-.253*	.001
Bodily image and appearance	Pedi	Venda	.392*	.000
		Tsonga	-.848*	.000
	Venda	Pedi	-.392*	.000
		Tsonga	-1.239*	.000
Negative feelings	Pedi	Venda	.297*	.000
		Tsonga	-1.184*	.000
	Venda	Pedi	-.297*	.000
		Tsonga	-1.481*	.000
Mobility	Pedi	Venda	.467*	.000
		Tsonga	-.420*	.000
	Venda	Pedi	-.467*	.000
		Tsonga	-.887*	.000
Activities of daily living	Pedi	Venda	.181*	.005
		Tsonga	-1.118*	.000
	Venda	Pedi	-.181*	.005
		Tsonga	-1.299*	.000
Dependence on medication or treatments	Pedi	Venda	-.195*	.001
		Tsonga	-.784*	.000
	Venda	Pedi	.195*	.001
		Tsonga	-.589*	.000
Work capacity	Pedi	Venda	.562*	.000
		Tsonga	-.715*	.000
	Venda	Pedi	-.562*	.000
		Tsonga	-1.277*	.000
Personal relationships	Pedi	Venda	-.027	.614
		Tsonga	-.996*	.000
	Venda	Pedi	.027	.614
		Tsonga	-.969*	.000
Social support	Pedi	Venda	-.866*	.000
		Tsonga	-1.125*	.000
	Venda	Pedi	.866*	.000

		Tsonga	-.259*	.001
Sexual activity	Pedi	Venda	-.190*	.003
		Tsonga	-.576*	.000
	Venda	Pedi	.190*	.003
		Tsonga	-.386*	.000
Social Inclusion	Pedi	Venda	.061	.298
		Tsonga	-.867*	.000
	Venda	Pedi	-.061	.298
		Tsonga	-.927*	.000
Physical safety and security	Pedi	Venda	.153*	.010
		Tsonga	-.319*	.000
	Venda	Pedi	-.153*	.010
		Tsonga	-.472*	.000
Home environment	Pedi	Venda	-.214*	.000
		Tsonga	-.056	.336
	Venda	Pedi	.214*	.000
		Tsonga	.158*	.014
Financial resources	Pedi	Venda	-.074	.263
		Tsonga	-1.066*	.000
	Venda	Pedi	.074	.263
		Tsonga	-.992*	.000
Health and social care: accessibility and quality	Pedi	Venda	.030	.659
		Tsonga	-.320*	.000
	Venda	Pedi	-.030	.659
		Tsonga	-.350*	.000
Opportunities for acquiring new information and skills	Pedi	Venda	.296*	.000
		Tsonga	-.001	.986
	Venda	Pedi	-.296*	.000
		Tsonga	-.297*	.000
Participation in and opportunities	Pedi	Venda	.172*	.002
		Tsonga	-.191*	.001
	Venda	Pedi	-.172*	.002

for recreation/ leisure activities		Tsonga	-.364*	.000
Physical environment (pollution/noise/traffic/climate)	Pedi	Venda	.258*	.000
		Tsonga	-.083	.138
	Venda	Pedi	-.258*	.000
		Tsonga	-.341*	.000
Transport	Pedi	Venda	.940*	.000
		Tsonga	-.005	.948
	Venda	Pedi	-.940*	.000
		Tsonga	-.944*	.000
Forgiveness and Blame	Pedi	Venda	.538*	.000
		Tsonga	-1.946*	.000
	Venda	Pedi	-.538*	.000
		Tsonga	-2.484*	.000
Concerns about the Future	Pedi	Venda	.663*	.000
		Tsonga	-1.287*	.000
	Venda	Pedi	-.663*	.000
		Tsonga	-1.950*	.000
Death and Dying	Pedi	Venda	.288*	.002
		Tsonga	-1.486*	.000
	Venda	Pedi	-.288*	.002
		Tsonga	-1.774*	.000
Overall quality of life and general health perceptions	Pedi	Venda	-.089	.158
		Tsonga	-.394*	.000
	Venda	Pedi	.089	.158
		Tsonga	-.305*	.000
Physical	Pedi	Venda	.423*	.028
		Tsonga	-5.308*	.000
	Venda	Pedi	-.423*	.028
		Tsonga	-5.730*	.000

Psychological	Pedi	Venda	.609*	.001
		Tsonga	-1.744*	.000
	Venda	Pedi	-.609*	.001
		Tsonga	-2.353*	.000
Level of Independence	Pedi	Venda	1.014*	.000
		Tsonga	-3.121*	.000
	Venda	Pedi	-1.014*	.000
		Tsonga	-4.135*	.000
Social Relationships	Pedi	Venda	-1.065*	.000
		Tsonga	-3.549*	.000
	Venda	Pedi	1.065*	.000
		Tsonga	-2.484*	.000
Environment	Pedi	Venda	.818*	.000
		Tsonga	-1.002*	.000
	Venda	Pedi	-.818*	.000
		Tsonga	-1.820*	.000

Appendix 5.4: Mean WHOQOL-HIV scale and domain scores showing significant difference by marital status

	Marital status	N	Mean	SD	F	Sig.
Symptoms of PLWH	Married	358	2.84	1.112	3.106	.045
	Never married	308	2.70	.903		
	Divorced/Separated/ Widowed	198	2.94	1.241		
Positive feelings	Married	359	2.88	.798	5.795	.003
	Never married	306	2.99	.770		
	Divorced/Separated/ Widowed	194	2.74	.830		
Social support	Married	356	3.13	.957	8.321	.000
	Never married	309	2.85	.841		
	Divorced/Separated/ Widowed	198	3.09	1.021		
Sexual activity	Married	353	2.91	.859	10.289	.000
	Never married	306	2.80	.781		
	Divorced/Separated/ Widowed	195	2.58	.773		
Social Inclusion	Married	351	3.56	.804	5.293	.005
	Never married	308	3.44	.815		
	Divorced/Separated/ Widowed	195	3.68	.794		
Financial resources	Married	350	1.70	.926	3.512	.030
	Never married	306	1.53	.842		
	Divorced/Separated/ Widowed	198	1.70	1.031		
Health and social care: accessibility and quality	Married	356	3.56	.811	4.821	.008
	Never married	304	3.51	.901		
	Divorced/Separated/ Widowed	198	3.75	.829		
Participation in and	Married	355	3.11	.744	3.093	.046
	Never married	302	3.18	.602		

opportunities for recreation/ leisure activities	Divorced/Separated/ Widowed	198	3.26	.726		
Transport	Married	354	3.01	.968	4.843	.008
	Never married	309	3.23	.979		
	Divorced/Separated/ Widowed	198	3.19	.967		
SRPB	Married	224	3.71	.770	4.291	.014
	Never married	258	3.76	.682		
	Divorced/Separated/ Widowed	140	3.92	.537		
Social Relationships	Married	329	13.23	2.554	6.242	.002
	Never married	301	12.56	2.104		
	Divorced/Separated/ Widowed	190	12.87	2.481		
Spirituality/Religion/ Personal Beliefs	Married	216	13.33	3.847	6.802	.001
	Never married	253	12.27	3.538		
	Divorced/Separated/ Widowed	137	13.48	3.716		

Appendix 5.5: LSD post hoc comparison of the mean WHOQOL-HIV scale and domain scores that differed significantly by marital status

Dependent Variable	(I) Marital groups	(J) Marital groups	Mean Difference (I-J)	Sig.
Symptoms of PLWH	Married	Never married	.134	.109
		Divorced/Separated/ Widowed	-.104	.274
	Never married	Married	-.134	.109
		Divorced/Separated/ Widowed	-.238*	.015
Positive feelings	Married	Never married	-.110	.076
		Divorced/Separated/ Widowed	.138	.052
	Never married	Married	.110	.076
		Divorced/Separated/ Widowed	.248*	.001
Social support	Married	Never married	.284*	.000
		Divorced/Separated/ Widowed	.046	.577
	Never married	Married	-.284*	.000
		Divorced/Separated/ Widowed	-.238*	.005
Sexual activity	Married	Never married	.115	.071
		Divorced/Separated/ Widowed	.329*	.000
	Never married	Married	-.115	.071
		Divorced/Separated/ Widowed	.214*	.004
Social Inclusion	Married	Never married	.119	.058
		Divorced/Separated/ Widowed	-.118	.102
	Never married	Married	-.119	.058

		Divorced/Separated/ Widowed	-.237*	.001
Financial resources	Married	Never married	.174*	.016
		Divorced/Separated/ Widowed	-.002	.980
	Never married	Married	-.174*	.016
		Divorced/Separated/ Widowed	-.176*	.037
Health and social care: accessibility and quality	Married	Never married	.051	.437
		Divorced/Separated/ Widowed	-.183*	.015
	Never married	Married	-.051	.437
		Divorced/Separated/ Widowed	-.234*	.003
Participation in and opportunities for recreation/ leisure activities	Married	Never married	-.075	.167
		Divorced/Separated/ Widowed	-.151*	.014
	Never married	Married	.075	.167
		Divorced/Separated/ Widowed	-.075	.234
Transport	Married	Never married	-.225*	.003
		Divorced/Separated/ Widowed	-.178*	.039
	Never married	Married	.225*	.003
		Divorced/Separated/ Widowed	.046	.602
SRPB	Married	Never married	-.046	.464
		Divorced/Separated/ Widowed	-.212*	.004
	Never married	Married	.046	.464
		Divorced/Separated/ Widowed	-.166*	.022
Social Relationships	Married	Never married	.670*	.000

		Divorced/Separated/ Widowed	.364	.094
	Never married	Married	-.670*	.000
		Divorced/Separated/ Widowed	-.306	.166
Spirituality/Religion/ Personal Beliefs	Married	Never married	1.056*	.002
		Divorced/Separated/ Widowed	-.153	.704
	Never married	Married	-1.056*	.002
		Divorced/Separated/ Widowed	-1.209*	.002

Appendix 5.6: Mean WHOQOL-HIV scale and domain scores showing significant difference between people with and without children

	Do you have children	n	Mean	SD	T	Sig.
Pain and discomfort	Yes	643	2.91	1.144	6.060	.000
	No	193	2.38	.748		
Energy and fatigue	Yes	647	2.81	.706	5.558	.000
	No	197	2.51	.521		
Sleep and rest	Yes	642	3.34	.950	4.860	.000
	No	192	2.99	.631		
Symptoms of PLWH	Yes	649	2.94	1.122	6.555	.000
	No	198	2.38	.742		
	No	198	3.35	.778		
Negative feelings	Yes	644	3.07	1.105	5.389	.000
	No	196	2.60	.862		
Activities of daily living	Yes	637	3.04	.978	4.617	.000
	No	195	2.69	.687		
Dependence on medication or treatments	Yes	644	1.81	.785	7.077	.000
	No	195	1.38	.609		
Work capacity	Yes	649	3.02	1.055	2.309	.021
	No	199	2.83	.709		
Personal relationships	Yes	649	3.61	.820	4.901	.000
	No	196	3.31	.589		
Social support	Yes	647	3.12	.932	6.759	.000
	No	197	2.62	.809		
Sexual activity	Yes	645	2.89	.818	5.621	.000
	No	193	2.52	.783		
Financial resources	Yes	642	1.74	.952	5.232	.000
	No	196	1.35	.773		
Health and social care: accessibility and quality	Yes	645	3.53	.862	-3.439	.001
	No	196	3.77	.812		
Opportunities for acquiring	Yes	650	3.72	.816	-3.522	.000

new information and skills	No	197	3.95	.720		
	No	197	3.46	.842		
Forgiveness and Blame	Yes	649	2.93	1.446	2.409	.016
	No	196	2.66	1.091		
Death and Dying	Yes	652	2.83	1.383	2.308	.021
	No	199	2.59	1.035		
Physical	Yes	618	11.97	3.488	6.416	.000
	No	186	10.24	2.067		
Psychological	Yes	597	13.15	2.400	2.251	.025
	No	194	12.71	2.135		
Level of Independence	Yes	611	11.02	2.853	4.915	.000
	No	192	9.94	1.896		
Social Relationships	Yes	619	13.16	2.430	6.649	.000
	No	188	11.89	1.785		
Spirituality/Religion/ Personal Beliefs	Yes	431	13.23	3.921	4.140	.000
	No	164	11.85	2.712		

Appendix 5.7: Mean WHOQOL-HIV scale and domain scores showing significant difference by support group membership

	Belong to support group	**N**	**Mean**	**SD**	**T**	**Sig**
Pain and discomfort	Yes	291	2.72	.899	-2.634	.009
	No	440	2.94	1.217		
Energy and fatigue	Yes	295	2.66	.590	-3.416	.001
	No	441	2.84	.760		
Symptoms of PLWH	Yes	299	2.65	.859s	-4.140	.000
	No	443	2.99	1.242		
Positive feelings	Yes	294	2.99	.784	2.273	.023
	No	443	2.84	.862		
Thinking, learning, memory and concentration	Yes	295	3.58	.594	2.382	.017
	No	439	3.46	.760		
Self-esteem	Yes	294	3.61	.656	2.387	.017
	No	436	3.46	.915		
Bodily image and appearance	Yes	297	3.54	.716	2.272	.023
	No	434	3.39	.924		
Negative feelings	Yes	294	2.72	.841	-4.410	.000
	No	439	3.08	1.203		
Dependence on medication or treatments	Yes	297	1.60	.742	-4.572	.000
	No	436	1.87	.785		
Personal relationships	Yes	297	3.40	.624	-4.653	.000
	No	441	3.68	.895		
Social support	Yes	297	2.76	.901	-7.961	.000
	No	442	3.31	.931		
Sexual activity	Yes	295	2.61	.806	-4.865	.000
	No	439	2.92	.839		
Financial resources	Yes	295	1.45	.806	-5.203	.000
	No	437	1.82	1.011		
Health and social care: accessibility and quality	Yes	298	3.87	.737	4.085	.000
	No	439	3.64	.784		

Opportunities for acquiring new information and skills	Yes No	297 443	3.96 3.70	.746 .883	4.188	.000
Participation in and opportunities for recreation/ leisure activities	Yes No	298 435	3.27 3.14	.604 .778	2.394	.017
Physical environment (pollution/noise/traffic/ climate)	Yes No	298 441	3.50 3.37	.604 .731	2.503	.013
Transport	Yes No	300 438	3.52 3.03	.848 .997	7.012	.000
Overall quality of life and general health perceptions	Yes No	298 441	3.55 3.40	.676 .874	2.465	.014
Psychological	Yes No	282 411	13.18 12.99	1.886 2.678	-2.944	.003
Social Relationships	Yes No	285 420	12.44 13.49	2.038 2.572	-5.781	.000
Environment	Yes No	288 399	13.15 12.74	1.561 2.298	2.617	.009
Spirituality/Religion/ Personal Beliefs	Yes No	251 254	12.39 14.52	3.254 3.673	-6.905	.000

Appendix 5.8: LSD post hoc comparison of the average WHOQOL-HIV domain scores at the three interview times

Scale and domains	(I) Time of interview	(J) Time of interview	Mean difference (I-J)	Sig.
Physical	Baseline	6 months	-3.079*	.000
		12 months	-2.229*	.000
	6 months	Baseline	3.079*	.000
		12 months	.849*	.001
Psychological	Baseline	6 months	-1.712*	.000
		12 months	-1.735*	.000
	6 months	Baseline	1.712*	.000
		12 months	-.023	.904
Level of Independence	Baseline	6 months	-2.504*	.000
		12 months	-2.320*	.000
	6 months	Baseline	2.504*	.000
		12 months	.184	.382
Social Relationships	Baseline	6 months	-1.771*	.000
		12 months	-1.325*	.000
	6 months	Baseline	1.771*	.000
		12 months	.446*	.022
Environment	Baseline	6 months	-2.095*	.000
		12 months	-2.172*	.000
	6 months	Baseline	2.095*	.000
		12 months	-.077	.607
Spirituality/Religion/ Personal Beliefs	Baseline	6 months	-5.050*	.000
		12 months	-4.277*	.000
	6 months	Baseline	5.050*	.000
		12 months	.773*	.008

Appendix 5.9 LDS Post hoc comparison of the average WHOQOL-HIV domains cores by CD4 count level

Dependent Variable	(I) CD4 cell count grouping	(J) CD4 cell count grouping	Mean Difference (I-J)	Sig.
Physical	0 - 200 cells/µl	201 - 349 cells/µl	-1.354*	.000
		350 - 500 cells/µl	-1.250*	.000
		> 500 cells/µl	-2.156*	.000
	201 - 349 cells/µl	0 - 200 cells/µl	1.354*	.000
		350 - 500 cells/µl	.104	.770
		> 500 cells/µl	-.801	.100
	350 - 500 cells/µl	0 - 200 cells/µl	1.250*	.000
		201 - 349 cells/µl	-.104	.770
		> 500 cells/µl	-.905	.076
Psychological	0 - 200 cells/µl	201 - 349 cells/µl	-.907*	.000
		350 - 500 cells/µl	-1.093*	.000
		> 500 cells/µl	-2.138*	.000
	201 - 349 cells/µl	0 - 200 cells/µl	.907*	.000
		350 - 500 cells/µl	-.186	.452
		> 500 cells/µl	-1.231*	.000
	350 - 500 cells/µl	0 - 200 cells/µl	1.093*	.000
		201 - 349 cells/µl	.186	.452
		> 500 cells/µl	-1.046*	.003
Level of Independence	0 - 200 cells/µl	201 - 349 cells/µl	-1.103*	.000
		350 - 500 cells/µl	-1.164*	.000
		> 500 cells/µl	-2.087*	.000
	201 - 349 cells/µl	0 - 200 cells/µl	1.103*	.000
		350 - 500 cells/µl	-.060	.833
		> 500 cells/µl	-.983*	.012
	350 - 500 cells/µl	0 - 200 cells/µl	1.164*	.000
		201 - 349 cells/µl	.060	.833
		> 500 cells/µl	-.923*	.024

Social Relationships	0 - 200 cells/µl	201 - 349 cells/µl	-.726*	.000
		350 - 500 cells/µl	-.405	.076
		> 500 cells/µl	-1.100*	.001
	201 - 349 cells/µl	0 - 200 cells/µl	.726*	.000
		350 - 500 cells/µl	.321	.208
		> 500 cells/µl	-.374	.290
	350 - 500 cells/µl	0 - 200 cells/µl	.405	.076
		201 - 349 cells/µl	-.321	.208
		> 500 cells/µl	-.695	.060
Environment	0 - 200 cells/µl	201 - 349 cells/µl	-1.033*	.000
		350 - 500 cells/µl	-1.419*	.000
		> 500 cells/µl	-1.610*	.000
	201 - 349 cells/µl	0 - 200 cells/µl	1.033*	.000
		350 - 500 cells/µl	-.387	.059
		> 500 cells/µl	-.578*	.039
	350 - 500 cells/µl	0 - 200 cells/µl	1.419*	.000
		201 - 349 cells/µl	.387	.059
		> 500 cells/µl	-.191	.514
Spirituality/Religion/ Personal Beliefs	0 - 200 cells/µl	201 - 349 cells/µl	-1.580*	.000
		350 - 500 cells/µl	-1.330*	.001
		> 500 cells/µl	-2.865*	.000
	201 - 349 cells/µl	0 - 200 cells/µl	1.580*	.000
		350 - 500 cells/µl	.250	.555
		> 500 cells/µl	-1.284*	.040
	350 - 500 cells/µl	0 - 200 cells/µl	1.330*	.001
		201 - 349 cells/µl	-.250	.555
		> 500 cells/µl	-1.534*	.018

Appendix 5.10: Selection of Physical domain items using item – total correlation and Cronbach's Alpha if item deleted

Items	Baseline		6 months		12 months	
	Corrected Item-Total Correlation	**Cronbach's Alpha if Item Deleted**	**Corrected Item-Total Correlation**	**Cronbach's Alpha if Item Deleted**	**Corrected Item-Total Correlation**	**Cronbach's Alpha if Item Deleted**
Do you have any difficulties with sleeping?	.771	.888	.746	.909	.776	.904
Do you have enough for everyday life?	-.578	.928	-.568	.940	-.764	.941
Do you worry about your pain or discomfort?	.701	.891	.813	.908	.885	.900
How difficult is it for you to handle any pain or discomfort?	.690	.891	.741	.910	.808	.903
How easily do you get tired?	.709	.891	.826	.908	.801	.904
How much are bothered by any unpleasant by any physical problems related to your HIV infection?	.758	.888	.819	.907	.873	.900
How much are you bothered by fatigue?	.744	.889	.834	.906	.886	.900
How much do any sleep problems worry you?	.680	.891	.346	.920	.279	.919
How often do you suffer (physical) pain?	.530	.897	.620	.913	.636	.909
How satisfied are you with the energy that you have?	.603	.894	.522	.916	.503	.913
How satisfied are you with your sleep?	.383	.901	.552	.915	.427	.915
How well do you sleep?	.469	.899	.571	.915	.530	.913
To what extent are you bothered by fears of developing any physical problem?	.727	.890	.779	.908	.835	.902
To what extent do you fear possible future (physical) pain?	.703	.890	.806	.907	.567	.911
To what extent do you feel any unpleasant physical problems prevent you from doing things that are important to you?	.473	.898	.591	.914	.700	.907
To what extent do you feel that (physical) pain prevents you from doing what you need to do?	.776	.888	.706	.911	.838	.902

Appendix 5.11: Selection of psychological domain items using item – total correlation and Cronbach's Alpha if item deleted

Items	Baseline		6 months		12 months	
	Corrected Item-Total Correlation	**Cronbach's Alpha if Item Deleted**	**Corrected Item-Total Correlation**	**Cronbach's Alpha if Item Deleted**	**Corrected Item-Total Correlation**	**Cronbach's Alpha if Item Deleted**
Are you able to accept your bodily appearance?	-.299	.873	.680	.845	-.142	.860
Do you feel inhibited by your looks?	.444	.846	.520	.852	.453	.826
Do you generally feel content?	.267	.852	-.391	.895	-.126	.862
How much confidence do you have in yourself?	.504	.844	.672	.849	.583	.823
How much do any feelings of depression bother you?	.528	.842	.491	.853	.677	.813
How much do any feelings of sadness or depression interfere with your everyday functioning?	.606	.838	.456	.854	.699	.812
How much do you enjoy life?	.375	.849	.569	.850	.598	.821
How much do you experience positive feelings in your life?	.120	.859	.243	.863	-.224	.857
How much do you value yourself?	.613	.839	.308	.859	.356	.831
How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	.504	.844	.528	.851	.582	.819
How positive do you feel about the future?	.530	.842	.623	.848	.586	.821
How satisfied are you with the way your body looks?	.480	.845	.757	.844	.703	.819
How satisfied are you with your abilities?	.533	.843	.676	.846	.572	.824
How satisfied are you with your ability to learn new information?	.404	.848	.428	.855	.385	.830
How satisfied are you with your ability to make decisions?	.503	.844	.645	.850	.573	.824
How satisfied are you with yourself?	.553	.841	.726	.845	.591	.824
How well are you able to concentrate	.509	.843	.206	.862	.375	.830
How worried do you feel?	.589	.839	.521	.851	.639	.815
How would you rate your memory?	.500	.844	.538	.852	.641	.823
Is there any part of your appearance which makes you feel uncomfortable?	.521	.842	.552	.850	.577	.820

Appendix 5.12: Selection of level of dependence domain items using item – total correlation and Cronbach's Alpha if item deleted

Items	**Baseline**		**6 months**		**12 months**	
	Corrected Item-Total Correlation	**Cronbach's Alpha if Item Deleted**	**Corrected Item-Total Correlation**	**Cronbach's Alpha if Item Deleted**	**Corrected Item-Total Correlation**	**Cronbach's Alpha if Item Deleted**
Are you able to work?	.771	.848	.722	.840	.746	.904
Do you feel able to carry out your duties?	.728	.850	.727	.839	.777	.903
How dependent are you on medications?	.237	.871	-.087	.871	-.032	.920
How much are you bothered by any limitations in performing everyday living activities?	.718	.850	.714	.837	.802	.900
How much do you any difficulties in mobility bother you?	.381	.867	.268	.867	.684	.905
How much do you need any medical treatment to function in your daily life?	.253	.869	.586	.845	.731	.903
How much do you need any medication to function in your daily life?	.238	.872	.521	.848	.754	.903
How satisfied are with your ability to perform your daily living activities?	.732	.850	.476	.851	.584	.909
How satisfied are you with your ability to move around?	.442	.864	.228	.860	.146	.918
How satisfied are you with your capacity to work?	.770	.848	.732	.840	.798	.903
How well are you able to get around?	.634	.854	.455	.852	.405	.913
How would you rate your ability to work?	.754	.849	.706	.841	.810	.903
To what extent are you able to carry out your daily activities?	.380	.866	.561	.847	.548	.909
To what extent do any difficulties in movement affect your way of life?	.274	.873	.272	.867	.666	.906
To what extent do you have difficulty in performing your routine activities?	.612	.855	.673	.840	.500	.911
To what extent does your quality of life depend on the use of medical substances or medical?	.168	.874	.467	.851	.553	.909

Appendix 5.13: Selection of social relationship domain items using item – total correlation and Cronbach's Alpha if item deleted

Items	Baseline		6 months		12 months	
	Corrected Item-Total Correlation	**Cronbach's Alpha if Item Deleted**	**Corrected Item-Total Correlation**	**Cronbach's Alpha if Item Deleted**	**Corrected Item-Total Correlation**	**Cronbach's Alpha if Item Deleted**
How alone do you feel in your life?	.112	.650	.202	.758	.216	.828
Do you feel happy about your relationship with your family members?	.437	.602	.532	.742	.568	.814
How satisfied are you with your personal relationships?	.540	.585	.594	.719	.675	.798
How satisfied are you with your ability to provide for or support others?	.530	.595	.523	.740	.571	.814
Do you get the kind of support from others that you need?	.368	.612	.428	.740	.587	.813
To what extent can you count on your friends when you need them?	.279	.622	.235	.762	.576	.807
How satisfied are you with the support you get from your family?	.471	.597	.540	.738	.570	.813
How satisfied are you with the support you get from your friends?	.456	.593	.421	.740	.676	.798
How would you rate your sex life?	.236	.629	.447	.737	.674	.799
How well are your sexual needs fulfilled?	.088	.651	.173	.761	.290	.827
How satisfied are you with your sex life?	.541	.584	.365	.746	.670	.800
Are you bothered by any difficulties in your sex life?	.029	.664	.080	.772	.132	.838
To what extent do you feel accepted by the people you know?	.478	.596	.547	.733	.564	.814
How often do you feel you are discriminated against because of your health condition?	-.072	.666	.280	.752	-.061	.837
To what extent do you feel accepted by your community?	.423	.605	.470	.738	.448	.818
How much do you feel alienated from those around you?	-.532	.721	.245	.759	.096	.834

Appendix 5.14: Selection of environmental domain items using item – total correlation and Cronbach's Alpha if item deleted

Items	Baseline		6 months		12 months	
	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Do you feel you are living in a safe and secure environment?	.604	.786	.564	.867	.680	.851
Do you have financial difficulties?	.011	.810	.296	.873	.169	.865
Have available to you is the information that you need in your day-to-day life?	.418	.794	.478	.868	.496	.856
Have you enough money to meet your needs?	.012	.810	.210	.875	.064	.866
How comfortable is the place where you live?	.700	.783	.498	.867	.600	.854
How concerned are you with the noise in the area you live in?	.015	.809	.205	.875	-.022	.870
How easily are you able to get good medical care?	.265	.800	.318	.871	.330	.859
How healthy is your physical environment?	.296	.799	.461	.868	.636	.853
How much are you able to relax and enjoy yourself?	.413	.794	.554	.866	.569	.854
How much do difficulties with transport restrict your life?	.133	.805	.305	.872	.261	.863
How much do you enjoy your free time?	.535	.789	.504	.867	.504	.855
How much do you like it where you live?	.554	.790	.382	.870	.598	.854
How much do you worry about money?	-.032	.811	.313	.873	.182	.865
How much do you worry about your safety and security?	-.062	.817	.251	.875	.254	.864
How safe do you feel in your daily life?	.542	.788	.578	.866	.575	.854
How satisfied are you with the climate of the place where you live?	.602	.786	.586	.866	.548	.855
How satisfied are you with the social care services?	.546	.790	.563	.867	.555	.854

Appendix 5.14: Selection of environmental domain items using item – total correlation and Cronbach's Alpha if item deleted (continued)

Items	Baseline		6 months		12 months	
	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
How satisfied are you with the way you spend your spare time?	.645	.785	.611	.866	.527	.855
How satisfied are you with your access to health services?	.167	.807	.528	.867	.595	.855
How satisfied are you with your financial situation?	.084	.806	.265	.875	.119	.868
How satisfied are you with your opportunities for acquiring new skills?	.611	.787	.621	.866	.480	.857
How satisfied are you with your opportunities to learn new information?	.663	.785	.579	.867	.436	.858
How satisfied are you with your physical environment (e.g. pollution, climate, noise, attractiveness?	-.045	.814	.568	.866	.391	.858
How satisfied are you with your physical safety and security?	.594	.788	.590	.867	.526	.856
How satisfied are you with your the conditions of your living place?	.569	.789	.631	.866	.598	.855
How satisfied are you with your transport?	.231	.801	.529	.866	.410	.857
How would you rate the quality of social services available to you?	.367	.797	.471	.869	.556	.855
To what degree does the quality of your home meet your needs?	.285	.799	.041	.879	.205	.863
To what extent do you have opportunities for acquiring the information that you feel you need?	.504	.792	.433	.869	.560	.854
To what extent do you have problems with transport?	.049	.808	.511	.866	.312	.861
To what extent do you have the opportunities for leisure activities?	-.013	.810	.021	.879	.399	.857
To what extent do you have adequate means of transport?	.098	.806	.515	.866	.390	.858

Appendix 5.15: Selection of SRPB domain items using item – total correlation and Cronbach's Alpha if item deleted

Items	Baseline		6 months		12 months	
	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Do your personal beliefs give meaning to your life?	.263	.890	.220	.917	.197	.961
How bothered are you by the thought of not being able to die the way you would want to?	.872	.866	.850	.900	.924	.948
How concerned are you about how where you will die?	.828	.868	.845	.900	.935	.948
How guilty do you feel about being HIV positive?	.690	.874	.792	.902	.943	.948
How much do you blame yourself for your HIV infection?	.745	.871	.800	.902	.931	.948
How much do you fear the future?	.539	.881	.747	.904	.664	.954
How much do you worry about death?	.716	.873	.862	.899	.864	.950
How much preoccupied are you about suffering before dying?	.803	.869	.706	.905	.882	.949
To what extent are you bothered by people blaming you for your HIV status?	.637	.877	.686	.906	.815	.951
To what extent are you concerned about how people will remember you when you are dead?	.558	.880	.741	.904	.942	.948
To what extent are you concerned about your HIV status breaking your family line and your future generations?	.622	.877	.712	.905	.883	.949
To what extent do any feelings you are suffering from fate or destiny bother you?	.650	.876	.138	.925	.587	.955
To what extent do you feel guilty when you need the help and care of others?	.398	.886	.767	.903	.806	.951
To what extent do your personal beliefs give you the strength to face difficulties?	-.145	.906	.059	.925	.257	.960
To what extent do your personal beliefs help you to understand difficulties in life?	.013	.899	.155	.920	.209	.960