PREDICTORS OF QUALITY OF LIFE ENJOYMENT AND SATISFACTION IN INDIVIDUALS LIVING WITH HIV AND AIDS IN A RESOURCE-CONSTRAINED SETTING

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A mini-thesis submitted in partial fulfillment of the requirements for the degree of Magister Artium in Child and Family Studies, Department of Social Work, Faculty of Community and Health Sciences, University of the Western Cape

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DECLARATION

I, the undersigned declare that the entirety of the work contained therein is my own, original work, that it has not previously in its entirety or in part been submitted at any other university for a degree, and that all the sources I have used or quote have been acknowledged and indicated by complete references. This study is part of a larger study however, which is entitled: *Implicative personal dilemmas and cognitive conflicts in health decision-making in HIV positive adults and adults with AIDS*. The larger study is being conducted and managed by the Principal Investigator.

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DEDICATION

This thesis is dedicated to the Heavenly Father God and my fiancé, who continuously motivated and stood by me throughout the process

“Be strong and courageous. Do not fear or be in dread of them, for it is the LORD your God who goes with you. He will not leave you or forsake you.”

(Deuteronomy, 31: 6)
ABSTRACT
The burden of HIV disease is concentrated in sub-Saharan Africa and South Africa (SA) is particularly affected. Whilst there have been many studies conducted on the biomedical and socio-psychological aspects of HIV and AIDS, insufficient attention has been paid to the quality of life of those infected with the virus. The primary purpose of this study was to determine the predictors of quality of life enjoyment and satisfaction (Q-LES) of individuals living with HIV and or AIDS and those on anti-retroviral treatment or being prepared for it. Further, the study determined the relationship between psychological distress and Q-LES of HIV positive individuals because psychological distress is reported to contribute substantially to the burden of the disease in sub-Saharan Africa, including SA. This quantitative study used a battery of questionnaires administered to 121 participants in an out-patient clinic setting. The main hypothesis tested in this study is: psychological distress is a strong predictor of Q-LES. The Hospital Anxiety and Depression Scale (HADS) was used to screen for psychological distress and the Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q) to assess the various components of QoL. A purposive sampling strategy was used to recruit participants into the study. Data analysis included descriptive and inferential statistics using SPSS to test the hypothesis. Of the total sample (N=121), 74% were females. The study found that a large proportion (49.5%) of the sample within the age group 25-49 years old had significant presence of psychological distress. Those not on ART yet were significantly affected (66%). The relationship between Q-LES subscales and psychological distress was significant (p< 0.01). The results show that psychological distress was significantly prevalent among HIV positive individuals and it was the strongest predictor of Q-LES among the study participants. Modifying the current psychological intervention programmes, in the public health clinics, for individuals
infected with the HI virus will assist in improving the current health outcomes and also help to achieve better Quality of Life outcomes.
Key words: Human Immunodeficiency Virus (HIV), Acquired Immune Deficiency Syndrome (AIDS), Quality of Life (QoL), Quality of Life Enjoyment and Satisfaction (Q-LES), Hospital Anxiety and Depression Scale (HADS), Psychological distress, Resource-constrained Setting, Antiretroviral Therapy (ART), Anxiety, Depression
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Chapter 1 introduces the scope of this study. It also includes the research problem, the research aims and objectives as well as the rationale of the study.

Chapter 2 discusses the theoretical framework underpinning the bases of the study and the relevant literature about HIV and AIDS, specifically focusing on the background context of the pandemic, health-related quality of life, along with predictors of quality of life in HIV and AIDS.

Chapter 3 outlines the research methodology, including the research design, sampling method, data collection and data analysis as well as ethical considerations.

Chapter 4 presents the analysis of the results. It further summarises the significant results.

Chapter 5 discusses the results presented in chapter four. It also presents the conclusion and recommendations for future research reached by the study.
1. Background and setting the context

An estimated 34 million people are living with HIV and AIDS worldwide; with 22.9 million in Sub Saharan Africa (UNAIDS, 2011; Merck Manual, 2008). Of the 3 million annual deaths and 11000 new daily infections, 95 percent of them occur in the developing world, in countries such as South Africa (SA). More than half of these new infections occur amongst women and children younger than 15 years. In SA, it is estimated that about 5.6 million people are living with HIV and AIDS, and that figure is higher than in any other country, UNAIDS (2011) reported (www.avert.org/worldstats.htm; Statistics SA, 2010).

HIV and AIDS are now considered to be chronic diseases because of the period it takes for the HIV infection to progress to AIDS; which can take many years from the initial infection. Many chronic diseases like HIV and AIDS have an adverse effect on the individual’s quality of life (QoL). The World Health Organization Quality of Life Group (WHOQOL) (1995) defined QoL as “individuals’ perception 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” (Lorenz, Shapiro, Asch, Bozette & Hays, 2001; WHOQOL HIV Group, 2004). QoL has also been defined in other dimensions that include illness or disease status, socioeconomic status, employment status, social support, spiritual well-being, as well as overall life satisfaction and happiness (Farquhar, 1995; Carr, Gibson & Robinson, 2001; Holmes, 2005; Vyavaharkar, Moneyham, Murdaugh & Tavakoli, 2012).
QoL is a broader construct of health-related quality of life (HRQOL). HRQOL is a multidimensional concept defined as one’s physical and mental health perceptions, as well as social well-being; including health risks and conditions, functional status, social support, and socioeconomic status (WHOQOL Group, 1993). Mental illness such as depression and anxiety, for example; was reported as the most disabling disease affecting not only the psychological well-being of the person affected with HIV and AIDS, but also the physical and social relations dimensions of the HRQOL (Basavaraj, Navya & Rashmi, 2010).

Although the number of people living with HIV and AIDS (PLWHA) is quite high, there is relatively little that is known about their quality of life (QoL); particularly in developing countries such as SA (Skevington & O’Connell, 2003). Besides biomedical factors, many other factors such as poverty, unemployment, gender inequality, as well as stigma affect PLWHA. Poverty negatively influences QoL particularly amongst the HIV infected individuals. The relationship between HIV and poverty often result in undesirable health outcomes such as the poor QoL. The AIDS pandemic has exacerbated this association between QoL and poverty due to the fact that both greatly reduce economic growth and income; further increasing poverty and stress on PLWHA, and their communities (Alleyne, 2001; Bearda, Feeleya & Rosen, 2009; Phaladze, Human, Dlamini, Hulela, Hadebe & Sukati, 2005). This could be the case for many South Africans and the communities they live in, as a result of the apartheid system that historically disadvantaged many South Africans and the socioeconomic status of the country (Myer, Ehrlich & Susser, 2004). The socioeconomic situation of SA; which is the unequal and inadequate distribution of resources that resulted from the apartheid system, such as public health funding and other public health resources; over and above poverty, has led to the vulnerability as well as increased exposure to HIV in the country. This effect has further substantial negative
effects on the QoL of PLWHA particularly in under-resourced settings (Phaladze et al., 2005). The shortcomings in the public health care systems also adversely affect QoL of PLWHA, for example the patient overload at the healthcare facilities, not enough staff personnel, lack of medical supplies, and lack of appropriate training for the HIV epidemic and improved new medicines overwhelming public health care personnel (Bearda et al., 2009; Phaladze et al., 2005).

HIV infection is related to psychological distress; which is further associated with psychiatric disorders such as anxiety and depression (Campos, Guimaraes & Remien, 2008; Chandra, Deepthivarma, Jairam & Thomas, 2003; Ciesla & Roberts, 2001). These disorders may also exacerbate immune-suppression, either directly or through a number of factors such as delayed testing, treatment adherence failure or follow-up interruption and thus, adversely affect QoL of PLWHA (Alciati, Ferri, Rozzi, Monforte, Colmegna, Valli, et al., 2001; Chandra et al., 2003; Evans, Leserman, Perkins, Stern, Murphy, Tamul, et al., 1995; Mannheimer, Matts, Telzak, Chesney, Child, Wu & Friedland, 2005). Therefore, psychological interventions can positively influence QoL among individuals living with HIV and AIDS as HIV infection also affects the central nervous system (Kumar, Abbas, Fausto, Robbins & Stanley, 2005; Loonat, 2010). However, there are considerably fewer studies on the prevalence of depression or anxiety (psychological distress) that have been conducted in non-western countries among PLWHA than in developed countries, Atkinson, Heaton, Patterson, Wolfson, Deutsch, Brown, et al., (2008) reported. Furthermore, only a small number of prevalence studies on common psychological disorders have been conducted in the sub-Saharan African countries, despite the disproportionate burden of the disease that these countries bear (Atkinson et al., 2008; Myer, Smit, Le Roux, Parker, Stein & Seedat, 2008; Phaladze et al., 2005).
1.2 HIV and AIDS

1.2.1 Epidemiology of HIV and AIDS

Sub-Saharan Africa was reported to be home to 22.9 million adults and children living with HIV by the end of 2010 (Global report, UNAIDS, 2011). The HIV virus spreads in two epidemiologically distinct patterns:

(a) Male homosexual intercourse or contact with infected blood (e.g., through sharing needles in IV drug users; before effective screening of donors and through transfusions),

and

(b) Heterosexual intercourse

The first pattern usually predominates in developed countries; while the second pattern predominates in Africa, South America, and Southern Asia. In some countries such as Brazil and Thailand, both patterns are common. In areas where heterosexual transmission is dominant such as SA; HIV infection is believed to follow routes of trade, transportation, and economic migration to cities and spreads secondarily to rural areas. Factors that perpetuate the spread of the HIV virus include poverty, poor education, a deficient system of medical care, and lack of effective drugs (Kumar & Clark, 2008; Merck Manual, 2008).

Many opportunistic infections that complicate HIV are reactivations of latent infections. Thus, epidemiological factors that determine the prevalence of latent infections also influence risk of specific opportunistic infections. In many developing countries, prevalence of toxoplasmosis and TB, particularly in SA; is high in the general population, and thus enormous increases in active TB have followed the HIV epidemic (Merck Manual, 2008).
1.2.2 Medical aspects of HIV and AIDS

Human immunodeficiency virus (HIV) is a retrovirus which causes chronic, progressive, immunological dysfunction (Chin, 2007). HIV infection results from 1 of 2 similar retroviruses (HIV-1 and HIV-2) that destroy CD4-positive lymphocytes and impair immunity, increasing risk of other infections and cancers. HIV-2 causes a substantial proportion of infections in parts of West Africa, whilst HIV-1 causes most HIV infections worldwide. However, both types of viruses are prevalent in some areas of West Africa, and may co-infect patients; although HIV-2 appears less virulent than HIV-1 (Kumar & Clark, 2008; Merck Manual, 2008). After the virus has been transmitted, HIV enters the blood stream and the cells of the body. This is the stage that the individual is regarded as having HIV. At this stage the individual is considered to be infectious, meaning that the individual has the ability to transmit HIV to another person (Jackson, 2002).

There are four stages of the infection namely; primary HIV infection, clinically asymptomatic, symptomatic HIV infection and finally, the AIDS stage. The first stage is regarded as acute HIV infection and it is the period from when the individual is first infected with HIV, to the period when proteins or antibodies are made by the immune system in response to the infection (San Francisco AIDS foundation, 2008; Merck Manual, 2008; http://www.avert.org). Thereafter an infected person could return to feeling and looking completely healthy. Some people may not experience symptoms at all or they may be acute and may not be aware that they are infected at all; this is referred to as being HIV asymptomatic. Individuals at this stage of the infection usually have a high HIV viral load, which is an indication of the amount of the virus in the body. The only indication the individual is infected with HIV at this stage is through testing and some patients present with swollen lymph glands (San Francisco AIDS foundation, 2008; Merck
Manual, 2008). During the last stage individuals may develop skin rashes, experience night sweats, constant fatigue, slight weight loss, mouth ulcers, and fungal skin and nail infections (Merck Manual, 2008). It is thus important to note these symptoms, which are biologically associated and are also similar manifestations in psychological disorders, such as depression and anxiety. Early detection and care of the HIV infection, therefore; can increase the chances of survival and improve QoL and this could possibly assist in increasing the QoL and health outcomes of individuals living with HIV or AIDS.

During the early stages, the infection may cause nonspecific febrile illness; and subsequently manifestations related to immunodeficiency are proportional to the level of CD4-positive lymphocytes. HIV manifestations range from asymptomatic stage to AIDS stage, which is defined by serious opportunistic infections or cancers or a CD4 count of less than 200/μL. Low levels of CD4-positive cells are associated with increased risk of developing life-threatening opportunistic infections; such as tuberculosis (TB), cancer and pneumonia. These opportunistic infections further increase the chances of developing acquired immunodeficiency syndrome (AIDS) or facilitate the progression from the HIV to AIDS stage. AIDS debilitates the immune system and eventually the system begins to fail, leading to death (Juvenile, 2009; Brannon & Feist, 2000).

Transmission of HIV requires contact with body fluids; specifically blood, semen, vaginal secretions, breast milk, saliva, or exudates from wounds or skin and mucosal lesions that contain infected cells (Merck Manual, 2008). Globally, heterosexual intercourse accounts for the vast majority of infections, and coexistent STIs, especially those causing genital ulceration, increase transmission rates (Kumar & Clark, 2008; Merck Manual, 2008).
The effects of HIV and AIDS can influence all aspects of one’s daily lives hence a healthy lifestyle and psychological well-being are so important for PLWHA to better their QoL (Tangkawanich, Yunibhand, Thanasilp & Magilvy, 2008).

1.2.3 Treatment of HIV and health outcome

The lengthy period of HIV infection, as described above; is further enhanced by antiretroviral therapy (ART) if the infected person is taking them. ART is a very potent drug “cocktail” designed to suppress the HIV virus from replicating; thus decreasing the viral load while increasing the CD4 count of an infected individual. The infected individual can live a long healthy life if their CD4 lymphocyte count is high and the viral load is low.

With regular care and implementation of other positive lifestyle factors such as emotional support, many long-term survivors have been living for more than two decades with HIV or AIDS. This highlights the importance of the treatment of the disease and depression, as well as enforcement of social changes to increase compliance to treatment, life expectancy and QoL. The earlier treatment of the HIV disease and the development of new treatment have shown to increase health outcomes (Shisana, Hall, Maluleke, Stoker, Schwabe, Colvin, et al., 2002; Natrass, 2006; San Francisco AIDS foundation, 2008). In SA, the use of the national antiretroviral (ARV) rollout programme has been implemented in order to ensure standardized guidelines for decision making in the selection of individuals and for the process to be followed for its use in treatment (Advanced Adult Antiretroviral Treatment Guidelines, 2008).
1.2.4 Neurological disease and HIV and AIDS

Infection of the nervous tissue occurs at an early stage, but clinical neurological involvement increases as HIV infection advances. This includes AIDS dementia complex (ADC), sensory polyneuropathy and aseptic meningitis. These conditions are much less common since the introduction of ART. The pathogenesis is thought to be due both to the release of neurotoxic products by HIV itself and to cytokine abnormalities secondary to immune dysregulation. ADC has varying degrees of severity, ranging from mild memory impairment and poor concentration through to severe cognitive deficit, personality change and psychomotor slowing. Changes in affect are common and depressive or psychotic features may be present. Sensory polyneuropathy is seen frequently in HIV infection, most commonly in the legs and feet, although hands may be affected in advanced disease. In its most severe form it causes intense pain, usually in the feet, which may disrupt sleep, impair mobility and generally reduce the quality of life. ART has been proven to have a beneficial effect on HIV neurological disease, with startling improvement in cognitive function in many patients with ADC, thus improving QoL of HIV positive patients with ADC (Kumar & Clark, 2008; Merck Manual, 2008).

1.3 Psycho-sociological aspects of HIV and AIDS and Quality of Life

Diagnosis of HIV and AIDS can be stressful and can affect both one’s physical and emotional well-being. In addition to the stress of being HIV infected one may also struggle to cope with other stressors related to health and social well-being. For example, being HIV-positive may bring about some financial strains and significant social stresses (Maj, 1990; Wadland & Gleeson, 1991). It has been reported that HIV-positive individuals employ maladaptive coping strategies while dealing with their HIV-positive status, such as disengagement, denial, avoidance or substance use; which are associated with decreases in both psychological and functional

The psychological aspect of HIV and AIDS in the context of this study is that HIV-positive individuals often develop psychological distress due to the changes in their self image and perception of themselves after the diagnosis of HIV. It is therefore useful to note that psychological distress not only affects the individual, leading to depression and poor QoL; but it could also possibly have an adverse effect on the immune system resulting in lower CD 4-positive cells which could further lead to the progression of HIV into AIDS.

A number of social factors have been associated with poorer QoL among PLWHA taking ART. These factors include older adults, unemployment, fewer years of education and female gender (Liu, Johnson, Ostrow, Silvestre, Visscher & Jacobson, et al., 2006; Mannheimer et al., 2005; Murri, Fantoni, Del, 2003; Murs, Williams, Tsevat, Cohn & Wu, 2005). As access to ART leads to increased life-expectancy for PLWHA throughout Africa, it is important to identify the factors influencing patients’ QoL that are most amenable to intervention in this context. For example, research into social factors such as household income show that those who earn a higher household monthly income report lower levels of psychological health disorders than those earning a lower household monthly income. Living in areas of high poverty, such as the one where this particular study is located; where economic resources are low have an impact on ones’ sense of well-being (Das, Do, Friedmann, Mckenzie & Scott, 2007; Bearda, Feeleya, & Rosen, 2009; Myer, et al., 2008; Subramaniana, Guptea, Dorairajb, Periannana, & Ma, 2009).
Stigma, another social factor associated with HIV has deleterious effects on HIV-positive individuals; due to fears of discrimination and physical violence, PLWHA may decide not to disclose their HIV status to family members, friends or sexual partners. This non-disclosure of one’s individual HIV-positive status has been linked to feelings of isolation and increased psychological distress among PLWHA (Herek, 1990; Chesney & Smith, 1999; Lee, Kochman & Sikkema, 2002).

Stigmatized individuals can also develop a negative view of society from their internalized stigma (Herek, 1990). Internalized stigma may make an individual more sensitive to stigmatization by others, which can negatively affect their psychological health (Chesney and Smith, 1999). Lee, Kochman and Sikkema (2002) indicated that internalized stigma related to HIV status contributed to significantly higher levels of depression and anxiety, supporting the internalized stigma effect among HIV-positive individuals.

Psychological distress is clearly of particular concern for HIV-positive patients because of its association with accelerated HIV disease progression (Leserman, Jackson, Petitto, Golden, Silva, Perkins, Cai, Folds & Evans, 1999). However, diagnosis and treatment for depression is currently not available in most African countries. Identifying psychological distress within HIV positive patients in SA could be an important step towards developing interventions that reduce psychological distress. While previous studies suggested that the socio-demographic factors associated with psychological distress in Africa may be similar to those in industrialized countries, it is unclear how clinical indicators of disease severity are associated with the prevalence of psychological distress among HIV positive patients (Campos, Guimaraes, &
Remien, 2008; Chandra, Deepthivarman, Jairam, & Thomas, 2003; Ciesla & Roberts, 2001; Kaharuza, Bunnell, Moss, Purcell, Bikaako-Kajura, Wamai, Dowining, Solberg, Coutinho, & Mermin, 2006; Olley, Seedat, Nei, & Stein, 2004; Leserman et al., 1999).

1.4 Problem Statement and Rationale for this study

There is evidence in the literature that there is high prevalence of psychological distress such as depression and anxiety among PLWHA (Myer et al., 2008). However, research into the determinants of these psychological distress disorders in this population, as well as simple screening tools of these co-morbidities in the public health care settings is limited (Myer et al., 2010). There is also increasing evidence that demonstrates that psychological health distress impacts on the QoL of PLWHA and the course of HIV infection, although few studies have explored the demographic and clinical predictors of these disorders among this population (Tate, Paul, Flanigan, Tashima, Nash, Adair, Boland, & Cohen, 2003). Therefore; there is increasing need for determining predictors of Q-LES among PLWHA in order to develop psychological interventions that can positively influence the QoL and the disease progression among these individuals, in addition to ART (Loonat, 2010; Tate et al., 2003). Predicting the Q-LES in PLWHA will assist in improving the current health outcomes and also help in modifying the current intervention programmes, such as including psychological interventions for PLWHA to better their QoL outcomes. Therefore; the primary research question in this study is: what are the predictors of Quality of Life and Enjoyment Satisfaction among individuals living with HIV or AIDS?

This particular study is located within a larger study titled: ‘Implicative personal dilemmas and cognitive conflicts in health decision-making in HIV positive adults and adults with AIDS’
The larger study focuses on addressing the interface between psychological and public health factors in trying to understand the comorbidity of HIV or AIDS and mental health and its influence on health decision-making and adherence to treatment regimens, which influences the health outcomes of the infected individual.

In order to understand psychological distress and Q-LES, Q-LES needs to be examined so as to improve psychological treatment programmes for individuals infected with HIV or AIDS.

1.5 Aims and Objectives of the Study

1.5.1 Aims

The aims of this study, which are derived from the research question, are:

1. To determine the relationship between psychological distress and quality of life enjoyment and satisfaction among individuals living with HIV and AIDS in an under-resourced setting.

2. To determine the predictors of quality of life enjoyment and satisfaction among PLWHA.

1.5.2 Objectives

The objectives in relation to the first aim are:

1. To determine the prevalence of psychological distress among individuals living with HIV and AIDS in an under-resourced setting and to disaggregate the data according to age, sex, marital status and income, where possible.

2. To determine the level of functioning of the components measured on the quality of life enjoyment and satisfaction scale.
The objectives in relation to the second aim are:

1. To determine the demographic and socio-psychological profile of the participants under study.
2. To determine the relationships between the demographic factors, social factors and psychological factors.
3. To determine the strongest predictor(s) of quality of life enjoyment and satisfaction.

1.6 Chapter Summary

The background and scope of the study was introduced in this chapter. The rationale, the aims and objectives and the possible contributions of the study were also highlighted.
CHAPTER 2

THEORETICAL FRAMEWORK AND REVIEW OF LITERATURE

Introduction

This chapter focuses on the background and the relevant literature that is appropriate for the variables under investigation in this study. Firstly the theoretical framework underpinning the basis of the study is outlined and secondly, the relevant literature such as issues on psychological health and quality of life related to HIV and AIDS is discussed.

2.1 Theoretical Framework

Psychological health outcomes appear to be consequences of complex relationships between HIV-positive status and other psycho-social factors, such as social support and socio-economic status in HIV and AIDS (Vosvick et al., 2003). A diagnosis of a life-threatening disease such as HIV is a major source of stress that can compromise one’s security; ranging from financial insecurity to unwelcome changes in lifestyle and close relationships (Maj, 1990; Wadland & Gleeson, 1991; Riggs, Vosvick & Stallings, 2007). Financial insecurity is likely to trigger the attachment system and can affect both one’s physical and psychological well-being. In addition to the stress of a chronic illness, HIV-positive individuals may also struggle to cope with other significant stressors, such as anxiety regarding their illness and worries or concerns for their loved ones. As a result of this significant social stress, many HIV infected adults turn to maladaptive coping strategies, such as disengagement, denial, avoidance, or substance use (Komiti et al., 2003; Penedo et al., 2001), which are associated with decrease in both psychological and functional quality of life (Vosvick et al., 2003, 2002).
The maladaptive coping strategies that the HIV infected individual possesses can make the adult insecure according to the insecure adult attachment style; which is based on attachment theory (first described by Bowlby, 1969; Komiti et al., 2003; Penedo et al., 2001). The attachment style of the insecure adult is characterized by negative internal working models of self and or other (Riggs et al., 2007). Preoccupied individuals, such as HIV-positive individuals, may experience high levels of attachment anxiety due to many reasons including fear of being rejected upon disclosing their HIV-positive status, feeling unworthy of love and fear of being stigmatized (Riggs et al., 2007). Secure individuals on the other hand, are likely to demonstrate better coping strategies such as seeking medical care during ill-health; while insecure individuals demonstrate unhealthy coping strategies like severe emotional distress leading to depression and anxiety (psychological distress) (Ashton, Vosvick, Chesney, Gore-Felton, Koopman, O’Shea, 2005; Komiti et al., 2003). Research suggests that attachment security may play an important role in psychological adjustment and treatment outcomes among PLWHA (Schmidt, Nachtigall, Wuethrich-Martone & Strauss, 2002; Vosvick et al., 2003, 2002; Riggs et al., 2007).

However, as relevant as the attachment style theory is to the HIV and AIDS matter; it does not account for all the HIV and AIDS complexity. Another model that can help describe a theory that supports the behaviour or response of HIV-positive individuals is the Health Belief Model (HBM). According to the HBM; an individual will seek help if he or she believes that he or she is susceptible to a particular condition, there are potentially serious consequences of bearing the condition, the benefits of taking action will outweigh the susceptibility or severity of the condition and the anticipated barriers (DiClemente & Petersen, 1994). However, just as attachment theory was not a good fit holistically for this particular study, this also applies to the HBM. HIV and AIDS are complicated diseases with many other factors like stigma playing a role; which the HBM model does not holistically capture, as indicated.
Thus, for the purpose of this study the Biopsychosocial (BPS) model; which is a more holistic model, is a general model that describes the biological, psychological, and social factors, that all play a significant role in human functioning in the context of disease or illness (Engel, 1977). Therefore, the BPS model is a more appropriate model which underpins the basis of this particular study. The BPS model includes biological and psycho-social components that play a role during illness. The biological components of the BPS focus on the biomedical aspects of the illness (Walby, 2006).

In HIV and AIDS, biomedical aspects of the BPS model such as symptomology, CD4 proliferation, disease stage and disease progression and its impact on general well-being are of importance (Walby, 2006). According to Engel (1977), the BPS model seeks to understand how the cause of the illness affects the functioning of the individual's body. The psychosocial components of the BPS model, on the other hand look for potential psychological and social causes of health-related problems such as lack of self-control, emotional disturbance, negative thinking, living conditions, socioeconomic status, culture, poverty, technology, and religion that can influence an individual’s health and well-being (Engel, 1977; Taylor, Repetti & Seeman, 1997).

2.1.1 The Biopsychosocial (BPS) model

According to Marks, Murray, Evans, Willig, Woodall and Sykes (2006) the BPS model states that health and illness is a product of a combination of factors including biological characteristics, behavioural factors, and social conditions. Psychological and social factors should be taken into consideration when trying to understand health, and subsequently a more
holistic approach to healthcare should be adopted. Health can only be understood once the relationship between biological, psychological and social factors is identified (Naidoo, 2004). The biological aspect of HIV and AIDS aid in understanding the disease characteristics regarding compromised immune system that leads to vulnerability to infections such as tuberculosis (TB) which is a co-morbid factor.

Psychological distress in this study was measured using the Hospital Anxiety and Depression Scale (HADS) and the quality of life using the Quality of Life Enjoyment and Satisfaction questionnaires (Q-LES-Q). According to Zigmond and Snaith (1983) the HADS is a self-report scale especially designed to assess anxiety and depression in people affected with a physical illness. The depression subscale mainly assesses anhedonia and does not comprise of a somatic item that can be confused with physical illness symptoms that come with HIV infection, which represents a major advantage in comparison to other existing depression measures (Zigmond & Snaith, 1983). HADS has a 4 point (0-3) response category. Accumulating data suggest that the HADS provides a valid and a reliable assessment of depression and anxiety for a wide variety of populations (Savard, Laberge, Gauthier & Bergeron, 1999).

2.2 Review of Literature

2.2.1 Psychological Health and Quality of Life

A study by Moore, Hofer, McGee, and Ring (2005) on the relationship between depression and QoL demonstrated that depression and a sense of hopelessness were perceived to be associated with poorer QoL, but depression was not found to have a larger gap between their actual present QoL. Thus research indicates that changes in the QoL are influenced by depression and hopelessness (Moore et al., 2005). Other studies confirmed this as they found that major
depression significantly impaired the individuals QoL (Angelettie, 2009; Seeweward, Laberge, Gaunthier, Fournier, Bounchard, Baril & Beergeron, 1998). In review of studies over the past 28 years it was found that generally, lower QoL in people with schizophrenia showed a strong correlation with depression, positive symptoms, greater cognitive deficits and physical disorders (Bartels & Pratt, 2009). This depicts the link between lower QoL and psychological health between individuals that had a psychological disorder.

Research studies investigating the impact of depressive disorders on QoL shows that people with psychological distress have diminished QoL. This was found in English speaking populations, as well as in a Brazilian study (Berlim, Mattevi & Fleck, 2003; Demyttenaere, Fruyt & Huygens, 2002; Sartorious, 2001). Thus similarities in findings across populations and diverse cultures were found in the latter studies. In another review of studies on QoL and mental illness, there were two studies which showed that mood disturbance was a strong predictor of poorer QoL (Tostes, Chalubs & Patel, 2006). However, it is imperative to take culture into account as SA has a multi-cultural society where depression may be manifested and QoL may be experienced in differing ways, according to differing cultural beliefs and values to that of western societies (Mukherjie, 1995).

2.2.2 Psychological Health and HIV and AIDS

Psychological distress among HIV positive individuals has been linked to internalized stigma, dysfunctional attitudes and maladaptive coping strategies, medications frequently used to treat HIV, HIV-related symptomatology, major life stresses and a lack of social support as already mentioned above. Increasing body of research indicates that HIV positive status is significantly related to depression, and other psychosocial factors, such as age, employment, and social
support are thought to fully mediate the relationship (Gore-Felton, Vosvick, Brondino, Winningham, Koopman, & Spiegel, 2006; Kalichman, Rompa, & Cage, 2000; Lee et al., 2002; McClure, Catz, Prejean, Brantley, & Jones, 1996; Penedo et al., 2001). Studies which investigated the relationship between HIV infection and risk for depressive disorders demonstrate that individuals diagnosed with HIV are not at greater risk for depression than individuals without HIV (Atkinson et al., 1998; Williams, Rabkin, Remien, Gorman & Ehrhardt, 1991; Perkins et al., 1999; Rabkin, Ferrando, Jacobsberg & fishman, 1997; Kelly, Raphael, Judd, Perdices, Kernutt, Burnett, et al., 1998). However, in a study which examined the relationship between HIV and depression showed that the diagnosis with HIV puts an individual at high risk for developing major depressive disorder compared to an individual without an HIV diagnosis (Ciesla & Roberts, 2001). This was confirmed by another study which demonstrated that anxiety and post traumatic stress disorder (PTSD) is often prevalent in adults with HIV or AIDS and that depression is the most prevalent co-morbid disorder (Rabkin, Ferrado, van Gorp, Rieppi, McElhiney & Sewell, 2000; Tate et al, 2003; Bradley, Gaynes, Pence, Eron & Miller, 2008; Myer et al., 2008).

Blumberg and Dickey (2003) found that adults with at least one of three psychiatric disorders, namely depression, generalized anxiety disorder and panic attacks, were more likely to partake in high risk behaviours. Depression and high risk behaviours are often mediated by substance abuse and violence in urban areas (Johnsons, Cunningham-Williams & Cottler, 2003). However, the severity of the depression does not appear to be related to the disease stage of the infected individuals, in a study on the intensity of depression (Ciesla & Roberts, 2001). Furthermore, depression and other psychological illness can arise independently of HIV infection, can predispose HIV through risk –related behaviours or can be a psychological consequence of the
HIV diagnosis and disease factors. This co-morbidity poses a challenge for HIV care for professionals and the individuals affected, and therefore results in the need for the development of more complex treatment (Davis, 2005).

Myer et al., (2010) reported that neuropsychiatric aspects of HIV and AIDS are strongly associated with overall QoL outcomes among PLWHA. The association between psychiatric morbidity and poorer QoL was verified not only on the scales more strongly associated with psychological disorders, but also on the scales more strongly associated with physical aspects of health (Tate et al., 2003). According to Tate et al., (2003) depression is associated with reduced QoL and poor adherence to HIV treatment regimens and also strongly associated with ratings of HRQOL. The efavirenz drug from the non-nucleoside reverse transcriptase inhibitor (NNRTI) group of ART has been associated with neuropsychiatric disorders, but little is known about depression and the quality of life in sub-Saharan Africa, where NNRTI-based regimens are still the first-line treatment recommended by the WHO and are still widely prescribed. Two psychosocial factors have also been consistently associated with QoL among HIV-infected individuals taking ART; one being the social support that has been associated with improved QoL, while presence of depressive symptoms has been significantly associated with poorer QoL (Jia, Uphold, Faan, Wu, Chen & Duncan, 2004; Jia et al., 2005; Liu et al., 2006). This emphasises the importance of the knowledge about factors that influence QoL among persons taking ART in under-resourced settings, which is currently extremely limited. This gap further undermines the ability of clinicians, policy makers and program planners to improve functioning and well-being among PLWHA taking ART.
It is well noted that symptoms of depression are often misinterpreted as a result of being diagnosed with HIV, despite the fact that one in three people with HIV suffer from depression, according a study by NIH (2002) which investigated the prevalence of depression within a previously disadvantaged group of adults with HIV or AIDS (NIH, 2002). The study by NIH (2002) also noted that it is important that clinicians focus on the depression as an important neuropsychiatric symptom which is associated with HIV (NIH, 2002; Tate et al., 2003).

2.2.3 Psychological health, Quality of Life and HIV & AIDS

The QoL of PLWHA is multifaceted with a group of disease, poverty, stigma, discrimination, and lack of treatment combined with family life, work, and social activities (Phaladze et al., 2005). SA, as a developing country has limited resources amongst other factors that prevent adequate management of HIV and AIDS such as stigma and isolation. These factors often result in psychological disorders such as depression and anxiety, and have negative effect on the QoL of the individuals infected with HIV or AIDS, as well as on the disease progression. QoL assessment has a major role to play in evaluating outcomes of all forms of interventions in HIV and AIDS (Farquhar, 1995; Carr, Gibson & Robinson, 2001; Holmes, 2005) (cited in Vyavaharkar, Moneyham, Murdaugh, & Tavakoli, 2011).

QoL and poverty have been shown to be negatively associated and the AIDS pandemic has exacerbated the association as it greatly reduces economic growth and income, further increasing poverty on PLWHA (Alleyne, 2001; Phaladze et al., 2005). Research evidence shows that there are significant differences in QoL of PLWHA that are accounted for by a number of factors across various domains, such as physical, psychological, and social factors (Vyavaharkar et al, 2011). A review of psychosocial consequences of HIV and AIDS disease impacting on QoL
suggested that poverty, HIV-related stigma, depression, substance abuse, and domestic violence influence a person’s willingness to seek medical care and motivation to adhere to therapy, and thus ultimately affecting his/her QoL (Aranda-Naranjo, 2004). According to Rao, Hahn, Cella and Hernandez (2007) study on socio-demographic and clinical factors influence on the different dimensions of QoL in PLWHA; particularly psychological well-being, CD4 cell count, living arrangement, gender, language preference, and race appear to be important factors contributing to the physical, functional, emotional, and social aspects of health-related QoL. Quality of life is looked at as a product of physical, social, emotional and environmental well-being and thus maintaining these factors on average healthy levels has the potential to produce better quality of life outcomes.

3. Chapter Summary

The chapter discussed theories framing the study particularly the theory underpinning the basis of the study. The literature review focused on previous and current studies, indicating the impact of psychological distress on HIV infected individuals and their quality of life outcomes. The review of literature also highlights the limited studies on the quality of life of people living with HIV/AIDS, particularly in the Sub-Saharan Africa.
CHAPTER 3

METHODOLOGY

Introduction

This study is located within a larger quantitative study entitled ‘Implicative personal dilemmas and cognitive conflicts in health decision-making in HIV positive adults and adults with AIDS’ (Naidoo, 2009). The larger study focuses on addressing the interface between psychological and public health factors in trying to understand the comorbidity of HIV or AIDS, psychological well-being and its influence on health decision-making and adherence to treatment regimens, which ultimately influences the health outcomes of the infected individual.

3.1 Research Design

This study is a quantitative one. A quantitative research design includes descriptive or experimental studies which aid in proving or disproving a stated hypothesis (Hopkins, 2000). It is a design related to knowledge from previous research that is organized into theory; given what is known and what one’s best guess about reality in order to build the strongest argument that may answer the research question (Hopkins, 2000). This study used structured questionnaires to obtain information from participants in order to address the aims and objectives of the study. Participants were asked specific questions in order to obtain the quantitative data that is required to answer the research question and test the hypotheses generated. The main hypothesis is as follows: psychological distress is the strongest predictor of quality of life, enjoyment and satisfaction among individuals with HIV and AIDS. Consequently, demographic and disease variables were treated as the independent variables (IVs), psychological distress as the mediating variable and QoL Enjoyment and Satisfaction as the dependent (outcome) variable.
3.2 Research Setting

The study took place at a primary health care clinic in an under-resourced community in the Cape Metropol Region. The clinic is surrounded by a number of brick houses, although there is nearly 40 percent (40%) of informal settlements and other forms of diverse living arrangements. HIV and AIDS in this area have been identified as two of the highest burden of diseases (City of Cape Town, 2008). Other social factors that are negatively impacting this particular community include unemployment, crime, gangs, teenage pregnancy, and drugs. Xhosa is the first language spoken in the community, thus 84% of the residents are Xhosa-speaking. Afrikaans is the second language spoken in the community and nine percent of the residents are Afrikaans-speaking. The majority of the residents in this township had basic understanding of English with only two percent of the community residents are English-speaking (http://www.dtbof.co.za; Njomo, 2006). The unemployment rate in this community is quite high at an estimated 40% (City of Cape Town Census, 2011).

3.3 Sampling

A purposive sampling technique was used to recruit 121 participants within the larger study. Purposive sampling is a type of sampling technique in which particular settings, persons, or events are deliberately selected for the important information that a particular study is researching, that cannot otherwise be easily obtained from other types of sampling (Babbie & Mouton, 2001; Maxwell, 1997; Teddlie & Yu, 2007). This technique was chosen because it involves selecting cases based on a specific purpose. Participants in this study are adult males and females who have been diagnosed with HIV or AIDS. The patients attending the out-patient clinic include those who are receiving ART, those that are being prepared for ART and those who need assessment of their CD4 counts and not were receiving medication when selected.
Only those participants who met the criteria for inclusion and attending the outpatient clinic at the time of data collection were included in the study if they consented. The inclusion criteria for sampling were: males and females 18 years and older, having a diagnosis of HIV or AIDS and receiving ART or undergoing ART preparation at the clinic as mentioned above. The sample also included participants who were co-infected with TB, as TB co-infection is relatively common among HIV infected individuals (Mcphee, Lingappa & Ganong, 2002; Brannon & Feist, 2007). Exclusion criteria were as follows: individuals with psychotic symptoms and those who were in an advanced stage of AIDS and who were too ill to participate in the study. Also, HIV and AIDS infected persons with clearly significant cognitive dysfunction, including mental retardation were not included in the study.

3.4 Procedure

Participants were approached and recruited for the study by trained clinic staff during the time they were receiving primary healthcare. The clinic staff was trained by the Principal Investigator (PI) for the purpose of the larger study. Recruited participants were shown to a private room. Once they agreed to take part in the study they were informed about the rationale of the study in the language of their choice in greater detail. This fulfilled the ethical procedure of informing the participant about the nature and intention of the study and that participation was free and voluntary. The procedure was also stipulated in the information sheet; which the researcher (trained research assistant) read through and provided to the participants to read through and ask questions on if they were not clear about the process. Upon understanding the procedure, the participants were then asked to sign a consent form which was in the language of their choice. Assistance was provided to those participants who could not read or write by trained research assistants. Light refreshments were served to the participants during or after completion of questionnaires.
Ethical Considerations

The study falls under a larger study; which already has been granted ethical clearance from the University of the Western Cape. The Ethics number for this study is 08/06/05. Participants were provided with an information sheet which explains the aims and purpose of the study and an informed consent form for the participants to sign. The consent form was separate from the questionnaire to maintain confidentiality and anonymity as the information sheet explained the confidentiality and anonymity of the participants. Participants participated voluntarily and were free to leave at any stage during the research process. Clear information and contact details of the researcher and supervisor were provided in the information sheet that the participants kept for themselves so they would be able to contact the researcher when they needed to do so. Personal identification was protected as the questionnaires were coded using a number instead of the participants real name for the purpose of identification during the process of analysis. Thus participants remained anonymous. Completed questionnaires were kept in a safe place and locked up. Only the PI is able to access them. After we entered data on the computer, we created a protected file that only the researchers can enter with a password for the data management and data analysis.

3.5 Data Collection Instruments

A battery of validated instruments; including the socio-biodemographic questionnaire was used to collect data. The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) was used to screen for psychological distress (measuring clinical symptoms of anxiety and depression). The Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q) was used to assess the components of quality of life (Endicott, Harrison & Blumenthal, 1993). The instruments are further described below.
3.5.1 Socio-bio-demographical information

A biodemographical questionnaire was administered in order to obtain information regarding the participants’ age, gender, marital status, and employment status. Information regarding their known CD 4 count, whether they are on ARV treatments or not, their HIV status as well as any other co-morbid factors that existed such as TB co-infection was also obtained.

3.5.2 Hospital Anxiety and Depression Scale (HADS)

The HADS is a self-report scale that contains 14 items; of which seven measure depression and seven assess anxiety in people affected with a physical illness such as HIV and AIDS. The depression subscale mainly assesses anhedonia and does not comprise any somatic item that can be confused with physical illness symptoms that comes with HIV infection; which represents a major advantage in comparison to other existing depression measures like The Beck Depression Inventory-II (BDI-II) (Zigmond & Snaith, 1983; Savard, et al., 1999). The total score (adding anxiety and depression scores) was used as a measure of psychological distress because this was found to be more reliable based on calculations using the Cronbach α than when it used separately. The scores indicate absence, possible presence (borderline) or probable presence of each state. For each subscale, a score below eight (<8) is in the normal range while 8–10 is a borderline result. A score greater than 10 (11+) for either subscale indicates a probable mood state disorder. The range of scores on the psychological distress measure using the HADS is 0 minimum to 42 maximum. The HADS was translated into Xhosa for use in this study. To ensure correctness of the translation version, the Xhosa translated version of the instrument was further back-translated from Xhosa to English for verification purposes.
3.5.3 Reliability and validity of the HADS

The HADS instrument was found to be reliable and it possesses both construct and criterion validity (Herrmann, 1997). The HADS has been used in a number of studies (Naidoo 2009; Savard, et al., 1999) and has shown to be valid, reliable and comparable. The HADS is a widely used and popular self-report measure that has been extensively translated and utilized in a broad variety of clinical populations. A relatively consistent finding of previous reviews of this instrument is that it is a reliable and valid measure of two independent and separable dimensions of anxiety and depression; indeed this aspect of the HADS is crucial to the validity of the measure in clinical practice (Martin, 2005). The administering of the HADS questionnaire took about 10 minutes to complete in this study. It was found to perform well in assessing severity and caseness of anxiety disorders and depression in both somatic and psychiatric cases and (not only in hospital practice for which it was first designed for) in primary care patients and the general population (Snaith, 2003). In addition to frequent validation for use in the elderly the HADS has been validated for use in adolescents too (Snaith, 2003). The Cronbach alpha for HADS for this study is 0.67 when the anxiety and depression scales were combined to produce a score for psychological distress. The recommended coefficient of the Cronbach alpha is said to be above .60 in order for the instrument to be considered a reliable instrument (Bjelland, Dahl, Haug & Neckelmann, 2002). Thus, the good and reliable Cronbach alpha for the HADS validates its use in the study.

3.5.4 Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q)

The Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q) was used to obtain information pertaining to the degree of enjoyment and satisfaction the participant experiences given the fact that they are infected with the HI virus. It is used to measure health-related QoL in
studies on depression amongst other mood and anxiety disorders and for measuring the relationship between depression and QoL. The Q-LES-Q consists of 93-items from the following domains: physical health, subjective feelings, leisure-time activities and social activities, work activities, schoolwork activities, household duties, and general activities. For the purpose of this study, this instrument was translated into isiXhosa. It is worth noting that there were some challenges in this process as some words used in the instrument are not available in the Xhosa vocabulary, and thus a compromise was made. The translations were back translated from Xhosa to English in order to ascertain accuracy of the Xhosa translated version and maintain the meaning from the English version. The questions were rated on a Likert scale from 1-5. The ranges within each domain were between 1.8 minimum and 112.5 maximum, except for work and school work domains (Daly, Trivedi, Wisniewski, Nierenberg, Gaynes, Warden, Morris, Luther, Farabaugh, Cook & Rush, 2010).

3.5.5 Validity and Reliability of Q-LES-Q

Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q) has been widely used in QOL outcome studies of mentally disabled patients since 1993. Researchers found the Q-LES-Q to be a useful instrument for assessing treatment of depression; for evaluating QoL in chronic depression, and bipolar disorder (Ritsner, Kurs, Gibel, Ratner & Endicott, 2005). The Q-LES-Q showed that the test-reset reliability showed high reliability and validity with a Cronbach alpha coefficient for the Q-Physical domain of 0.88 and for the Q-Feelings domain being 0.83 (Ritsner & Eward, 2007; Hakuzimanana, 2005). The Cronbach alpha coefficient indicates an overall high internal consistency which is 0.77 for all the domains of the Q-LES-Q in this study.
3.6 Data analysis

The data was analyzed using the Statistical Program for Social Science (SPSS), version 19 (SPSS-SA, 2010). The statistical analysis used descriptive statistics and inferential statistics. Descriptive statistics were used to summarize and organize the data, while inferential statistics was used to generalize and draw conclusions from the data (Pretorius, 2007). Descriptive statistics was also used to describe the data by the scores as it relates to variables such as socio-demographic factors, disease profile and depression and whether the scores on each variable are interrelated (Terre Blanch & Durrheim, 1999). Inferential statistics was used to help provide information regarding the relationships between the variables and to test the hypothesis of the study. Regression analysis was used to determine the strongest predictors of Q-LES (Pretorius, 2007; Terre Blanch & Durrheim, 1999).

3.7 Chapter Summary

This chapter describes the methodology used in the study. It describes the research design, the participants, sampling method and the data collection tools. The chapter also explains the procedure of data collection, the method of data analysis as well as discussion around the ethical considerations regarding the study. The following chapter will give a presentation of the statistical analyses, which includes descriptive statistics and inferential statistics.
CHAPTER 4

RESULTS

Introduction

The results are presented in the following way: (1) social, bio-demographic and psychological distress characteristics of the sample, (2) the nature of the relationships between the variables under study, and (3) the predictive characteristics of biodemographics, psychological distress and quality of life enjoyment and satisfaction of adults diagnosed with HIV or AIDS.

4.1 Description of the Sample

The sample consisted of 121 HIV positive adults in total. A large proportion of the total sample (68.5%) was diagnosed with full blown AIDS, which is an advanced stage (stage three) of the disease and only 31.5% (n=35) reported to be diagnosed with HIV or in the early stages of the disease. The demographic characteristics of the sample are presented below, in Table 4.1.

The sample consisted of 90 females and 31 males. The majority of the participants were clearly females (74.4%) while only 25.6% of the sample was male participants. The mean age of the sample is 31.6 years with standard deviation (SD) of 7.95. A large percentage of the sample fell onto the age ranges of 25 to 49 years old, 81% of the sample. Majority of the participants (91.6%) within the sample were Xhosa-speaking participants, 3.4% were English speaking and 5% was speaking other languages such as seSotho. More than half of the sample was never married before, that is they are single or not legally married, 54.2% of the sample, followed by 24.6% that were married, 13.6% were living together with the partner, 2.5 percent were divorced
and 1.7% were widowed. A large proportion of the sample was unemployed, which is 101 participants (85.6%) of our sample while only 17 participants (14.4%) were employed.

Table 4.1 Descriptive Characteristics of the Sample

<table>
<thead>
<tr>
<th>Variables</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (N=121)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minimum</td>
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</tr>
<tr>
<td>Maximum</td>
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<td></td>
</tr>
<tr>
<td>Mean</td>
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<td></td>
</tr>
<tr>
<td>Standard Deviation (SD)</td>
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<tr>
<td><strong>Sex (N=121)</strong></td>
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</tr>
<tr>
<td>Males</td>
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<td>25.6</td>
</tr>
<tr>
<td>Females</td>
<td>90</td>
<td>74.4</td>
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<tr>
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</tr>
<tr>
<td>Xhosa</td>
<td>109</td>
<td>91.6</td>
</tr>
<tr>
<td>Other</td>
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<tr>
<td><strong>Marital Status (N=118)</strong></td>
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<tr>
<td>Never Married</td>
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<td>54.2</td>
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<tr>
<td>Living with partner</td>
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<td>13.6</td>
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<tr>
<td>Separated</td>
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<tr>
<td>Married</td>
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<td>2.5</td>
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<tr>
<td>Widowed</td>
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<td>1.7</td>
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<td><strong>Employment Status (N=118)</strong></td>
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<td><strong>Diagnosed with HIV or AIDS (N=111)</strong></td>
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<td>AIDS</td>
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<td><strong>Stage of disease (medical) (N=98)</strong></td>
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<td></td>
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<tr>
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</tr>
<tr>
<td>No</td>
<td>40</td>
<td>33.3</td>
</tr>
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<td><strong>TB (N=113)</strong></td>
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<td>29.2</td>
</tr>
<tr>
<td>No</td>
<td>80</td>
<td>70.8</td>
</tr>
</tbody>
</table>

* Either did not know the stage, reported “early stages” or reported “just found out”
Biomedical characteristics

Amongst those that reported to be diagnosed with AIDS (n=76), 56.1% of them were in stage three of the disease or AIDS stage as mentioned above, 21.4% were in stage two, and only 17.4% were in stage one or asymptomatic stage of the AIDS clinical stage categories. The remaining 5.1% of the study participants either didn’t know of their stage or had just found out of their HIV status at the time of data collection. A large proportion (66.7%) of the sample population was taking ART. The others were either being prepared for ART or awaiting their CD count levels. With regards to co-existing medical conditions, 29.2% (n=33) of the participants had TB as a co-infection.

Psychological Distress

Table 4.2 below presents the percentages for different categories of the psychological distress variable. For the category 0-7 which is normal indicating no presence of psychological distress, only 15.1% of the participants scored under this category, 34.5% scored under category 8-12 which is borderline and the large proportion (50.4%) scored under the category 13 and above which is serious presence of psychological distress. Thus, a large proportion of the study sample had a presence of psychological distress.

Table 4.2 Psychological Distress

<table>
<thead>
<tr>
<th>Variable Categories</th>
<th>N(119)</th>
<th>%</th>
</tr>
</thead>
<tbody>
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<td>Normal (0-7)</td>
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<td>15.1</td>
</tr>
<tr>
<td>Borderline (8-12)</td>
<td>41</td>
<td>34.5</td>
</tr>
<tr>
<td>Severe (13+)</td>
<td>60</td>
<td>50.4</td>
</tr>
</tbody>
</table>

Quality of life and Enjoyment Satisfaction

Table 4.3 below shows descriptive statistics of various domains of the quality of life measured from the participants. The percentage means for work and school work domains were very low especially on the school work domain at 4.57 with standard deviation (SD) of 12.5.
Table 4.3 Means and SD of Total Scores for the Q-LES-Q

<table>
<thead>
<tr>
<th>Quality of Life Domains</th>
<th>% Mean</th>
<th>Std. Error of Mean</th>
<th>Std. Deviation</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q-Physical (N=119)</td>
<td>40.24</td>
<td>1.006</td>
<td>10.975</td>
<td>16</td>
<td>65</td>
</tr>
<tr>
<td>Q-Feelings (N=119)</td>
<td>45.79</td>
<td>1.162</td>
<td>12.680</td>
<td>13</td>
<td>70</td>
</tr>
<tr>
<td>Q-Work (N=103)</td>
<td>10.80</td>
<td>1.992</td>
<td>20.220</td>
<td>0</td>
<td>65</td>
</tr>
<tr>
<td>Q-Household duties (N=119)</td>
<td>29.50</td>
<td>1.162</td>
<td>12.672</td>
<td>0</td>
<td>50</td>
</tr>
<tr>
<td>Q-School Work (N=97)</td>
<td>4.57</td>
<td>1.271</td>
<td>12.516</td>
<td>0</td>
<td>50</td>
</tr>
<tr>
<td>Q-Leisure (N=119)</td>
<td>19.05</td>
<td>.636</td>
<td>6.938</td>
<td>0</td>
<td>30</td>
</tr>
<tr>
<td>Q-Social Relations (N=119)</td>
<td>38.25</td>
<td>.865</td>
<td>9.433</td>
<td>0</td>
<td>55</td>
</tr>
<tr>
<td>Q-General (N=119)</td>
<td>49.19</td>
<td>1.281</td>
<td>13.971</td>
<td>0</td>
<td>80</td>
</tr>
</tbody>
</table>

4.2 Psychological Distress and biodemographical characteristics

General cross tabulation of the biodemographic characteristics against psychological distress in Table 4.4 below yielded the following: 48 counts of the 97 in total (49.5%) of the age group 25-49 year olds sample, 10 counts of the 19 in total (52.6%) of the 18-24 age group sample, and 2 (66.7%) out of the 3 in total of the 50 year old and above sample, had significant presence of psychological distress. The highest frequency of the psychological distress was found in 18 – 24 years age group at 52.6%, followed by 49.5 % of the age group 25-49 year olds as indicated above. Further cross-tabulation against between psychological distress and males revealed that 16 (53.3%) of the 30 total males had presence of psychological distress, compared to 44 (48.9%) of the 90 in total females. On the other hand, 11 males (36.7%) and 30 females (33.2%) scored on the borderline category of psychological distress.

With regards to marital status, 32 (50%) of the total 64 of those that reported never married, followed by 14 (50%) of the 28 in total of those who were currently married, and 9 (56.2%) of the 16 of those living with the partner, had presence of psychological distress. On the other hand, 8 (53.3%) of the 15 in total employed participants reported presence of the psychological
distress; compared to a rather very large number of those unemployed, which is 51 (50.5%) of the total 101 unemployed participants who also scored on the probable (severe) presence of psychological distress category.

The table below (Table 4.4) also shows that 65.8% of those who were not on ART yet were distress psychologically, compared to those who were already taking ART at 42.5% who also scored on the category of presence of psychological distress. Overall, about 50% of the total sample had presence of psychological distress. More of the descriptive statistics of biodemographic characteristics are shown in Table 4.4 below.

4.3 Association between biodemographics, psychological distress and QoL

Table 4.5 below shows the association between psychological distress and biodemographics of the participants using the Pearson’s correlation coefficients. There was a negative relationship between ART and psychological distress, and that ART was significantly correlated (r= -.244, p<0.01) with psychological distress at 0.01 level, 2-tailed. This means that those who were on ART during the time of the study were less likely to be psychologically distressed compared to those not taking ART. On the other hand, there was a positive relationship between TB and psychological distress (r=.183, p<0.05) and were significantly correlated at 0.05 level, meaning that the diagnosis of TB is an added burden among PLWHA and it increases the risk for psychological distress.
<table>
<thead>
<tr>
<th>Biodemographic Variables</th>
<th>Psychological Distress Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0-7</td>
</tr>
<tr>
<td><strong>Age Groups in years</strong></td>
<td></td>
</tr>
<tr>
<td>18-24 (N=19)</td>
<td>5 (26.3%)</td>
</tr>
<tr>
<td>25-49 (N=97)</td>
<td>12 (12.4%)</td>
</tr>
<tr>
<td>50+ (N=3)</td>
<td>1 (33.3%)</td>
</tr>
<tr>
<td><strong>Total (119)</strong></td>
<td>18 (15.1%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male (N=30)</td>
<td>3 (10%)</td>
</tr>
<tr>
<td>Female (N=90)</td>
<td>15 (16.7%)</td>
</tr>
<tr>
<td><strong>Total (120)</strong></td>
<td>18 (15%)</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
</tr>
<tr>
<td>Employed (N=15)</td>
<td>0</td>
</tr>
<tr>
<td>Unemployed (N=101)</td>
<td>17 (100%)</td>
</tr>
<tr>
<td><strong>Total (116)</strong></td>
<td>17 (100%)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Never married (N=64)</td>
<td>12 (18.8%)</td>
</tr>
<tr>
<td>Living with partner (N=16)</td>
<td>0</td>
</tr>
<tr>
<td>Separated (N=3)</td>
<td>0</td>
</tr>
<tr>
<td>Married (N=28)</td>
<td>4 (14.3%)</td>
</tr>
<tr>
<td>Divorced (N=3)</td>
<td>1 (33.3%)</td>
</tr>
<tr>
<td>Widowed (N=2)</td>
<td>1 (50%)</td>
</tr>
<tr>
<td><strong>Total (116)</strong></td>
<td>18 (15.5%)</td>
</tr>
<tr>
<td><strong>On ARV (Yes or No)</strong></td>
<td></td>
</tr>
<tr>
<td>Yes (80)</td>
<td>16 (20.0%)</td>
</tr>
<tr>
<td>No (38)</td>
<td>2 (5.3%)</td>
</tr>
<tr>
<td><strong>Total (118)</strong></td>
<td>18 (15.3%)</td>
</tr>
<tr>
<td><strong>TB</strong></td>
<td></td>
</tr>
<tr>
<td>Yes (33)</td>
<td>2 (11.1%)</td>
</tr>
<tr>
<td>No (80)</td>
<td>16 (88.9%)</td>
</tr>
<tr>
<td><strong>Total (113)</strong></td>
<td>18 (16%)</td>
</tr>
</tbody>
</table>
Table 4.5 Association between Psychological Distress and Biodemographics

<table>
<thead>
<tr>
<th>Biodemographic Variables</th>
<th>Psychological Distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>ART</td>
<td>-0.244**</td>
</tr>
<tr>
<td>TB</td>
<td>0.183*</td>
</tr>
</tbody>
</table>

**.Correlation significant at the 0.01 level (2-tailed)
*.Correlation significant at the 0.05 level (2-tailed)

Table 4.6 below shows Pearson’s correlation coefficients between QLES domains and biodemographic characteristics of the participants. ART and TB were again significantly correlated (p<0.01) with physical, feelings, leisure, social relations and the general domains of the Q-LES. The relationship between Q-LES domains and TB was negative. Therefore TB has a negative impact on Q-LES of PLWHA. The relationship between ART and Q-LES domains was a positive relationship meaning that being on ART has a positive and beneficial effect on Q-LES of PLWHA.

Table 4.7 below shows Pearson’s correlation coefficients between total Q-LES and biodemographic characteristics of the participants. Employment Status, being diagnosed with AIDS, late stage of disease (late clinical AIDS stage), taking ART, and having co-existing medical condition (TB) were again significantly correlated (p<0.01) with overall Q-LES of the participants. All these biodemographic variables had a negative relationship with total Q-LES, except for TB which had a positive relationship with total Q-LES. This means that these factors impact on overall Q-LES of PLWHA negatively, and hence PLWHA reported poor on overall enjoyment and satisfaction. However, as noted in Table 4.6 above, some of these factors (i.e. ART) have a positive impact on the separate domains of Q-LES.
**Table 4.6 Association between Q-LES Domains of life and Biodemographics**

<table>
<thead>
<tr>
<th>Biodemographics</th>
<th>Q-Physical</th>
<th>Q-Feelings</th>
<th>Q-Work</th>
<th>Q-Household duties</th>
<th>Q-School Work</th>
<th>Q-Leisure</th>
<th>Q-Social Relations</th>
<th>Q-General</th>
</tr>
</thead>
<tbody>
<tr>
<td>On ART</td>
<td>.255**</td>
<td>.244**</td>
<td>.065</td>
<td>.179</td>
<td>.030</td>
<td>.313**</td>
<td>.212*</td>
<td>.276**</td>
</tr>
<tr>
<td>TB</td>
<td>-.266**</td>
<td>-.290**</td>
<td>-.262**</td>
<td>-.097</td>
<td>-.043</td>
<td>-.213*</td>
<td>-.359**</td>
<td>-.242**</td>
</tr>
</tbody>
</table>

**.Correlation significant at the 0.01 level (2-tailed)
*.Correlation significant at the 0.05 level (2-tailed)

**Table 4.7 Association between total Q-LES and Biodemographics**

<table>
<thead>
<tr>
<th>Biodemographics</th>
<th>Q-LES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage of disease (medical)</td>
<td>-.382**</td>
</tr>
<tr>
<td>On ART</td>
<td>.257*</td>
</tr>
<tr>
<td>TB</td>
<td>-.353**</td>
</tr>
<tr>
<td>Psychological Distress</td>
<td>-.307**</td>
</tr>
</tbody>
</table>

**.Correlation significant at the 0.01 level (2-tailed)
*. Correlation significant at the 0.05 level (2-tailed)

Table 4.8 below shows Pearson’s correlation coefficients between Q-LES domains and psychological distress among the participants. Except for the domains: work and school work, all other domains of Q-LES were significantly correlated (p<0.01) with psychological distress and the correlation was negative. Therefore, the participants with psychological distress scored poor on Q-LES domains and thus psychological distress negatively affects Q-LES of PLWHA.
Table 4.8 Association between Q-LES Domains and Psychological Distress

<table>
<thead>
<tr>
<th>Quality of life Domains</th>
<th>Psychological Distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q-Physical</td>
<td>-.285**</td>
</tr>
<tr>
<td>Q-Feelings</td>
<td>-.295**</td>
</tr>
<tr>
<td>Q-Work</td>
<td>.035</td>
</tr>
<tr>
<td>Q-Household duties</td>
<td>-.237*</td>
</tr>
<tr>
<td>Q-School Work</td>
<td>-.149</td>
</tr>
<tr>
<td>Q-Leisure</td>
<td>-.295**</td>
</tr>
<tr>
<td>Q-Social Relations</td>
<td>-.340**</td>
</tr>
<tr>
<td>Q-General</td>
<td>-.336**</td>
</tr>
<tr>
<td><strong>Total QoL</strong></td>
<td><strong>-.307</strong></td>
</tr>
</tbody>
</table>

**. Correlation significant at the 0.01 level (1-tailed)
*. Correlation significant at the 0.05 level (2-tailed)

4.4 Predicting Quality of Life Enjoyment and Satisfaction

Table 4.9 below shows regression analysis for Q-LES, psychological distress and biodemographics of the participants in the study. Psychological distress and TB were the strongest predictors of poor Q-LES (p<0.01) for both, followed by ART for good Q-LES (p=0.01). This demonstrates that having psychological distress and a TB diagnosis has a negative impact on the outcomes Q-LES while being on ART improves the outcomes of Q-LES of PLWHA.
Table 4.9 Regression Analysis for Q-LES, Psychological Distress and Biodemographics
Predicting Q-LES (ANOVA) ($R^2=0.33$ F (5.9) = 19.47)

<table>
<thead>
<tr>
<th>Predictors</th>
<th>B</th>
<th>t</th>
<th>Partial R</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group</td>
<td>.118</td>
<td>1.23</td>
<td>1.34</td>
</tr>
<tr>
<td>Sex (Female)</td>
<td>.059</td>
<td>.60</td>
<td>.066</td>
</tr>
<tr>
<td>Marital Status</td>
<td>-.122</td>
<td>-1.28</td>
<td>-.140</td>
</tr>
<tr>
<td>Employment Status</td>
<td>.334*</td>
<td>3.37</td>
<td>.347</td>
</tr>
<tr>
<td>On ART</td>
<td>.216*</td>
<td>2.32</td>
<td>.246</td>
</tr>
<tr>
<td>TB</td>
<td>-.238*</td>
<td>-2.53</td>
<td>-.268</td>
</tr>
<tr>
<td>Psychological Distress</td>
<td>-.249*</td>
<td>-2.62</td>
<td>-.277</td>
</tr>
</tbody>
</table>

*p <0.05

Table 4.10 below also shows regression analysis for the specific Q-LES domains, psychological distress and significant biodemographics of the participants in the study. Under the domains: physical and feelings, being on ART, TB and psychological distress were the strongest predictors of Q-LES (p<0.01) in these two domains. ART and psychological distress also were the strongest predictors of Q-LES (p<0.01) in the domains of leisure and general. Psychological distress was the strongest predictor of Q-LES (p<0.01) in the in the domains of leisure, social relations and general as well as TB except for the leisure domain.

Table 4.10 Regression Analysis for Q-LES domains and Biodemographics

<table>
<thead>
<tr>
<th>Biodemographics</th>
<th>Q-Physical</th>
<th>Q-Feelings</th>
<th>Q-Work</th>
<th>Q-Household duties</th>
<th>Q-School Work</th>
<th>Q-Leisure</th>
<th>Q-Social Relations</th>
<th>Q-General</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment Status/ School</td>
<td>.621</td>
<td>.192</td>
<td>.000</td>
<td>.283</td>
<td>.068</td>
<td>.394</td>
<td>.901</td>
<td>.603</td>
</tr>
<tr>
<td>On ART</td>
<td>.005*</td>
<td>.008*</td>
<td>.516</td>
<td>.053</td>
<td>.769</td>
<td>.001*</td>
<td>.021</td>
<td>.002*</td>
</tr>
<tr>
<td>TB</td>
<td>.004*</td>
<td>.002*</td>
<td>.009*</td>
<td>.304</td>
<td>.683</td>
<td>.024</td>
<td>.000*</td>
<td>.010*</td>
</tr>
<tr>
<td>Psychological Distress</td>
<td>.002*</td>
<td>.001*</td>
<td>.726</td>
<td>.010*</td>
<td>.150</td>
<td>.001*</td>
<td>.000*</td>
<td>.000*</td>
</tr>
</tbody>
</table>

*. Significant at the 0.01 level (p <0.01)
4.5 Conclusion
More than a third of this study sample received ART, and their total psychological distress and Q-LES scores were significantly different from those who were not on ART yet. Those who were on ART scored better on the psychological distress and had a higher quality of life enjoyment satisfaction than those who were not on ART. Another third of the study sample had a co-existing medical condition; tuberculosis (TB). These variables (predictors) were the variables that predicted Q-LES strongest with p-value \( \leq 0.01 \). In the case of TB, participants who were co-infected with TB scored lower on the Q-LES compared to participants who were not co-infected.

The results of this chapter were presented in the form of descriptive and inferential statistics, and will now be briefly discussed in an integrated manner in the next chapter, including the limitations of the study and recommendations for future research.
CHAPTER 5

DISCUSSION

Introduction

The primary research question in this study was: what are the predictors of Quality of Life Enjoyment and Satisfaction among individuals living with HIV or AIDS? In order to answer the research question statistical tests were carried out to determine the association between psychological distress and quality of life enjoyment and satisfaction (Q-LES), as well as to determine the predictors of Q-LES among individuals living with HIV or AIDS in an under-resourced setting. The significant findings of the study are discussed in this chapter. This chapter will begin by discussing the biodemographic characteristics of the sample in relation to quality of life and psychological distress. It will then end with the relationships between biodemographic characteristics, psychological distress and quality of life and enjoyment satisfaction. The study findings are examined in relation to the aims and objectives as well as the hypotheses of the study, integrating the theoretical framework discussed in Chapter 2.

5.1 Characteristics of the sample

Biodemographic Profile

Women in South Africa, as in many other countries are overwhelmingly affected by HIV and AIDS. For example, women in sub-Saharan Africa represent 58% of the people living with HIV and bear the greatest burden of care (UNAIDS, 2012). Our study sample consisted of 74% women with only 26% of the sample were men, who are HIV positive, consistent with previous and current research (WHO, 2007; Freeman, Nkomo, Kafaar, & Kelly, 2007; Shisana et al., 2009; UNAIDS, 2012). Clearly, the number of women in this study is much higher than that of
men. However, women could be over-represented because they agreed to participate more than men as the study used a purposive sampling method. With regards to age a large proportion of the sample was in the age group 25 to 49 years old. Consistent with our findings, previous research also indicated that HIV infection and mortality is extensive in this reproductive age group (Myer et al., 2009). Majority of the participants were also not legally married before, with smaller proportions married; and a few were living together with the partner, divorced and or widowed. These results are not unique as previous research has indicated that HIV prevalence is higher amongst the people that were never married before (Freeman et al., 2007; Shisana et al., 2005; Myer et al., 2009; Shisana et al., 2009; UNAIDS, 2012).

A large proportion (91.6%) of the participants was Xhosa speaking people with some of them having some form of basic understanding of English. In SA, the language Xhosa is a predominant African language in the Eastern and Western Cape regions of the country. This particular study was undertaken in an under-resourced setting or low income community, as mentioned in earlier chapters; hence the lower socioeconomic status of the participants as the majority was unemployed (85.6%) and were Xhosa speaking (Njomo, 2006; du Preez, 2008). The lower socioeconomic and unemployment rates in SA adds a burden on HIV vulnerability as noted by Kaharuza et al., (2006) study in Uganda and supported by Havenaar, Geerlings, Collinson, Robertson, (2008) study on unemployment and lack of education that have been associated with increased risks of psychological disorders in South Africa and potentially increase HIV infection risks. Women are especially affected by this association due to social and economic power imbalances between the genders and thus many women have little or no power to negotiate safe sex in order to protect themselves from HIV (UNAIDS, 2012). This imbalance is further emphasised by the high number of participants in the advanced stages of the disease. In
this study more than half of the participants (56%) were in stage three of the disease or AIDS stage, followed by 21.4% in stage two, and an even smaller proportion was in stage one or asymptomatic stage, consistent with the previous and current status of the epidemic (UNAIDS, 2011 & 2012). The remaining 5% of the participants either didn’t know of their stage or had just found out of their HIV status at the time of data collection. Finally, more than half of the sample population (66.7 %) was taking ART, also consistent with the epidemic status (UNAIDS, 2011). The relatively high number of participants on ART could be the result of the escalated ART roll-out programme in the country in order to mitigate the HIV and AIDS burden. The others were either being prepared for ART or awaiting their CD count levels.

5.2 Prevalence of Psychological Distress

The prevalence of psychological distress in this study is relatively high with more than half of the participants on the significant psychological distress category. Psychological distress, among HIV positive patients has been reported to be associated with accelerated HIV progression to AIDS (Leserman et al., 1999) and that raises concern and creates difficulty in the management of the disease by health care practitioners. Our study revealed that 50.4% had significant presence of (category 13 and above) psychological distress while 34.5% had borderline (category 8-12) presence of psychological distress when screened by the HADS. Thus, more than half of the study participants had a presence of psychological distress. Our findings support previous findings. In a study conducted by Herman, Stein, Seedat, Heeringa, Moomal, and Williams (2009) found that the Western Cape region, the region where the present study was also conducted, has the highest prevalence of common mental disorders, including anxiety and depression (Herman et al., 2009). Also, it has been reported that one in three people with HIV
suffer from depression (Bing, Burnam, Longshore, Fleishman, Sherbourne, London, Turner, Eggnan, Beckman, Vitiello, Morton, Orlando, Bozzette, Ortiz-Barron, Shapiro, 2001; NIH, 2002).

The study revealed that 53.3% of the men in the study had significant presence of psychological distress (category 13 and above or severe) compared to 48.9% of the female population. It is important however, to note that the male population of this study was relative smaller than the female population as mention above, although these findings are consistent with previous research. For example, a comparison study of the demographic characteristics and HIV status reported similar findings (Stranix-Chibanda, Chingono, Montgomery, Wells, Maldonado, Chipato & Shetty; 2005). Also, the psycho-social factors affecting both men and women in SA are perceived differently by both genders due to cultural and societal connotations surrounding both genders. It is also worth noting that the highest frequency of the psychological distress was clearly evident in 18 – 24 years age group at 52.6% despite its overall population size (n=19) being smaller than that of the 25-49 year olds. This is generally a vulnerable group in HIV and AIDS, particularly women in this age group. Besides HIV and AIDS, they experience other psycho-social issues such as peer pressure, identity crisis and a sense of love and belonging. Therefore, it is not surprising that many of them had a presence of psychological distress.

With regards to marital status, both those that were never married before as well as those that were currently married scored under the upper category of psychological distress in our study. However, there were more participants who were never married before or not legally married in the study than those who were married. Thus, participants who were never married before had a presence of psychological distress (50%) compared to those that were currently married or living with a partner. The results also show that slightly more employed people (53 %) in the study
were psychologically distressed compared to the unemployed group of people (50%), although the unemployed participants had significant value statistically as they were more unemployed participants (n=101) compared to the employed participants (n=17) in this study. The psychological distress among the unemployed participants could also be due to the added burden of lack of finances to support and maintain their needs and living expenses. This could be very worrying indeed to the ill person as their basic health care needs are difficult to meet, in addition to coping with the straining demands of living with their HIV status. Consistent with our findings, Myer et al., (2008) reported that individuals from low socio-economic stratum (SES) are at 1.5–2.0 more at risk of a major depressive episode compared to individuals from the highest socioeconomic stratum (Myer et al., 2008). It has been well documented that poverty not only drives the spread of HIV infection particularly among women, but also has a negative effect on psychological well-being on an individual. As Das et al., (2007) reported that individuals from lower SES report more psychological disorders than their counter parts; hence these findings are not surprising.

Our findings also revealed that more people (65.8%, n=38) who were not on ART yet were significantly distressed, compared to those who were already taking ART at 42.5% (n=80) who also scored on the category of significant presence of psychological distress. With the revised CD4 count start off for ART initiation, it is expected that individual who are initiated on ART before their CD4 count dropped too low would respond better to treatment and that would also decrease chances of development of other opportunistic infection and minimize treatment side effects. ART improves the immune system functioning and therefore makes ones’ condition manageable. With any disease under control, one gradually turns to do better physically and emotionally. Therefore this can offer an explanation to the fewer participants on ART scoring on
the significant category of psychological distress than those not on ART yet as they could still be overwhelmed with and in distress about their disease. They could also be simply anxious about the manifestation and possibly the disease progression and or be overwhelmed with other opportunistic infection and thus presenting with deteriorating health. Our findings are not unique from previous research as Freeman et al., (2007) reported that overall prevalence of psychological disorder was 43.7% and even higher in Stage three of the AIDS disease (Freeman et al., 2007) where it is expected to drastically progress and affects one’s health, lifestyle and functioning. The more advance the stage of the disease the higher the chances of development of other opportunistic infections, the more unbearable are the signs and symptoms, and thus one would be in distress.

5.3 Association between biodemographics, psychological distress, and Q-LES

Psychological well-being is essential in mind–body healing and its association with natural killer (NK) cell activities is well known (Hasanah, Zaliha, & Mahiran; 2011). It lowers their production and affects their functioning negatively. This further diminishes the bodies’ ability to naturally protect itself from opportunistic infection. Our study found a negative relationship between ART and psychological distress, and that the correlation was significant (r= -.244, p<0.01). This means that participants who were not on ART scored higher on psychological distress and those that were on ART scored lower. Therefore being on ART appears to be beneficial among the study population by decreasing the chances of being psychologically distressed. On the other hand, there was a positive relationship between TB and psychological distress (r=.183, p<0.05) and that means that TB as an HIV and AIDS co-infection significantly increases psychological distress. In other words participants who were co-infected with TB scored higher on psychological distress, and that means that individuals having TB diagnosis in
addition to HIV infection increases their psychological distress. Further associations were found between employment status and psychological distress, supporting findings found by (Myer et al., 2008) where low levels of SES were persistently associated with increased non-specific psychological distress experienced in the previous 30 days in their study. Also, depression has been associated with low quality of life in men and women living with HIV (Molassiotis, Callaghan, Twinn & Lam, 2001). In another study, similar to our findings, only advanced stage of HIV disease was negatively associated with poor QoL in a study by (Woods, Moore, Weber & Grant, 2009). As mentioned earlier, advanced stage of the disease increases chances of opportunistic infections, slows ART response as the viral load is quite high at this stage and there is also extensive signs and symptoms that add stress onto ones’ health.

Psychological distress consistently appeared as significant associations (p< 0.01) to general or overall QoL and the five other domains of Q-LES. Research findings have found that adults with severe psychological disorders have been unequally and disproportionally affected by HIV or AIDS epidemic (Meade & Sikkema, 2005). This was confirmed by several other studies which showed an increase in HIV infection amongst acute and chronic psychologically ill adults in urban areas (Kelly, Murphy, Sikkema, Somlai, Mulry, Fernandez, Miller & Stevenson, 1995). This also demonstrated that individuals with psychological disorders are more at risk for contracting HIV and AIDS. HIV is known to attack the brain quickly, suggesting another reason for the increase in psychological health disorder amongst people diagnosed with HIV and AIDS (Palitza, 2009). Therefore, empirical evidence supports the fact that psychological illness can be a result of the, as well as be a consequence of the HIV and AIDS disease (NIH, 2002; Tate et al., 2003; Palitza, 2009).
Psychological distress can substantially affect the quality of life of HIV-infected persons. In addition to poor quality of life, psychological distress particularly, is likely to adversely affect adherence to ART (Walkup, Wei, Sambamoorthi, & Crystal; 2008) which in turn affects health outcomes. Indeed, it has been shown that HIV-infected persons who received treatment for their psychological conditions, such as depression were likely to be more adherent than those who remained untreated (Dalessandro et al., 2007).

5.4 Factors affecting Quality of Life and Enjoyment Satisfaction (Q-LES) among PLWHA

Factors affecting the quality of life and enjoyment satisfaction of individuals living with HIV or AIDS in this study were unemployment, ART, tuberculosis (TB) and psychological distress. Unemployment revealed a significant relationship to quality of life (p<0.05), consistent with Eriksson’s et al., (2000) study, significant positive relationships between higher level of education, being employed, and better quality of life were found (Eriksson, Berglund & Sandstrom; 2000). Unemployment is a psychosocial stressor on its own. One cannot argue the fact that the lack of financial support or income adds an added stress onto ones’ well-being as one has to worry about basics means of survival, such as food over and above worrying about their health status. Another study supporting these findings is a study by (Stangl, Wamai, Mermin, Awor & Bunnel, 2007) which reported that depression, lower CD4 counts, higher HIV RNA levels, economic dependence, and lower education levels predicted poor HR-QOL (Stangl et al., 2007). The study also reported that unemployment or financial insecurity was, however the strongest predictor of poor HR-QOL (Stangl et al., 2007). Consistent with our findings, Stangl et al., (2007) also found similar clinical, socio-economic, and psychosocial factors predictive of better HR-QOL. These findings are consistent with our findings where unemployment had a
significant relationship to quality of life, meaning that the lack of income impedes quality of life enjoyment and satisfaction.

In the era of ART, when quality of life issues are of paramount importance, strategies to improve social support, coping, and particularly, alleviation of depressive symptoms are strongly encouraged (Jia, Uphold, Wu, Reid, Findley, & Duncan, 2004). A recent survey on patients receiving ART showed that anxiety was more frequent in the following situations: female gender; low education level; unemployment; no steady partner; side effects of ART; and detectable viral load (Preau et al., 2008). This is consistent with our findings, whereby there was a negative correlation between ART and psychological distress (p< 0.01). This means that participants who were not taking ART were psychologically distressed compared to those who were taking ART. However, Nachera et al., (2010) argues that patients who are recently put on ART had higher incidence of depression and generalized anxiety than those who were not treated (Nachera, Adrioucha, Sebillottea, Hanfa, Vantilckec, Guedjc, et al., 2010). This presumably reflected the psychological and physical distress due to treatment initiation, although a study on efavirenz revealed no association with an increased incidence of depression but was significantly related to generalised anxiety as presumably thought. It was reported that depression increases in the more severely immune-compromised patients with impeding QoL, Nachera, et al., (2010) further elaborates.

ART initiation can improve patients’ health related-QoL if initiated in the early stages of the disease, on the other hand, it can further deteriorate patients’ health related-QoL if started late in the disease stage of progression as the immune system is weaker at this stage- cannot handle the works of ART in the body. Previous studies have shown a positive effect of ART on patients’
QoL because of the delay of disease progression (Nieuwkerk, Hillebrand-Haverkort, Vriesendorp, Frissen, de Wolf & Sprangers, 2007). At the same time, ART can have a negative effect on patients’ QoL because of the toxicities and inconveniences associated with most regimens. The extent to which these potential negative effects of ART on QoL are outweighed by positive effects may depend on the timing of ART initiation (Nieuwkerk, et al., 2007).

The significant impact of the AIDS clinical stage of disease on the quality of life enjoyment and satisfaction of the participants in this study reflects the hindering nature of the disease which affects various aspects of the Q-LES of those infected. However, the most important problems of our participants were related to the feelings, social relations, general and physical aspect of the Q-LES domains. As Ichikawa and Natpartan (2006) showed in their study, having social acceptability has the most significant relationship with better quality of life and the social supporting regardless of clinical stage of the disease, had desired impact on psychosocial aspects of patients’ life. Also in other studies, the relationship between HIV or AIDS, patients’ quality of life and their socioeconomic status was linear (Ichikawa & Natpartan, 2006; Stangl et al., 2007; Eriksson’s et al., 2000).

5.5 Predictors of Quality of Life and Enjoyment Satisfaction (Q-LES)

Demographic characteristics such as age, sex and marital status did not show any significance in predicting Q-LES. Only unemployment was a strong predictor of Q-LES with a p-value of .002, supporting previous research. This is not unique to the HIV and AIDS epidemiological status as it has been well reported that low SES or poverty is one of the major structural factors which are key drivers of HIV infection, particularly amongst women in the Southern Africa. For example, sociodemographic characteristics such as education and financial dependence in a study by
Stangl et al., (2007) mentioned above were the only significant predictors of QoL (Stangl et al., 2007).

The predictive models presented below (Figure 1 and Figure 2) illustrate the effects of the bio-demographics on the psychological well-being of PLWHA and their Q-LES. Model A shows the bio-demographics that affect Q-LES negatively, while Model B shows the bio-demographics that affect Q-LES positively.

As illustrated, group of factors such as social support (not having a stable relationship or being single), unemployment, not taking ART, and a co-infection (TB) result in psychological distress which in turn diminishes Q-LES among PLWHA. These factors also accelerate the disease progression. Low SES has also been shown to be linked to poor QoL (Alleyne, 2001) and according to this model (Model A); it shows that unemployment has a negative effect on psychological well-being as well as on the Q-LES of the study participants. Therefore, unemployment greatly increases psychological distress risks and further exacerbates Q-LES of PLWHA. Also, female gender is linked to increased psychological distress. This could be due to the fact that violence against women is relatively high, increasing their psychological distress and thus putting a strain on women’s Q-LES. These factors, including TB predicted poor Q-LES among PLWHA in our study, as shown below in Figure 1.
Figure 1: Factors Predicting Quality of Life Enjoyment and Satisfaction (Negative)

Figure 2 below illustrates factors that affect psychological well-being positively and therefore predicts better Q-LES of PLWHA. Employment as well as absence of TB co-infection has a positive effect on psychological well-being, thus minimising psychological distress. TB co-infection adds more burden on the PLWHA as it affects general health and well-being over and above living with HIV and AIDS. On the hand, ART alleviates HIV and AIDS signs and symptoms, further improving health while enhancing Q-LES. Managing HIV and AIDS greatly improves psychological well-being as one would live life similar to any other person with a
chronic disease. This obviously decreases psychological distress of the individual and thus predicts better Q-LES of PLWHA (see Figure 2 below).

**The Predictive Model: B**

![Diagram](image)

*Figure 2: Factors Predicting Quality of Life Enjoyment and Satisfaction (Positive)*

In this study psychological distress and TB were the strongest predictors of Q-LES with a p-value less than 0.01. This means that having psychological distress, as well as TB co-infection affects the Q-LES of PLWHA negatively. In addition, our regression model consistently showed that psychological distress and TB had a significant impact on most aspects of the Q-LES domains. These findings support previous research, for example, among the clinical variables, high CD4 cell count was the strongest predictor of better QoL at ART initiation while presence of depressive symptoms among study participants predicted poor QoL, in a study by (Campos et
These findings suggest that our findings support previous research that identified psychological distress symptoms as a key factor affecting QoL among persons infected with HIV or AIDS (Jia et al., 2004; Tate et al., 2003; Campos et al., 2008). Psychological distress, such as depression, as shown by Molassiotis, et al., (2001) was associated with low quality of life in men and women living with HIV. Another study also found psychological distress to be the strongest predictor of poor QoL in men and women with advanced or late stage HIV/AIDS (Kempainen, 2001). Psychological distress affects ones’ thinking, functioning and coping mechanisms, making it difficult for one to live life and perform the normal activities one usual performs, and thus further exacerbates the distress. It is very stressful for any individual, with or without HIV to not being able to perform their normal activities. PLWHA tend to feel stress, depression, and anxiety regarding their illness and the progression of the disease, as well as concerns about financial problems and their family even to the point of deterring them from seeking medical care. HIV infected individuals are also faced with social stigma, long-term physical discomfort and illness, and eventually death. All these factors significantly affect their psychological well-being as well as their Q-LES negatively and further making it difficult for them to cope with their illness both physically and emotionally. Furthermore, it is useful to note that psychological distress not only affects the individual, leading to depression and poor Q-LES; but it could also possibly have an adverse effect on the immune system resulting in lower CD 4+ cells which could further lead to the progression of HIV into AIDS. Our findings supports the conclusion drawn by other studies that HIV status alone, is not a strong predictor of QoL, but instead it interacts with other psychosocial characteristics of the individual as reported in Dickey et al., (1999); Rabkin, (1996). Therefore, factors predictive of better Q-LES scores include, but not limited to, clinical factors (e.g., fewer AIDS-related symptoms, higher CD4 counts, lower clinical staging, and psychological well-being).
Conclusion
In summarizing the results of this study, it appeared that the most important biodemographic factors that have association with the quality of life enjoyment and satisfaction of the patients were unemployment, ART, TB and psychological distress (p<0.01). Psychological distress is significantly prevalent among HIV positive individuals and was found to be the strongest predictor of Q-LES among the study population followed by TB and ART. This suggests and highlights the importance of detecting psychological distress by simple screening methods and developing special interventions for individuals living with HIV and AIDS. Early detection of psychological distress will impact Q-LES of PLWHA positively, and will improve their psychological well-being; which in turn will significantly improve the overall health-related quality of life (HRQOL).

5.6 Contributions of the study
The outcomes of the study are intended to help build the practitioners’ knowledge and understanding of psychological distress conditions, as co-morbid disorders in individuals infected with HIV or AIDS. Including and modifying the current psychological intervention programmes for individuals infected with the HI virus will assist in improving the current health outcomes and also help to achieve better QoL outcomes. Also, the findings of the study hope to inform the larger study on the factors influencing QoL and contribute to the development of future intervention programmes.

5.7 Limitations of the study
In interpreting the results, some important limitations of the study were taken into account. One such important limitation was that of the number of males in the study being very small relative to the number of women. However, it should be noted that women attend the primary healthcare
facilities way better than men, probably because of cultural and societal connotations related to the male figures in the South African context; as well as due to stigma although the latter also applies to women too. Another important limitation is the fact that the study findings are not generalisable due the sample size and the fact that the study participants were purposively selected and thus may not necessarily be good representative of the general population. Despite these limitations, our findings have several clinical and research implications and add to our understanding of the processes by which psychosocial variables impact on different dimensions of the Q-LES.

5.8 Recommendations
Identifying psychological distress within HIV positive patients in South Africa could be an important step towards developing interventions that reduce depression and anxiety in HIV positive patients. Future studies should address, in detail, the role of bio-demographic characteristics in psychiatric morbidity. Q-LES measures, on the other hand, may add to biological measures of ART response to assess resource allocation and improve health outcomes. Furthermore, ART can lengthen the disease progression and also improve Q-LES of PLWHA. Also, the ultimate goal of primary healthcare should be to maintain and or improve the quality of life of people living with HIV and AIDS and thus improved Q-LES can help influence life expectancy; hence, the importance of psychological interventions and better –Q-LES among PLWHA. Finally, predicting the Q-LES in PLWHA will assist in improving the current health outcomes and also help in modifying the current intervention programmes, such as including psychological interventions for PLWHA to better their Q-LES outcomes.
REFERENCES


Brown, J.E., King, M.T., Butow, P.N., Dunn, S.M. & Coates, A.S., (2000b). Patterns over time in quality of life, coping and psychological adjustment in late stage melanoma patients: An application of multilevel models. *Quality of Life Research, 9*(1), 75–85.


[http://www.nih.com](http://www.nih.com) [accessed 22/10/12]


www.avert.org/worldstats.htm, viewed on 31/03/2011.
Project Title: IMPLICATIVE PERSONAL DILEMMAS AND COGNITIVE CONFLICTS IN HEALTH DECISION-MAKING IN HIV POSITIVE ADULTS AND ADULTS WITH AIDS

What is this study about?

This is a research project being conducted by Professor Pamela Naidoo at the University of the Western Cape. We are inviting you to participate in this research project because you have tested positive for the HI Virus and you are already on a treatment programme, which includes anti-retro viral therapy. The purpose of this research project is to try and understand how you think about your life and the fact that you are HIV positive, and how you arrive at the decision you make regarding your health. You are aware that you can infect others with the HI Virus if you do not take the necessary precautions, such as using protective devices (e.g. a condom) whilst you are involved with other individuals during periods of intimacy. You are also aware that you have to follow a particular life-style, such as not engaging in risky behaviour, which can compromise your health. Not taking the anti-retro viral therapy as the doctor or the nurse advises you to take it, for example, may lead you to suffer ill health.

Very often despite individuals knowing that, certain behaviours are bad for theirs and other individual’s health, they make decisions that may endanger theirs and the lives of others. This study, therefore, focuses on the difficulties that individuals, who are HIV positive, face when making health decisions. The study also attempts to understand how HIV positive individuals arrive at making health decisions that are good for them and other individuals that form part of their lives.

Once we are better able to understand the way you think about your health and how this thinking influences the decisions you make about taking care of our health, we will try to use this understanding to make changes to your current treatment programme. Once these changes are made and you receive the newly developed programme we will monitor the programme to assess whether it works well. Only one of the two clinics that is involved in the study will provide the new programme because we still need to test whether the programme works better than the previous programme before all the clinics provide it.
What will I be asked to do if I agree to participate?

You will be asked to fill in a number of questionnaires in a language of your choice. You will be assisted and guided by a research assistant. There will be a special room where you will be able to sit comfortably and fill in all the questionnaires. Please do not hesitate to inform the research assistant if you are experiencing any discomfort or if you want to have a rest before completing the questionnaires. You should be able to complete the questionnaires within one and a half (to two) hours. Light refreshments will be provided.

About 6 to 8 months after the new treatment programme is given to you at your clinic, we will ask you and the patients from the clinic that did not provide the programme to fill in another set of questionnaires, which should take an hour and a half to complete. This will be done at one of your follow-up visits. Once again, you will be given the questionnaires in a special room where light refreshments will also be provided.

If you are required to come in when it is not your clinic follow-up visit, then you will be given money for you transport.

Would my participation in this study be kept confidential?

We will do our best to keep your personal information confidential. To help protect your confidentiality, we will not write your name on each of the questionnaires but we will use a code so that the main researchers can identify you. This is important because we would like you to benefit from this study. We would like you to participate in the follow-up phase of the study, after the new programme is provided at the clinic. It is for this reason that the main researchers need to be able to identify you.

Please be assured that the questionnaires you answer will be locked in a safe place and only the main researchers will be able to access it. After we enter your answers on the computer, we will create a protected file that only the main researchers can enter with a pass word.

If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

What are the risks of this research?

There are no known risks associated with participating in this research project. However, you are at liberty to rest if you get tired whilst you are filling in the questionnaires.

What are the benefits of this research?

The benefits to you if you receive the new treatment programme include the fact that you will be able to express the way you think and feel about being HIV positive. You will be given the choice to have more counselling about your health status.
You and the patients who do not receive the new programme, will also be helping other people who are HIV positive, indirectly, to benefit. By testing the new programme, we will be able to advise all the health practitioners involved in your treatment what the best method of treatment is so that you can live a better life by making better decisions.

**Do I have to be in this research and may I stop participating at any time?**

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

**Is any assistance available if I am negatively affected by participating in this study?**

Yes, the research assistants will be able to help you during the time that you are participating in the research. If you feel that you want to talk more about your experiences of being HIV positive, the research assistant will arrange for the appropriate professional person to see you. If this happens, you will have to provide permission for the research assistant to refer you.

**What if I have questions?**

This research is being conducted by Professor Pamela Naidoo of the department of Psychology at the University of the Western Cape. If you have any questions about the research study itself, please contact me at: the Department of Psychology at the University of the Western Cape. Tel: 021 959 2835/2283/2453.

Should you have any further questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Principal Investigator: Prof Pamela Naidoo  
Dean of the Faculty of Community and Health Sciences: Prof R Mpofu  
University of the Western Cape  
Private Bag X17  
Bellville 7535

This research has been approved by the University of the Western Cape’s Senate Research Committee and Ethics Committee.
Appendix B

CONSENT FORM

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2835/2283

Title of Research Project: IMPLICATIVE PERSONAL DILEMMAS AND COGNITIVE CONFLICTS IN HEALTH DECISION-MAKING IN HIV POSITIVE ADULTS AND ADULTS WITH AIDS

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and his will not negatively affect me in any way.

PARTICIPANT’S NAME……………………………………

PARTICIPANT’S SIGNATURE…………………………………………

DATE………………………………

Should you have any questions regarding this study or wish to report any problems you have experiences related to the study, please contact the study coordinator:

Study Coordinator’s Name: PROFESSOR PAMELA NAIDOO

University of the Western Cape

Private Bag X17, Bellville 7535

Telephone: (021)959-2835

Cell: 083 776 1144

Email: pnaidoo@uwc.ac.za
Hospital Anxiety and Depression Scale (HADS)

Patients are asked to choose one response from the four given for each interview. They should give an immediate response and be dissuaded from thinking too long about their answers. The questions relating to anxiety are marked "A", and to depression "D". The score for each answer is given in the right column. Instruct the patient to answer how it currently describes their feelings.

<table>
<thead>
<tr>
<th>A</th>
<th>I feel tense or 'wound up':</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Most of the time</td>
</tr>
<tr>
<td></td>
<td>A lot of the time</td>
</tr>
<tr>
<td></td>
<td>From time to time, occasionally</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>D</th>
<th>I still enjoy the things I used to enjoy:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Definitely as much</td>
</tr>
<tr>
<td></td>
<td>Not quite so much</td>
</tr>
<tr>
<td></td>
<td>Only a little</td>
</tr>
<tr>
<td></td>
<td>Hardly at all</td>
</tr>
</tbody>
</table>
A I get a sort of frightened feeling as if something awful is about to happen:

- Very definitely and quite badly: 3
- Yes, but not too badly: 2
- A little, but it doesn't worry me: 1
- Not at all: 0

D I can laugh and see the funny side of things:

- As much as I always could: 0
- Not quite so much now: 1
- Definitely not so much now: 2
- Not at all: 3

A Worrying thoughts go through my mind:

- A great deal of the time: 3
- A lot of the time: 2
- From time to time, but not too often: 1
- Only occasionally: 0
### I feel cheerful:

<table>
<thead>
<tr>
<th>Response</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>3</td>
</tr>
<tr>
<td>Not often</td>
<td>2</td>
</tr>
<tr>
<td>Sometimes</td>
<td>1</td>
</tr>
<tr>
<td>Most of the time</td>
<td>0</td>
</tr>
</tbody>
</table>

### I can sit at ease and feel relaxed:

<table>
<thead>
<tr>
<th>Response</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely</td>
<td>0</td>
</tr>
<tr>
<td>Usually</td>
<td>1</td>
</tr>
<tr>
<td>Not Often</td>
<td>2</td>
</tr>
<tr>
<td>Not at all</td>
<td>3</td>
</tr>
</tbody>
</table>

### I feel as if I am slowed down:

<table>
<thead>
<tr>
<th>Response</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nearly all the time</td>
<td>3</td>
</tr>
<tr>
<td>Very often</td>
<td>2</td>
</tr>
<tr>
<td>Sometimes</td>
<td>1</td>
</tr>
<tr>
<td>Not at all</td>
<td>0</td>
</tr>
</tbody>
</table>

### I get a sort of frightened feeling like 'butterflies' in the stomach:

<table>
<thead>
<tr>
<th>Response</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Appearance</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Not at all</td>
<td>0</td>
</tr>
<tr>
<td>Occasionally</td>
<td>1</td>
</tr>
<tr>
<td>Quite Often</td>
<td>2</td>
</tr>
<tr>
<td>Very Often</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Movement</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Very much indeed</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Quite a lot</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Not very much</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Enjoyment</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>As much as I ever did</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Rather less than I used to</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Definitively less than I used to</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>---------------------------------</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>Hardly at all</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>A - I get sudden feelings of panic:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very often indeed</td>
</tr>
<tr>
<td>Quite often</td>
</tr>
<tr>
<td>Not very often</td>
</tr>
<tr>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>D - I can enjoy a good book or radio or TV program:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Often</td>
</tr>
<tr>
<td>Sometimes</td>
</tr>
<tr>
<td>Not often</td>
</tr>
<tr>
<td>Very seldom</td>
</tr>
</tbody>
</table>

Scoring (add the As = Anxiety. Add the Ds = Depression). The norms below will give you an idea of the level of Anxiety and Depression.

0-7 = Normal
<table>
<thead>
<tr>
<th>Score Range</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>8-10</td>
<td>Borderline abnormal</td>
</tr>
<tr>
<td>11-21</td>
<td>Abnormal</td>
</tr>
</tbody>
</table>
Appendix D

Q-LES-Q (Self-Report)

UNIVERSITY OF THE WESTERN CAPE

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Page 1 of 8

PHYSICAL HEALTH/ACTIVITIES

Circle the most appropriate answer

1 Not at all (never)
2 Rarely
3 Some of the time
4 Often or most of the time
5 Frequently or all the time

With regard to your physical health, during the past week how much of the time you have…

… been completely free of aches, pain, or discomfort?
1 2 3 4 5 (25)

… felt rested?
1 2 3 4 5 (26)

… felt energetic
1 2 3 4 5 (27)

… felt in excellent physical health?
1 2 3 4 5 (28)

… felt in all least very good physical health?
1 2 3 4 5 (29)

… been free of worry about your physical health?
1 2 3 4 5 (30)

… felt you got enough sleep
1 2 3 4 5 (31)

… felt able to be as physical active as needed?
1 2 3 4 5 (32)

… felt well coordinated?
1 2 3 4 5 (33)

… felt you memory was functioning well?
1 2 3 4 5 (34)

… felt good physical?
1 2 3 4 5 (35)

… felt full of pep and vitality?
1 2 3 4 5 (36)

… been free of visual problems?
1 2 3 4 5 (37)
FEELING

Circle the most appropriate answer

1. Not at all (never)
2. Rarely
3. Some of the time
4. Often or most of the time
5. Frequently or all the time

During the past week how much of the time you have...

felt clearheaded? 1 2 3 4 5 (38)
felt satisfied with your life? 1 2 3 4 5 (39)
felt good about your appearance? 1 2 3 4 5 (40)
felt happy or cheerful? 1 2 3 4 5 (41)
felt independent? 1 2 3 4 5 (42)
felt content? 1 2 3 4 5 (43)
felt able to communicate with others? 1 2 3 4 5 (44)
felt interested in taking care of your appearance (hair, clothing) and personal hygiene (bathing, dressing)? 1 2 3 4 5 (45)
felt able to make decisions? 1 2 3 4 5 (46)
felt relaxed? 1 2 3 4 5 (47)
felt good about your life? 1 2 3 4 5 (48)
felt able to travel to get things done when needed (walk, use car, bus, train or whatever is available as needed)? 1 2 3 4 5 (49)
felt able to deal with life’s problem? 1 2 3 4 5 (50)
Felt able to take care of yourself? 1 2 3 4 5 (51)
Q-LES-Q (Self-Report)

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WORK

Do you: have a job_____, work for yourself_____, do you volunteer work____?

If – NO to all3 (Note reason & SKIP to Page 4)
- Yes to any of the 3 (COMPLETE THIS SECTION) (55)
  ________________________________ (Specify other reason) (56)

Circle the most appropriate answer

1 Not at all (never)
2 Rarely
3 Some of the time
4 Often or most of the time
5 Frequently or all the time

During the past week how often have you...

enjoyed work?  1  2  3  4  5 (57)
solved work problems or dealt with them without undue stress?  1  2  3  4  5 (58)
thought clearly about work?  1  2  3  4  5 (59)
been decisive about work, or made decision when needed?  1  2  3  4  5 (60)
accomplished what you wanted to do?  1  2  3  4  5 (61)
worked well?  1  2  3  4  5 (63)
been interested in your work?  1  2  3  4  5 (64)
concentrated on your work?  1  2  3  4  5 (65)
work carefully?  1  2  3  4  5 (66)
kept up with expected work?  1  2  3  4  5 (67)
taken care of work by yourself when it was necessary?  1  2  3  4  5 (68)
communicated and interacted with ease with others?  1  2  3  4  5 (69)
HOUSEHOLD DUTIES

Are you responsible for any household duties/house work/homemaker activities (e.g. cleaning, shopping, doing dishes food shopping or preparation)

If: 1 NO (Note reason & SKIP to Page 5)
   2 Yes (COMPLETE THIS SECTION) (70)

   Reason 1. Too ill physically 2. Too emotionally upset 3. Not expected to anything for yourself or other people? 4. Other _________________ (Specify other reason) (71)

Circle the most appropriate answer

1 Not at all (never)
2 Rarely
3 Some of the time
4 Often or most of the time
5 Frequently or all the time

During the past week how often have you...

kept your room/apartment/house cleaned to your satisfaction? 1 2 3 4 5 (72)
paid bills, done the banking to your satisfaction? 1 2 3 4 5 (73)
shopped for food or other household items to your satisfaction? 1 2 3 4 5 (74)
prepared food or obtain food to your satisfaction? 1 2 3 4 5 (75)
taken care of the laundry/cleaning to your satisfaction? 1 2 3 4 5 (76)
had a feeling of accomplishment with regard to household activities? 1 2 3 4 5 (225)
concentrated and thought clearly about what household activities needed to be done? 1 2 3 4 5 (226)
solved household problems or dealt with them without undue stress? 1 2 3 4 5 (227)
Been decisive or made decision when needed with regard to household activities? 1 2 3 4 5 (228)
made repairs or taken care of household maintenance as needed? 1 2 3 4 5 (229)
SCHOOL/COURSE WORK

Have you in taking any courses, going class, or been involved in any type of course work, school or college studies during the past week?

IF: 1 NO (Note reason & SKIP to Page 6)

2 YES (COMPLETE THIS SECTION) (230)

Reason:

1. Too ill physically
2. Too emotionally upset
3. Not expected to anything?
4. Other
   __________________________ (Specify other reason) (231)

(Write in reason)

Circle the most appropriate answer

1. Not at all (never)
2. Rarely
3. Some of the time
4. Often or most of the time
5. Frequently or all the time

During the past week how much of your time have you ...

enjoyed the course/class work? 1 2 3 4 5 (232)
looked forward to getting to work on the course/class work? 1 2 3 4 5 (233)
dealt with the course/class work without undue stress? 1 2 3 4 5 (234)
thought clearly about the course/class work? 1 2 3 4 5 (235)
been decisive about the course/class work? 1 2 3 4 5 (236)
been please with your course/class work accomplishment? 1 2 3 4 5 (237)
been interested in your course/class work? 1 2 3 4 5 (238)
concentrated on the course/class work? 1 2 3 4 5 (239)
felt good while doing your course/class work? 1 2 3 4 5 (240)
communicated and interacted with ease with others at your course/class? 1 2 3 4 5 (232)
LEISURE TIME ACTIVITIES

The following questions refer to leisure time activities such as watching T.V, reading the paper or magazines, tending house plants or gardening, hobbies, going to museums or the movies, or to sports events, etc.

Circle the most appropriate answer

1. Not at all (never)
2. Rarely
3. Some of the time
4. Often or most of the time
5. Frequently or all the time

During the past week...

When you had time, how often did you use that time for a leisure time activity? 1 2 3 4 5 (244)

how often did you enjoy the leisure activities? 1 2 3 4 5 (245)

how often did you look forward to the leisure activities before spending time at them? 1 2 3 4 5 (246)

how often did you concentrate on the leisure activities and pay attention to them? 1 2 3 4 5 (247)

if a problem arose in your leisure activities, how often did you solve it deal without undue stress? 1 2 3 4 5 (248)

how often did the leisure activities sustain your interest? 1 2 3 4 5 (249)
### SOCIAL RELATIONS

Circle the most appropriate answer

1. Not at all (never)
2. Rarely
3. Some of the time
4. Often or most of the time
5. Frequently or all the time

During the past week how often have you ...

<table>
<thead>
<tr>
<th>Question</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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</thead>
<tbody>
<tr>
<td>enjoy talking with or being with friends or relatives?</td>
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<td>looked forward to getting together with friends or relatives?</td>
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<td>made social plans with friends or relatives for future activities?</td>
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<tr>
<td>enjoyed talking with co-workers or neighbors?</td>
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<td>been patient with others when others were irritating in their actions or words</td>
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<td>been interested in the problems of other people?</td>
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<td>felt affection toward one or more people?</td>
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<td>gotten along well with other people?</td>
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<td>joked or laughed with other people?</td>
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<td>felt you met the needs of friends or, relatives?</td>
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<td>felt your relationship with your friends or relatives were without major problems or conflicts?</td>
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</tbody>
</table>
Q-LES-Q (Self-Report)

GENERAL ACTIVITIES
Taking everything into consideration, during the past week how satisfied have you been with your ...
Circle the most appropriate answer – OVERALL LEVEL OF SATISFACTION

1 Very Poor
2 Poor
3 Fair
4 Good
5 Very Good

Physical health? 1 2 3 4 5 (261)
Mood? 1 2 3 4 5 (262)
Work? 1 2 3 4 5 (263)
Household activities? 1 2 3 4 5 (264)
Social relationships? 1 2 3 4 5 (265)
Family relationship? 1 2 3 4 5 (266)
Leisure time activities? 1 2 3 4 5 (267)
Ability to function in daily life? 1 2 3 4 5 (268)
Sexual drive, interest and/or performance?* 1 2 3 4 5 (269)
Economic status? 1 2 3 4 5 (270)
Living/house situation? 1 2 3 4 5 (271)
Ability to get around physically without feeling dizzy or unsteady or falling? 1 2 3 4 5 (272)
Your vision in terms of ability to do work or hobbies?* 1 2 3 4 5 (273)
Overall sense of well being? 1 2 3 4 5 (274)
Medication (if not taking any, check here_______ and leave item blank) (275) 1 2 3 4 5 (276)

How would you rate your overall life satisfaction and contentment during the past week? 1 2 3 4 5 (277)

*If satisfaction is very poor, poor or fair on these items, please UNDERLINE the factor(s) associated with a lack of satisfaction.