

**PERIPHERAL NEUROPATHY AND QUALITY OF LIFE OF ADULTS LIVING
WITH HIV/AIDS IN RULINDO DISTRICT IN RWANDA**

BIRAGUMA JUVENAL

STUDENT NO: 2743257

The logo of the University of the Western Cape, featuring a classical building with columns and a pediment, rendered in a light blue color.

**UNIVERSITY of the
WESTERN CAPE**

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University of the Western Cape in partial fulfillment of the requirement for the
degree of Magister Scientiae (Physiotherapy).**

Supervisor: Mrs. Anthea Rhoda

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KEYWORDS

- Human Immunodeficiency Virus
- Acquired Immune Deficiency Syndrome
- Distal symmetrical polyneuropathy
- Quality of life
- People living with HIV/AIDS
- Rwanda



ABSTRACT

Peripheral neuropathy (PN) is a common neurological complication occurring in the asymptomatic and symptomatic stages of human immune deficiency virus (HIV) infection. The pain and other symptoms caused by PN can impair functional ability and limit physical activity that could affect quality of life (QoL). Additionally, studies done on quality of life of people living with HIV/AIDS have shown that, HIV-related neurological syndromes, including PN, significantly reduce QoL. The aim of this study was to determine the prevalence of peripheral neuropathy amongst and the quality of life of adults living with HIV/AIDS attending the out-patient clinic at Rutongo Hospital in Rulindo District in Rwanda. The contributing factors for QoL in people living with HIV/AIDS (PLWHs) were also highlighted. A cross-sectional descriptive design using a quantitative research method was used. A time constrained sample of 185 of adult PLWHs attending out-patient clinic at Rutongo hospital was recruited. The Subjective Peripheral Neuropathy Screen (SPNS) was used to screen for the presence of peripheral neuropathy and the World Health Organization Quality of Life, short form (WHOQOL BREF) to assess quality of life. The Statistical Package for the Social Sciences (SPSS) was used to analyse the data. Chi-square Tests were used to demonstrate association between demographic characteristics and severity of peripheral neuropathy. Permission was sought from relevant committees at University of Western Cape and relevant authorities from Rwanda. Written consent was sought from the participants and they were assured of respect, confidentiality and anonymity. Participation in the study was voluntary and participants were free to withdraw from the study at any time if they so wished. One hundred and eighty five adult PLWHs attending out-patients clinic at

Rutongo Hospital received and completed the SPNS. The study indicated that 75 (40.5%) of respondents experienced peripheral neuropathy in varying grades; 44 (58.7 %) were in grade 1 whereas 10 (13.3 %) were in grade 2 and 21 (28 %) in grade 3. In the present study, PLWHs had quality of life scores in the physical health, psychological, social relationship and environmental domains that fell in intermediate level (between 10 and 14.9 with psychological health domain (14.81) close to the high level (between 15 and 20) and participants scored lower in the physical (12.72) and environmental (12.57) domains. Additionally, this study found that education significantly affected the physical health, psychological, social and environment domains; Age significantly affected psychological domain ($P=0.028$). Lower scores were seen among subjects who were older than 60 years compared to those who were less than 30 years old, while gender, marital status and time elapsed since HIV diagnosis significantly affected social domain. The results of the indicated that a percentage of PLWHs attending the out-patient clinics at Rutongo Hospital in Rwanda had peripheral neuropathy. Various domains of quality of life were also affected in some of the participants. The findings suggest that the assessment of both peripheral neuropathy and quality of life be included in the intervention programmes designed for people living with HIV/Aids.

DECLARATION

I declare that this mini-thesis **“Peripheral neuropathy and quality of life of adults living with HIV/AIDS in Rulindo District in Rwanda”**, is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by complete references and that this work has not been submitted before for any other degree at any other university.

Juvenal BIRAGUMA

November 2008



Signature.....

Anthea RHODA

Witness.....

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First and foremost, I wish to give all honour and praise to my Creator, for bestowing the necessary courage, good health and mental ability to complete the study.

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LIST OF ABBREVIATIONS USED IN STUDY

AIDS	Acquired Immune-Deficiency Syndrome
ANOVA	Analysis of Variance
ART	Antiretroviral therapy
CD4	Cluster Differentiation 4
d4T	Stavudine
ddI	Didanosine
DSPN	Distal Sensory Polyneuropathy
HAART	Highly active antiretroviral therapy
HIV	Human Immuno-Deficiency Virus
HRQOL	Health-Related Quality of Life
NGO	Non-governmental organization
NNRTI	Nonnucleoside Reverse Transcriptase Inhibitor
NRTI	Nucleoside/nucleotide Reverse Transcriptase Inhibitor
PLWHs	People Living with HIV/AIDS
QoL	Quality of Life
SPSS	Statistical Package for Social Sciences
SQV	Saquinavir
TRAC	Treatment and Research AIDS Center
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary Counseling and HIV testing
WHOQOL BREF	World Health Organization Quality of life assessment, short form

APPENDICES

- Appendix A:** Letter of approval to conduct research by ethics committee and senate of University of the Western Cape
- Appendix B:** Request to the Minister of state in charge of HIV/AIDS and other epidemics in the Ministry of Health to carry out the study in Rwanda
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CHAPTER ONE

INTRODUCTION

1.1 INTRODUCTION TO THE CHAPTER

This chapter covers the background information on peripheral neuropathy and quality of life of adults living with HIV/AIDS worldwide including the situation in Rwanda. The statement of the problem, the research questions, the aim, the objectives, and the significance of study are also described. This chapter ends with the definitions of terms used as well as the outlines of chapters of this thesis.

1.2 BACKGROUND

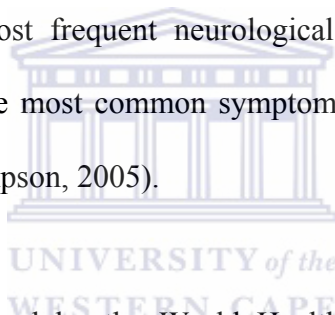
Globally, the estimated number of persons infected with the human immune deficiency virus (HIV) is 33.2 million people; of these 22.5 million people are living in Sub-Saharan Africa. This 22.5 million constitutes more than two thirds of all people worldwide (UNAIDS/WHO, 2007). In addition, unlike other regions the majority of people living with HIV in Sub-Saharan Africa (61%) are women. In Rwanda the number of adults living with HIV/AIDS was estimated at 150,000 out of 9,609,000 of the general population of which 49,000 were receiving antiretroviral therapy (UNAIDS, 2007). People living with HIV/AIDS (PLWHs) are likely to experience a steady decline in function, as their immune system could become increasingly compromised in the absence of antiretroviral therapy (Hughes, Jelsma, Maclean, Darder & Tinise, 2004). Coping with HIV/AIDS as a chronic disease presents major medical, psychological and psychosocial challenges (Vetter & Donnelly, 2006). Many PLWHs find it challenging to perform activities of daily living, participate in moderate to vigorous physical activities, or have

sufficient energy or vitality to engage in an active social life while managing HIV/AIDS (Vosvick et al., 2003). Moreover, in earlier studies, involvement of the central or peripheral nervous system was found to occur across the spectrum of HIV disease (Swanson, Zeller & Paice, 1998; Schifitto et al., 2002) and is often associated with antiretroviral therapy (Moore, Wong, Keruly & McArthur, 2000). Neurological disorders related to HIV often result in reduced quality of life and shortened survival, especially in people with more advanced HIV disease (Lichtenstein et al., 2005).

Peripheral neuropathy (PN) is a common neurological complication occurring in the asymptomatic and symptomatic stages of HIV infection (Zanetti, Manzano & Gabbai, 2004). The same authors, in their study conducted in Brasil revealed that 34 of 49 (69.4%) of the PLWHs having PN; while Parry et al. (1997) found 44% in Zimbabwe. With regards to peripheral neuropathy in people living with HIV/AIDS limited information is available in Africa, particularly in Rwanda.

Peripheral Neuropathy can be among the most painful and debilitating of the many symptoms associated with HIV/AIDS and its treatment (Ferrari et al., 2006). People living with HIV/AIDS may experience a variety of different types of peripheral neuropathy (Nicholas et al., 2007). The most common syndrome is distal sensory polyneuropathy (DSPN) which occurs mainly in individuals with advanced immunosuppression and may occur because of the dideoxy-nucleoside reverse transcriptase inhibitors (NRTI) class of antiretroviral therapy (ART)(Lichtenstein et al., 2005). Other types of PN seen in people with HIV/AIDS include inflammatory

demyelinating polyneuropathy; autonomic neuropathy, polyradiculopathy, and mononeuropathy multiplex (Wulf, Wang & Simpson, 2000). In people with HIV/AIDS, PN most often affects the feet and later the hands, causing numbness, tingling, and/or pain (Delakas, 2001). Pain, parasthesias and numbness caused by peripheral neuropathy can impair functional ability and limit physical activity, affecting Quality of life (QoL) in HIV-positive patients (Swanson et al., 1998). Diagnosis and treatment of PN in the highly active antiretroviral therapy (HAART) era represent a challenge because of the overlap of clinical symptoms, complexity of treatment choices, and a possible abnormal presentation of symptoms of PN during immune reconstitution (Manji & Miller, 2004). Earlier, PN has been found to be the most frequent neurological complication in HIV-infected individuals where pain was the most common symptom that could significantly impair QoL (Verma, Estanislao & Simpson, 2005).



Quality of life (QoL) is defined by the World Health Organisation Quality of Life (WHOQOL) Group (1995) as an individuals' perception of their health in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns. Quality of life is becoming an important issue for the growing numbers of individuals including those living with HIV/AIDS who need to adapt to severe and chronic disablement (Casado, 2005). The quality of life of people living with HIV/AIDS in Sub-Saharan Africa is a complex constellation of disease, stigma, discrimination, and lack of treatment combined with family life, work, and social activities (Phaladze et al., 2005). Therefore, QoL measures are increasingly being recognised as important when comparing the efficacy of AIDS therapies (Casado, 2005),

assessing the impact of HIV/AIDS on peoples' lives (Wig et al., 2006), and determining the impact on quality of life in HIV/AIDS patients for estimating the burden of the disease (Sowell et al., 1997). Moreover, QoL in HIV-infected patients is a concept that has received increased attention in the literature, as it is recognized that HIV illness can impact all aspects of patients' lives (Molassiotis, Callaghan, Twinn & Lam, 2001).

Studies on HIV patients and quality of life have shown that, compared with patients with various other chronic conditions; patients with symptomatic HIV scored their Health-Related Quality of Life (HRQoL) as poor, while patients with asymptomatic HIV scored it better (Globe, Hays, & Cunningham, 1999; Eriksson, Nordstrom, Berglund, & Andstrom, 2000). Furthermore, Pandya, Krentz, and Power (2005) found that HIV-related neurological syndromes, including neuropathy, significantly reduce quality of life. Fortunately, there are medical treatments and other measures people with HIV/AIDS can take to ameliorate neuropathy symptoms and improve their quality of life. Griswold, Evans, Spielman and Fishman (2005) examined coping strategies of HIV patients with peripheral neuropathy and found that these strategies may differ according to age, gender and ethnic background of those living with HIV. Nicholas et al. (2007) stated that pharmacologic approaches, complementary therapies, and self-care behaviors may improve quality of life and limit symptoms of distal symmetric peripheral neuropathy.

In Rwanda, HIV/AIDS causes extreme hardship in an already impoverished population. USAID report states that only 28 percent of households with a PLWH are able to pay for basic care, causing families to borrow money, and sell assets (Uwimana, 2005). In

addition, in Rwanda, the gross domestic product (GDP) per capita is \$ 250 (National Institute of Rwanda (NISR), 2007), making Rwanda one of the poorest countries in the world. With a current human resources crisis and a desperate need for qualified health professionals, addressing the HIV epidemic has been a difficult challenge. In summary report on Rwanda Human Resources Assessment for HIV/AIDS scale-up have shown that there was only one doctor for over 50,000 people, and one nurse for every 3,900 people (Furth, Gass, & Kagubare, 2006). This problem is much worse in rural areas (Ministry of Health (MOH). A large number of HIV/AIDS patients are poor and live in rural areas where there are limited health facilities; therefore they do not have access to counseling and testing services (GoR & William John Foundation, 2003). A study conducted in Rwanda indicated that PLWHs face many problems as a result of the illness. These include neurological, psychosocial complications and financial difficulties (Uwimana, 2005). In addressing the problem of the HIV/AIDS, the strategy of the government of Rwanda places particular emphasis on prevention, while at the same time providing prophylaxis and treatment for opportunistic infections and antiretroviral therapy to all people living with HIV/AIDS irrespective of their social status (Ministry of Health, 2005).

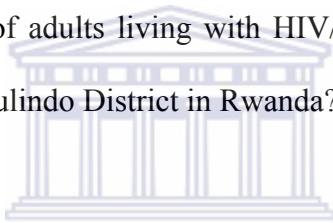
1.3 STATEMENT OF THE PROBLEM

As people living with HIV/AIDS (PLWHs) are living longer, they are beginning to have more chronic health problems (Gale, 2003). The incidence of neurologic disease and central nervous system infections associated with HIV has declined with the advent of HAART (Philips, Skelton, & Hand, 2004). Peripheral neuropathy (PN) is one condition

associated with functional limitations and affecting quality of life (QoL) of patients. To date, there have been many studies on peripheral neuropathy and HIV disease (Figg, 1991; Parry et al., 1999; Zanetti et al., 2004). However, little have been done in Africa and none in Rwanda. There is therefore a need to determine the prevalence of peripheral neuropathy and the quality of life of adults living with HIV/AIDS.

1.4 RESEARCH QUESTIONS

1. What is the prevalence of peripheral neuropathy in adults living with HIV/AIDS attending the out-patient clinic at Rutongo Hospital in Rulindo District in Rwanda?
2. What is the quality of life of adults living with HIV/AIDS attending the out-patient clinic at Rutongo Hospital in Rulindo District in Rwanda?



1.5 THE AIM OF THE STUDY

The aim of this study is to determine the prevalence of peripheral neuropathy amongst and the quality of life of adults living with HIV/AIDS attending the out-patient clinic at Rutongo Hospital in Rulindo District in Rwanda?

1.6 SPECIFIC OBJECTIVES

1. To determine the prevalence of peripheral neuropathy in adults living with HIV/AIDS attending the out-patient clinic at Rutongo Hospital in Rulindo District in Rwanda.
2. To assess the quality of life of adults living with HIV/AIDS attending the out-patient clinic at Rutongo Hospital in Rulindo District in Rwanda.

2.1. To determine physical health and Level of independency of adults living with HIV/AIDS attending the out-patient clinic at Rutongo Hospital in Rulindo District in Rwanda.

2.2. To determine psychological well being of adults living with HIV/AIDS attending the out-patient clinic at Rutongo Hospital in Rulindo District in Rwanda.

2.3. To determine the social relationship of adults living with HIV/AIDS attending the out-patient clinic at Rutongo Hospital in Rulindo District in Rwanda.

2.4. To determine the environment of adults living with HIV/AIDS attending the out-patient clinic at Rutongo Hospital in Rulindo District in Rwanda.

1.8 DEFINITION OF TERMS

Quality of life: is defined by the World Health Organisation Quality of life (WHOQOL) Group (1995) as individuals' perception of their position in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns.

Peripheral neuropathy: Condition characterized by sensory loss, pain, muscle weakness, and wasting of muscle in the hands or legs and feet. It may start with burning or tingling sensations or numbness in the toes and fingers. In severe cases, paralysis may result. Peripheral neuropathy may arise from an HIV-related condition or be the side effect of certain drugs, some of the nucleoside analogs in particular (ATIS, 2002).

Adult: Any person who has reached the age of eighteen (18) years and above.

PLWHs: A general term referring to all people infected with HIV, whether or not they show the infection symptoms.

Antiretrovirals/Antiretroviral Treatment/Antiretroviral Therapy (ARVs/ART): The medication for people living with HIV/AIDS that can work to inhibit the weakening of and sometimes even strengthen the immune system, protecting patients from developing opportunistic infections and allowing for increased life expectancy. There are four categories of antiretrovirals: 1) nucleoside reverse transcriptase inhibitors 2) non-nucleoside reverse transcription inhibitors, 3) protease inhibitors, and 4) fusion or entry inhibitors. Combination therapies, like Highly Active Antiretroviral Therapy (HAART), reduce the development of drug resistance. Specific drugs may not be effective in everyone and side-effects will vary by person (Fan, Conner, & Villareal, 2004).

1.8 OUTLINE OF CHAPTERS

Chapter one covers the background information on peripheral neuropathy and quality of life of adults living with HIV/AIDS worldwide including the situation in Rwanda. The statement of the problem, the research questions, the aim, the objectives, and the significance of study are also described. This chapter ends with the definitions of terms used in the study.

Chapter two presents a review of the literature concerning peripheral neuropathy and quality of life of people living with HIV/AIDS. This chapter provides insight into the

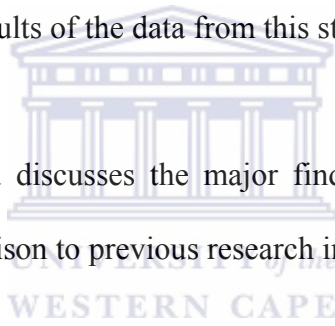
impact of HIV/AIDS on the quality of life. The relationship between peripheral neuropathy and quality of life are also highlighted. Finally, the current therapies of HIV/AIDS related peripheral neuropathy are presented.

Chapter three outlines the methods used in the study. It explains the rationale for the study design chosen and describes the research setting. The population, the sampling method, data collection and analysis are described. Finally, the ethical considerations regarding the study are described.

Chapter four describes the results of the data from this study.

Chapter five summarises and discusses the major findings relating to the objectives within the study with a comparison to previous research in the area. The limitations of the study are also highlighted.

Chapter six summarises the important points of the current study. Recommendations related to the findings are also proposed.



CHAPTER TWO

REVIEW OF LITERATURE

2.1 INTRODUCTION

This chapter reviews literature related to the causes, prevalence, symptoms, and prognosis of peripheral neuropathy among adults living with HIV/AIDS, as the majority of those affected are adults. Literature on the impact of HIV/AIDS on the quality of life as well as the relationship between peripheral neuropathy and quality of life is also reviewed.

Data for this review were based on information obtained from data bases such as Academic Search Premier, Cinahl, PubMed (Medline), Science direct, Eric and manual searches of the English literature from early 1995 through 2008. Key words or text words included as search terms for the review was: Quality of life AND assessment OR measurement OR examination; Quality of life AND HIV/AIDS; HIV/AIDS OR infection HIV; Peripheral neuropathy; Distal symmetrical polyneuropathy. A manual search was performed for the references cited in relevant studies.

2.2 HIV/AIDS

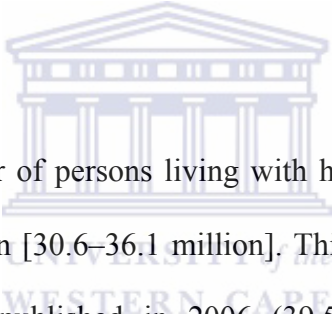
2.2.1 Description of HIV

The human immunodeficiency virus (HIV) is a retrovirus which causes chronic, progressive, immunological dysfunction (Chin, 2007). Infection with HIV is characterized by a long period with no or minor symptoms, but the virus causes declining levels of T-helper (CD4-positive) lymphocytes. Low levels of CD4-positive lymphocytes are associated with increased risk of the acquired immunodeficiency syndrome (AIDS), a

condition in humans in which the immune system begins to fail, leading to life-threatening opportunistic infections. A person may live with HIV for up to 10 years before developing AIDS. AIDS eventually leads to death due to the development of opportunistic infection such as viral, bacterial and fungal infections (Fan et al., 2004). HIV may be transmitted through blood or, most often, through sexual fluids.

2.2.2 Prevalence of HIV/AIDS

This section includes the general overview of HIV/AIDS worldwide, in Sub-Saharan Africa including the situation in Rwanda on impacts of HIV/AIDS on health system and strides in antiretroviral therapy.



Globally, the estimated number of persons living with human immune deficiency virus (HIV) in 2007 was 33.2 million [30.6–36.1 million]. This indicated a reduction of 16% compared with the estimate published in 2006 (39.5 million [34.7–47.1 million]) (UNAIDS/WHO, 2006). The HIV and acquired immunodeficiency diseases (AIDS) pandemic has become a major challenge to health, development and humanity (UNAIDS/WHO, 2006). Although, HIV and AIDS are found in all parts of the world, some areas are more afflicted than others. HIV/AIDS affects many different populations, and occurs in every country in the world; however, a disproportionate number of these affected live in the poorer countries of the world. In addition, around 80% of the global populations live in developing countries, but these countries are home to 95% of those with HIV/AIDS.

According to the UNAIDS (2007) report, the sub-Saharan Africa region is more heavily affected by HIV and AIDS than any other region of the world. More than two thirds (68%) of all people who are HIV-positive live in this region where more than three quarters (76%) of all AIDS deaths in 2007 occurred. Unlike other regions, the majority of people living with HIV in sub-Saharan Africa (61%) are women. In four sub-Saharan African countries, national adult prevalence has raised higher than was once thought possible, exceeding 30% in Botswana (38.8%), Lesotho (31%), Swaziland (33.4%) and Zimbabwe (33.7%) (UNAIDS, 2002). In addition, UNAIDS report states that 24.5 million people were living with HIV at the end of 2005 and approximately 2.7 million additional people were infected with HIV during that year. In 2004, the AIDS epidemic in Africa has claimed the lives of an estimated 2 million people in this region. More than twelve million children have been orphaned by AIDS. They further reported that both HIV prevalence rates and the numbers of people dying from AIDS vary greatly between African countries. For example, in Somalia and Senegal the HIV prevalence is under 1% of the adult population, whereas in South Africa and Zambia around 15-20% of adults are infected with HIV.

In spite of improved access to antiretroviral treatment and care in many parts of the world, an estimated 3.1 million people lost their lives to the disease in 2005 (UNAIDS, 2005). Moreover, the government of Rwanda is committed to providing its population with required HIV/AIDS health services. To meet the urgent needs of Rwandans for HIV/AIDS prevention, care and treatment, the Ministry of Health aims to scale-up HIV/AIDS service provision to treat 100,000 antiretroviral therapy (ART) clients by

2007 (TRAC, 2004). However, Rwanda has made remarkable strides in antiretroviral therapy and care of opportunistic infections. As of July 2004, 23 sites were offering HIV/AIDS care and treatment services and as of the end of September 2004, a total of 6,230 clients had started ARVs. Although, Nicholas et al. (2007) stated that with antiretroviral therapy, PLWHs are expected to develop peripheral neuropathy, the most common neurological complication in HIV.

2.3 PERIPHERAL NEUROPATHY IN HIV/AIDS

2.3.1 Definition of peripheral neuropathy

Peripheral neuropathy (PN) is damage to the peripheral nerves and is characterized as an injury, inflammation, or degeneration of the peripheral nerves fibers (Pascuzzi, 2003). The peripheral nerves represent the nerves outside the brain and spinal cord and consist of motor, sensory, and autonomic nerve fibers. Depending on the fiber classes affected, neuropathies are subdivided into motor, motor and sensory, and pure sensory forms. In addition, autonomic disturbances may be present leading to the additional classification into autonomic or autonomic and sensory neuropathies. Sensory neuropathies affect the sensory nerves, which are the nerves responsible for sensation throughout the body. Most commonly sensory neuropathies affect the feet and legs, and less frequently the hands and arms. The diagnosis of sensory neuropathy requires a history compatible with predominantly sensory dysfunction and a physical examination notable for abnormal sensory findings at least in the feet, with reduced or absent ankle jerks (Armstrong, 2000).

2.3.2 Peripheral neuropathy and HIV/AIDS

This section focuses on peripheral neuropathy in HIV/AIDS and discusses the causes, prevalence and incidence, symptoms, and prognosis of this disorder. Distal sensory polyneuropathy (DSPN) is described in more detail.

2.3.2.1 Causes of peripheral neuropathy

Peripheral neuropathy is one of the most frequent neurologic disorders associated with HIV infection (Wulff et al., 2000; Cherry, Wesselingh, Lal & McArthur, 2005; Lichtenstein et al., 2005; Dorsey & Morton, 2006; Ferrari et al., 2006). Its symptoms cause substantial morbidity and discomfort to patients with AIDS. PN can result from the direct infection of neurons with human immunodeficiency virus (HIV), opportunistic infection of neurons because of generalized immunosuppression, and from highly active antiretroviral therapy (HAART) (Hurst, 1999; Moyle & Sadler, 1998). As neuropathy results from HAART treatment as well as HIV infection, it does not improve dramatically with HAART-related reductions in HIV viral load (Simpson & Tigliati, 1995). A 30%–35% prevalence of peripheral neuropathy has been documented in PLWHs, but autopsy based studies have found it in nearly 100% of patients who died of AIDS. HIV-associated PN is known to exist in at least six patterns such with distal sensory polyneuropathy (DSPN) as the most frequently occurring (Nicholas et al., 2007). Other types of peripheral neuropathy include inflammatory demyelinating polyneuropathy, progressive polyradiculopathy, mononeuropathy multiplex, autonomic neuropathy, and diffuse infiltrative lymphocytosis syndrome (Wulff et al., 2000). The DSPN associated with HIV occurs in the later stages of HIV disease, usually after the patient has had other AIDS

defining illnesses. Symptoms of HIV - associated sensory neuropathies are almost identical to those of other sensory neuropathies. Therefore, because DSPN is the most common type of HIV/AIDS-related neuropathy, “peripheral neuropathy” and “PN” will be used to refer to DSPN throughout the rest of this review of literature unless otherwise stated.

Distal sensory polyneuropathy (DSPN) occurs mainly in individuals with advanced immunosuppression and may occur because of the dideoxy-nucleoside reverse transcriptase inhibitors (NRTI) class of antiretroviral therapy (ART) (Lichtenstein et al., 2005). Delakas (2001) and Simpson & Cikurel (2006) suggest that the symptoms of nucleoside reverse transcriptase inhibitor (NRTI)-related DSPN are essentially identical to the syndrome of DSPN that is associated with HIV disease, thus potentially confounding the diagnosis and treatment of neuropathy. They further suggest that distinguishing HIV-associated neuropathy from NRTI-related neuropathy may be accomplished by examining the temporal association of symptoms with initiation of NRTI treatment, clinical or electrophysiologic improvement after dose reduction or drug discontinuation, and the “coasting” effect, in which symptoms increase for 2 to 4 weeks after drug discontinuation, followed by clinical improvement. Dieterich (2003) suggests that NRTI-related neuropathy is more likely than HIV-induced neuropathy to be painful, have an abrupt onset, and progress rapidly.

Pardo, McArthur and Griffin (2001) suggest that the pathophysiology of DSPN and antiretroviral toxic neuropathies (ATN) includes three specific mechanisms: “dying

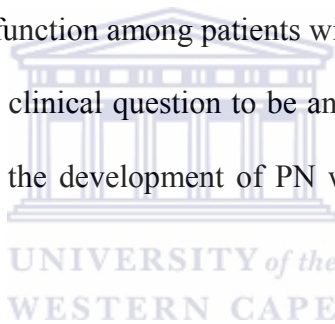
back” axonal degeneration of long axons in distal regions, loss of unmyelinated fibers, and a variable degree of macrophage infiltration in peripheral nerves and dorsal root ganglia. HIV-associated neuropathies differ from ATN neuropathies. For ATN-associated neuropathies, interference with DNA synthesis and mitochondrial abnormalities produced by nucleoside ART were linked to the symptom manifestation (Simpson & Cikurel, 2006).

2.3.2.2 Prevalence and incidence of peripheral neuropathy

It is reported that 39%-70% of all people living with HIV/AIDS developed neurological disorders (Janssen, 1997). Pre-HAART studies have shown that advanced immunosuppression, as reflected by reduced CD4+ cell counts and increased HIV viral load increases the risk and severity of neuropathy (Lichtenstein et al., 2005). Additionally, highly active antiretroviral therapy (HAART) has led to an increasing pool of long-term survivors with HIV disease and this may in turn lead to an increase in the prevalence of neurologic conditions, particularly as some individuals experience virologic failure of their ARV therapy.

Peripheral neuropathy has not declined in frequency, even in the HAART era, particularly in recipients of d-drug ARV regimens. This may, in part, explain a diminished impact of HAART on the incidence of PN. According to Sacktor (2002) the increased life expectancy of HIV-infected individuals through highly active antiretroviral therapy (HAART) increases the prevalence of peripheral neuropathies. The increase in DSPN has occurred in relation to the increased use of potentially neurotoxic antiretroviral

drugs (Schifitto et al., 2005; Simpson et al., 2003), as well as advanced HIV disease. As DSPN has emerged as a major side-effect of antiretroviral therapy, persons with any stage of HIV may be affected. In an earlier study, DSPN was found to occur across the spectrum of HIV disease and its incidence was increasing due to prolonged survival rates and the development of HAART (Dorsey & Morton, 2006). Contrary, HAART lessens disease progression, improves immunity, and widens the ratio of therapeutic to toxic effects of individual antiretroviral drugs, resulting in a significantly lower risk of developing DSPN (Schifitto et al., 2005) and since HAART was introduced, the incidence of DSPN has decreased. However, recent reports suggest that HAART may have a beneficial effect on PN function among patients with early disease (Simpson et al., 2006). Therefore, an important clinical question to be answered is how to predict which patients are at highest risk for the development of PN while being treated with d-drug regimens.



Different prevalence rates of peripheral neuropathy in people living with HIV/AIDS have been reported in the literature. This may be due to different methodology, defining criteria, and patient populations. The reported frequency of HIV peripheral neuropathy ranges from 10 to 35% (Snider et al., 1983; Cornblath and McArthur, 1988; So, Holtzman, Abrams, & Olney, 1988; McArthur et al., 1989; Schifitto et al., 2002), although this varies when the diagnosis is based on only neurological exams (e.g. 10%) (Cornblath and McArthur, 1988), or on EMG (e.g. 35%) (So et al., 1988). Importantly, the frequency of symptomatic peripheral neuropathy has remained unchanged (e.g. 35%) (Schifitto et al., 2002), even after the introduction of antiretroviral medication and

HAART, which appears to be due to the neurotoxic effect of these medications. For example, ddC has been implicated in the etiology of peripheral neuropathy in HIV-infected patients (Blum et al., 1996).

DSPN is detected by clinical examination in 30% of infected patients (Swanson et al., 1998; Zanetti et al., 2004). Neurologic examination reveals depressed or absent ankle tendon reflexes in 96% to 100% of cases in PLWHs with predominantly sensory neuropathy (Cornblath & McArthur, 1988). In addition, sensations of pain and temperature are impaired in the distal portion of the legs in 85% of patients. In one study, DSPN showed a significant decline in prevalence from 42.5% in 1995-1996 to 34.4% in 1997-1998 (Maschke et al, 2000). In contrast, the prevalence of suspected drug-induced polyneuropathy increased to 31% compared with 20% in 1995-1996. Moreover, after the introduction of HAART, DSPN was not associated with increased HIV-1 load or decreased CD4 T-cell count (Morgello, Estanislao & Simpson, 2004). Furthermore, DSPN occurs most frequently in advanced HIV infection and is inversely correlated with CD4 counts (Simpson & Tigliati, 1995). Tigliati, Grinnel, Godbold, and Simpson (1999) reported that the prevalence of HIV-associated neuropathy increases as immune function deteriorates. This relationship suggests that a patient presenting with high CD4 counts may not be suffering from HIV-associated DSPN alone, but also from neurotoxicity or other underlying conditions. The risk of developing DSPN increased during the initial period of drug therapy, especially when therapy was started in patients with low CD4 lymphocyte counts (50-90 cells/ μ L) and higher HIV-1 load (>10,000 copies/mL). The authors suggested that disease progression and host factors have a strong independent

association with an increased risk of the development of DSPN but also may predispose individuals to the neurotoxic effects of antiretroviral medications.

2.3.2.3 Symptoms of peripheral neuropathy

Individuals with HIV/AIDS experiencing DSPN may present with a number of different complaints; the earliest symptoms of peripheral neuropathy are pain, numbness, and tingling in the hands and feet in the classic "sock and glove" distribution (Delakas, 2001; Simpson & Cikurel, 2006). Verma et al. (2005) in their study on controlling neuropathic pain in HIV reported that neuropathic pain constitutes approximately 25% to 50% of all pain clinic visits. Some people describe an altered sensation when picking up objects, as if their fingers are "made of plastic", or feelings of their hands and feet falling asleep. The patient may complain of their feet throbbing or cramping at night or of stumbling when they try to walk. The symptoms are generally symmetric (occur on both sides of the body), although they may be more severe on one side. If the neuropathy is severe, touching the affected extremity can feel like an open wound is being touched. Additionally, many people with early or mild PN do not experience any symptoms and, again, the worst symptoms generally occur in people with more advanced immunosuppression (lower CD4 cell counts) (Simpson & Cikurel, 2006).

Symptom progression may be very gradual, or may worsen rapidly over a period of days or weeks. In most people with HIV/AIDS, altered sensations and pain occur first in the toes and soles of the feet; then, as nerve injury progresses, pain and numbness may extend to the ankles (Swanson et al., 1998). The same author stated that any tactile

stimuli to the affected area such as socks, bed sheets, or shoes can cause discomfort in some cases. In late stages of DSPN, the upper extremities may also be affected with involvement of the fingers, hands, and wrists respectively. Research reports that when asked to describe their symptoms of peripheral neuropathy, the most frequent descriptor used is pain, followed by numbness, tingling, burning, and stinging (Nicholas et al., 2002). Furthermore, Uwimana (2005) found that the numbness and paraesthesia in hands and feet were most common symptoms among PLWHs in Rwanda. Other clinical features of DSPN include increased vibratory thresholds and reduced pinprick and temperature sensation in a stocking and glove distribution. Muscle strength and joint position sensation are relatively normal. Symptomatic weakness appears late in the disease and is generally restricted to the distal intrinsic foot muscles (Stokes, 2004).

2.3.2.4 Prognosis of peripheral neuropathy

The diagnosis of peripheral neuropathy can generally be made by a healthcare provider who is experienced in the treatment of HIV disease based on a history of the symptoms and a comprehensive physical examination which includes testing of the reflexes and evaluation of the sense of vibration, touch, pressure, and pain in the extremities (Swanson et al., 1998). On neurological exam, abnormalities may exist because of reduced or absent ankle reflexes and increased vibratory thresholds (Simpson & Cikurel, 2006). Nerve conduction studies can be useful to confirm the diagnosis of DSPN by revealing abnormal sensory nerve potential amplitudes and conduction velocity, especially of the sural nerve as suggested in the literature (Stokes, 2004). Electromyographic testing may be warranted with DSPN however, many have normal nerve conduction. Another

diagnostic approach may be to refer for skin biopsy visualization of the epidermal nerve fibers (Zanetti et al., 2004). Moreover, in a study done by Phillips et al. (2004), the subjective peripheral neuropathy screen (SPNS) was used to examine the pins and needle sensations and numbness. According to McArthur (1998), SPNS is a brief, self-report tool currently used to screen patients for sensory symptoms indicative of neuropathy in most of the primary infection protocols. Additionally, it is used to monitor antiretroviral neurotoxicity and to exclude patients with existing neuropathy from entry into clinical trials of potentially neurotoxic agents.

The management of peripheral neuropathy is targeted at relieving painful neuropathic symptoms and to educate patients regarding prevention of complications. A variety of measures can help to relieve the symptoms of PN. It is important to determine whether DSPN is related to the HIV disease and not to other causes such as HAART medications, nutritional deficiencies, diabetes mellitus, substance abuse, other medications, or medical comorbidities and treat accordingly. Treatment for DSPN related to HIV/AIDS may incorporate both pharmacologic and nonpharmacologic strategies. In individuals with mild symptoms, relief may be reported with lifestyle modifications such as avoiding walking long distances, standing for long periods of time, or wearing restrictive shoes (Swanson et al., 1998). Other self-care strategies that have been reported to be helpful include nutritional supplements, soaking feet in warm water, exercise, rest, elevation of extremities, and rubbing the feet with cream (Nicholas et al., 2007).

Complementary modalities have also been reported to be helpful for some individuals in the management of DSPN as well as for prevention and alleviation of ART side effects (Nicholas et al., 2007). Alternative treatments include Yoga, meditation, physical modalities (i.e., heat, whirlpool, and massage), traditional Chinese medicine (such as acupuncture and tai chi), hypnosis, and creative arts may be beneficial as adjuvant therapies and, in some instances, if preferred by patients, as primary pain management approaches (Breitbart & Dibiase, 2002). In a study performed to determine the effects of 5 weeks of individualized acupuncture treatment, delivered in a group setting, on pain and symptoms of peripheral neuropathy associated with HIV infection (Phillips et al., 2004), it was shown that acupuncture significantly reduced present pain, most and least pain in the past 24 hours, and total summary pain. In addition, the acupuncture regimen reduced pain/ aching/ burning and pins/ needles/ numbness in upper and lower limbs. Pharmacologic agents should be incorporated in the management of DSPN if lifestyle modifications and complementary modalities do not adequately control pain related to DSPN (Nicholas et al., 2007). However, symptomatic treatment with pharmacologic agents is often requested by patients, but no specific characteristics of the pain can predict which agents will be beneficial. The choice of medication is based on the severity of the patients' symptoms and the side - effect profile of the medication. Verma et al. (2005) suggest that although no standard treatment for DSPN is available, most therapies are directed toward relief of symptoms.

In some patients with mild neuropathic pain, the use of nonsteroidal anti-inflammatory agents such as ibuprofen might be successful. Simpson and Cikurel (2006) suggest that it is very important to offer appropriate, effective doses of analgesics, which may include

NSAIDS, topical medications, narcotics, and adjuvant analgesics. In particular, controlled studies of gabapentin and pregabalin have recently shown great benefit in the treatment of patients with painful peripheral neuropathies. Similarly, lamotrigine has been reported as a well-tolerated and effective treatment for HIV-associated neuropathic pain (Backonja, 2002; Simpson et al., 2000). For patients with very severe neuropathic pain, the use of opiates and narcotic agents may be necessary. Like the tricyclics, these agents must be titrated to the minimum effective dose required for improvement (Auer-Grumbach, Mauko, Auer-Grumbach, & Pieber, 2006). Furthermore, treatments of DSPN have been used to improve neuropathic symptoms and energy levels in individuals living with HIV, with many experiencing improved quality of life (Agnolotto, Chiaffarino, Nasta, Rossi, & Parazzini, 2003). Thus, effective management of symptoms is important for improving QoL. According to Lorenz, Shapiro, Asch, Bozzette and Hays (2001), most persons living with chronic illnesses appraise their quality of life (QoL), at least in part, according to the symptoms (including treatment side effects) they experience. As mentioned above a variety of measures can help to relieve the symptoms of PN. Table 2.1 summarises the intervention studies in the management of peripheral neuropathy.

Table 2.1 Intervention studies in the management of peripheral neuropathy

Authors	Design	Intervention	Sample size	Outcome measure	Results
Shlay et al., 1998	RCT	Standardized acupuncture regimen (SAR) vs control points, amitriptyline (75 mg/d) vs placebo, or both for 14 weeks	250 total patient: 239 in acupuncture comparison (125 in the factorial option and 114 in the SAR option vs control points option), and 136 patients were in the amitriptyline comparison (125 in the factorial option and 11 in amitriptyline option vs placebo option).	Changes in mean pain scores at 6 and 14 weeks, using a pain scale ranging from 0.0 (no pain) to 1.75 (extremely intense), recorded daily.	Neither acupuncture nor amitriptyline was more effective than placebo in relieving pain caused by HIV-related peripheral neuropathy.
Phillips et al., 2004	Pre and post test case series	5 weeks of acupuncture treatment. -10-15 needle insertions in acupoints for 30-45 minutes	Twenty-one (21) subjects	Pain Rating Scale and the Subjective Peripheral Neuropathy Screen (SPNS)	Subjective pain and symptoms of peripheral neuropathy were reduced during the period of individual acupuncture therapy delivered in a group setting.
McArthur et al., 2000	RCT	Subcutaneous injections (0.1 µg/kg rhNGF, or 0.3 µg/kg rhNGF) twice weekly for 18 weeks.	270 patients with HIV-associated SN	- self-reported neuropathic pain intensity (Gracely Pain Scale). - Global improvement in neuropathy - punch skin biopsies for nerve fibre densities.	A positive effect of recombinant human nerve growth factor on neuropathic pain and pin sensitivity in HIV-associated sensory neuropathy. rhNGF was safe and well tolerated, but injection site pain was frequent.
Simpson et al., 2000	RCT	Lamotrigine was initiated at 25 mg per day and slowly titrated over 7 weeks to 300 mg per day	- Total 42 patients - 13 drop outs - 20 patients received placebo and 9 received lamotrigine	-change in pain on the modified Gracely scale secondary outcome measures -Change in neurologic examination, - Use of concomitant analgesic, medications, and global pain relief.	Lamotrigine showed promise in the treatment of pain associated with HIV-related DSP.

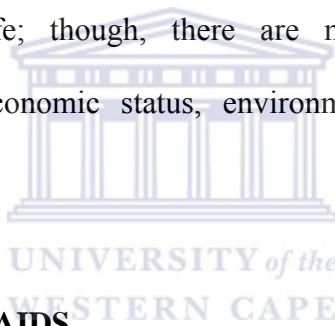
2.4 QUALITY OF LIFE OF PLWHs

2.4.1 Quality of life overview

The definitions and descriptions of quality of life include both objective (income, living situations and physical functioning) and subjective (individual's perception of important life domains and satisfaction with those domains) indicators of physical and psychological phenomena (Steenburgen & Rogers, 1997). A more operational definition of QoL has acknowledged that it is a complex and multidimensional concept that is difficult to define and measure (Casado, 2005). Quality of life is a term that is popularly used to convey an overall sense of well being and includes aspects such as happiness and satisfaction with life as a whole. However, the World Health Organisation has defined quality of life "as individuals' perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept incorporating in a complex the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of the environment" (WHO, 1999).

The quality of life as stated previously is a multidimensional concept and since quality of life assessment is essentially subjective it should include the patient's perspective (Cella & Tulsky, 1990). Health-related quality of life is one dimension of quality of life and has become increasingly important in recent decades as an outcome in health care (Testa & Simonson, 1996), especially when evaluating interventions for patients with chronic diseases (Patrick & Eriksson, 1993). Many publications focus on these components of quality of life as well as the fact that health-related quality of life is influenced both by

disease and treatment but also by personal characteristics such as coping or internal locus of control and by living conditions including for example, access to care and financial status (Bullinger & Von Mackensen, 2004). Additionally, health-related quality of life in clinical settings may be defined as a condition with specific symptoms which are body discomfort, social and role functioning, overall perception of health, cognitive status, and general well-being (Cleary et al., 1993); while in research, the quality of life instruments provide new insights into the nature of disease by assessing how disease impairs or impacts the subjective well-being of a person across a whole range of areas (Hakuzimana, 2005). The consequences of disease and its treatment represent only on group of influences on quality of life; though, there are many more aspects including demographics, personality, economic status, environment, social relationships, and culture.



2.4.2 Quality of life and HIV/AIDS

Quality of life among HIV-infected individuals has been studied extensively, and prior research has attempted to both assess quality of life and determine predictors for good or poor quality of life (Mweemba, 2008). Additionally, persons infected with HIV are not only concerned with a treatment's ability to extend life but also with the quality of the life they are able to lead (Demmer, 2001). Quality of life for patients living with HIV disease has become increasingly important, with the goals of therapy now including improvement of quality of life in addition to the reduction of symptoms, suppression of the virus, and extension of survival (Molassiotis et al., 2001).

People living with human immunodeficiency virus and acquired immunodeficiency syndrome (HIV/AIDS) experience numerous symptoms due to the disease, side effects of medication and comorbidities. Wachtel et al. (1992) found that patients with HIV/AIDS with severe symptoms had lower scores on quality of life, while Kemppainen (2001) found that quality of life deteriorated along with an increasing number of symptoms. The symptoms often experienced by patients with HIV/AIDS, such as fatigue, diarrhoea, insomnia and oral dryness, are often associated with the drug side effects of the drugs. Additionally, presence of physical symptoms, especially chronic diarrhea, is associated with low quality of life, irrespective of CD4 cell counts (Watson, Samore & Wanke, 1996). Quality of life in HIV-infected patients is a concept that has received increased attention in the literature, as it is recognized that HIV illness can impact all aspects of patients' lives (Lubeck & Fries, 1997). In addition, Yen et al. (2004) stated that quality of life levels of HIV/AIDS patients differed according to the method used to measure quality of life. In the same study, they found that male outpatients with few current HIV/AIDS-infection symptoms had medium quality of life levels according to the WHOQOL-BREF. Asymptomatic patients have been found to consistently report higher quality of life scores than symptomatic patients and patients with an AIDS diagnosis (Burgoyne & Saunders, 2001). Parsons, Braaten, Hall and Robertson (2006) maintain that quality of life in HIV is associated with disease stage and disease symptoms. Therefore, proper management of symptoms may improve the quality of life of these patients (Breitbart & Dibiase, 2002).

The results of previous research on the relationship of antiretroviral treatment and quality of life are mixed (Cohen, Revicki, Nabulsi, Sarocco, & Jiang, 1998; Nieuwkerk et al., 2000). Studies have shown that long-term use of highly active antiretroviral therapy (HAART) can control the disease, prolong survival, reduce incidence and mortality rates (Palella et al. 1998, Parsons et al., 2006); moderate the symptoms caused by HIV-infection, and slow the progression of AIDS. The comprehensive study on quality of life, emotional status, and adherence of HIV-1- infected patients treated with efavirenz versus protease inhibitor-containing regimes (Fumaz et al., 2002) highlighted that quality of life has been found to improve with antiretroviral therapy. Moreover, significantly improvements in the quality of life of symptomatic HIV subjects have been noted on quality of life measures following antiretroviral therapy (Nieuwkerk et al., 2001).

In a longitudinal study with a sample of 263 HIV-infected women from eight public-health HIV/AIDS clinics serving both rural and urban areas in the state of Georgia in the United States, social factors (disclosure and material resources) and psychological factors (fatalism, stigma, emotional distress, and intrusion) were found to be important determinants of quality of life in HIV (Sowell et al., 1997). In the same study, limited daily functioning was correlated with stigma, fatalism, employment status, and stage of disease.

Identifying factors that diminish QoL in HIV/AIDS cases is an important step towards improving QoL in this population; it allows clinicians to screen for these factors, and if present, intervene (Holmes, Bix, Meritz, Turner & Hutelmyer, 1997). Modern studies

have reported differing results, particularly when determining predictors of poor quality of life. Among socio-demographic variables, female gender, older age, black or Hispanic ethnicity, lack of private health insurance, and lower education have been associated with lower QoL in HIV-infected persons (Bastardo, & Kimberlin, 2000), while higher income and employment have been associated with better QoL (Viswanathan, Anderson, & Thomas, 2005). In addition, previous studies have found that employed subjects living with HIV have significantly higher overall QoL than unemployed subjects living with HIV (Blalock, McDaniel, & Farber, 2002; Swindells et al., 1999). Conflicting results have been given in regard to gender as a socio-demographic factor that might influence quality of life of HIV-infected people. Some researches have documented low performance for women in some aspects of quality of life (QoL) (Wachtel, et al., 1992). Married women appeared to be more vulnerable than were men to disruptions in quality of life over time (Sarna et al., 1999). Some reports in literature find younger age to be related with better QoL (Molassiotis, et al., 2001; Sowel et al., 1997). Worse quality of life in the areas of physical and social functioning has been attributed to older age among people living with HIV/AIDS (Piette, Wachtel, Mor & Mayer, 1995). Comparisons between educational groups showed that those with less education reported significantly poorer QoL than those with more education, according to some authors (Wachtel, et al., 1992; Lubeck & Fries, 1997). For the purpose of this study, we reviewed specific aspects of quality of life including physical, psychological, social relationship and environment in PLWHs.

2.4.2.1 Physical health

The physical health domain assesses the impact of disease on the activities of daily living, dependence on medical substances, a lack of energy and initiative, restricted mobility and the capacity to work (Skevington, 2002). Physical health gives an individual the ability to perform and adapt to the environment. Physical health is estimated by an individual's perceptions of energy and fatigue, pain and discomfort, and sleep and rest. The physical health domain has shown a positive relationship with overall quality of life. When one's physical status was reported as high, perceptions were that physical health and quality of life were more positive (Sousa et al., 1999). According to Kohli, Sane, Kumar, Paranjape and Mehendale (2005), the HIV infection affects various domains associated with physical health since frequent illness and increasing fatigue affect the individuals' ability to perform employment related and routine activities, and their overall perceptions of health. Fatigue and a CD4 T cell count less than 500 are associated with physical limitations and disability (Ferrando et al., 1998). Additionally, fatigue may affect one's activity level and is common when using antiretroviral therapies (ARTs) (Bormann, Shively, Smith, & Gifford, 2001). Responses to symptoms of fatigue and pain often result in elimination of leisure time and physical activities (Crystal, Fleishman, Hays, Shapiro, & Bozzette, 2000). Previous studies of quality of life among persons with HIV have suggested that as the disease progresses individuals experience more symptoms and more problems with physical function, and role functioning (de Boer, Van Dam & Sprangers, 1995; Franchi & Wenzel, 1998).

In previous studies on quality of life of people living with HIV/AIDS, the factors found to have significant affect on the physical health domain were occupation and education (Wig et al., 2006; dos Santos et al., 2007). Skilled workers and business persons had better physical health domain scores as compared to others, suggesting clearly that people with better occupation may have better physical health. In addition, lower scores were seen among subjects who did not attend school or completed middle school education compared to those with higher education.

Antiretroviral therapies taken as prescribed reduce viral loads and minimize the risk of drug-resistant strains of the virus (Liu et al., 2006); yet, non-adherence of ARTs ranges from 35% to 80% (Remien et al., 2005). Reasons for temporary discontinuation of ARTs include depression, poor quality of life, and ART side effects (Aversa, Kimberlin, & Segal, 1998). Moreover, some studies have found overall quality of life improved with the use of HAART (Nieuwker et al., 2000; Fumaz et al., 2002) and others observed that physical quality of life decreased under HAART (Gill et al., 2002). According to Liu et al. (2006), the decrease of physical health quality of life after HAART might be explained by the fact that HAART was initiated relatively early in the HIV infection. As in their study progressed the physical health of the men was still close to normal in early HIV infection, the HAART related side effects may have decreased physical health quality of life. Furthermore, by using HAART, many people with HIV who have been diagnosed with AIDS become healthy enough to return to work or school. Returning to work or school is often considered the benchmark of successful HIV treatment (Brooks & Klosinski, 1999).

2.4.2.2 Psychological health

The psychological domain accesses the patient's own thoughts about body image and appearance, negative feelings, positive feelings, self-esteem and person beliefs (Skevington, 2002). Psychological well being is the focus of intense research attention and is relevant to the experience of the individual (WHOQOL-HIV, 2003b). It is a person's evaluative reaction to his or her life; either in terms of life satisfaction (cognitive evaluations) or affect (ongoing emotional reaction). Psychological well-being has been found to be a source of resilience against stress and becoming ill. An individual's psychological well-being positively influences his/her quality of life (WHOQOL-HIV, 2003b). HIV disease not only severely affected the physical health of the patients, but also disease morbidity usually results in higher deterioration of psychological domain of quality of life (Liu et al., 2006). As documented by the previous studies, the most common emotional problems reported in people living with HIV/AIDS were anger, irritation, depression, tension and helplessness (Kohli et al., 2005), while Chesney and Folkman (1994) reported shock, denial, depression, helplessness, discouragement, guilt, anger and fear as the main emotional problems. Psychological comorbidities, particularly depression, often accompany HIV infection and add to the complexity of clinical management. Studies from western culture have found depression to be the most commonly observed mental health disorder among HIV-infected subjects, affecting up to 20% of patients (Komiti, Judd, & Grech, 2003). Depression may be associated with poor quality of life and shortened survival in subjects with HIV (Farinpour, Miller, & Satz, 2003). Additionally, the comprehensive study on relationship between depression and quality of life in persons with HIV infection in Nigeria (Adewuya et al., 2008) showed

that there was the significant association between the diagnosis of depression and poorer quality of life. In agreement with other studies (Farinpour, Miller, & Satz, 2003; Sherbourne et al., 2000), found that depression is a significant predictor of quality of life in people with HIV infection.

Highly active antiretroviral therapy (HAART) also may give hope and optimism to people with HIV. Researchers have found that having hope and an optimistic outlook, in turn, decreases their levels of depression, and even extends their life spans (Taylor, Kemeny, Reed, Bower, & Gruenewald, 2000). Despite these benefits, however, antiretroviral therapy can present significant psychological challenges to both those who respond well to the treatment and those who do not (Brashers et al, 1999). These can range from moodiness and aggressive behavior to severe depression, suicidal thoughts, paranoia, delusions and hallucinations. This emphasizes the need for psychological intervention for the affected individuals.

2.4.2.3 Social relationship

Social domain assesses personal relationships, social support and sexual activity (Skevington, 2002). People value their relationships with self and with others (WHOQOL-HIV, 2003a). Humans need to feel a sense of belonging and acceptance; they need to love and be loved both sexually and non-sexually. In the absence of such belonging, individuals become susceptible to loneliness, anxiety and depression. When an individual is no longer able to physically, emotionally, or sexually relate to self and others, quality of life is often negatively affected (WHOQOL-HIV, 2003a). Some authors

have suggested that earlier experiences and nowadays stigmatization may influence quality of life values (Watson et al., 1996). Social relationships were one of the main areas affected in people living with HIV/AIDS. Consequences within the social domains dominate; suggesting the severest impact of HIV extends across social aspect of QoL but also influences other important domains of health-related QoL (Sowel et al., 1997; Molassiotis, 2001). This is expected, as People with HIV infection often experience social isolation, derogation, stigmatization, discrimination and marginalization (Heckman et al., 1997). Stigmatization is a major stressor for individuals with HIV/AIDS (Brimbow, Cook, & Seaton, 2003). Brashers et al. (1999) noted that uncertainty (a chronic pervasive psychological distress) and stigma negatively affected adjustment and quality of life. Stigma influenced how individuals confronted their perception of an altered identity at diagnosis, lived with the illness, and dealt with the “social and physical death” of having HIV (Alonzo & Reynolds, 1995). Gray (1999) found that fear of stigma was more relevant to women (N = 80) living with HIV than was the fear of dying. In addition, poor social functioning may be associated with greater use of avoidance coping strategies such as withdrawal and conflictual social interactions. Social isolation and conflictual social interactions have been shown to interact to increase stress, resulting in poorer overall social functioning (Fleishman et al., 2000).

2.4.2.4 Environment

The environment does play a major role in determining health states. Environmental domain assesses influences of factors like financial resources, the work environment, accessibility to health and social care, freedom, security and participation and

opportunities for leisure activities on the QoL (Skevington, 2002). People would like to have the financial resources that they need to meet their daily needs (WHOQOL-HIV, 2003a). Physical safety and security are important aspects of the environment because they give the individual emotional freedom. It is also vital to have accessibility to good quality health and social care that provide opportunities for acquiring new information and skills. The environment provides for participation in opportunities for recreation and leisure. A safe and secure environment promotes a high level of quality of life (WHOQOL-HIV, 2003b). For working individuals, employment provides not only financial benefits but also structure for social support, role identity and personal meaning (Molassiotis et al., 2001). Adults with HIV/AIDS infection often struggle with vocational dilemmas. Previous study on the effect of employment on quality of life and psychological functioning in patients with HIV/AIDS has found that those employed have significantly higher overall QoL than unemployed subjects (Blalock et al., 2002). In earlier study on the impact of HIV/AIDS on the quality of life, family support and occupation significantly affected the environmental domain of quality of life in HIV patients (Wig et al., 2006). The effect of family support on the environmental domain was a significant observation. Family is usually the most important component of the immediate environment of the patient. The family of the patient can be a major support, in terms of not only financial support, but also safety and security. A good and supportive home environment can help the patient feel better. In the same study, skilled workers and business persons had better scores in environment domain scores. The authors concluded that improving the all-round environment surrounding of HIV infected individuals will lead to a better quality of life.

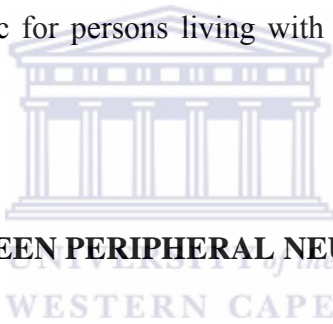
2.4.3 Quality of life measurement

Measurement of quality of life includes physical, functional, psychological, cognitive and social aspects of life which reflects the individual's subjective perception on his current overall health (Lubeck & Fries, 1997). This can be carried out by using either instruments specifically designed for a condition or generic instruments. Tools to measure quality of life have also surfaced in response to the recent interest in QOL research. Researchers differ in their perception of the components related to QOL; therefore, tools measure QOL differently.

The three most prominent HIV-specific quality of life instruments in the current circulating professional literature are (a) The Medical Outcomes Study – HIV (MOSHIV), (b) Multidimensional Quality of Life – HIV (MQOL-HIV), and (c) HIV Overview of Problems-Evaluation System (HOPES). A large body of literature examining the psychometrics of these tools exists (Wu et al, 1997; Revicki, Sorensen, & Wu, 1998; Badia et al, 2000).

The MOS-HIV is a tool specific for persons living with HIV based upon a well known validated, pre-existing QOL tool. It will be discussed at length following. HOPES determines QOL based upon five summary scales including physical, psychosocial, medical interaction, sexual and significant others/partners domain. The HOPES was adapted from a QOL tool first validated on cancer patients (Schag, Ganz, Kahn, Petersen, & 1992). According to Ganz et al. (1993) and Schag, Ganz, Kahn, and Peterson (1992), the HOPES instrument has been shown to be both reliable and valid with a stable factor

structure. The MQOL-HIV asks 40 questions which assess mental health, physical health, physical functioning, financial status, partner intimacy, sexual functioning and medical care. Studies have determined this tool is adequately reliable, valid, and sensitive to changes in QOL over time (Smith et al, 1997; Herdman, Fox-Rushby, Badia et al, 2000, & Badia, 1997), however Badia et al. (2000) have claimed that the MOS-HIV is more sensitive than the MQOL-HIV when used in clinical research. While each of the mentioned tools has its use, the MOS-HIV is very well known secondary to its well-known parent, the MOS tool. The MOS-HIV has demonstrated both validity and reliability (Franchi & Wenzel, 1997). The WHOQOL BREF was used in the current study because is a tool specific for persons living with HIV based upon a well known validated in Rwanda.



2.5 RELATIONSHIP BETWEEN PERIPHERAL NEUROPATHY AND QUALITY OF LIFE

Patients living with HIV/AIDS experience a wide range of symptoms associated with clinical manifestations of the disease, related opportunistic conditions and side-effects from medication (Demmer, 2001). In addition, previous studies have consistently shown that the presence, number, and severity of symptoms are the major determinants of quality of life in HIV-infected patients (Wu, 2000). The same author further stated that clinical stage has only a weak association with quality of life after adjusting for the number of symptoms. Moreover, by interfering with their daily activities and relationships with the external world, peripheral nervous system diseases can greatly

affect the quality of life (QoL) of patients, and a worsening QoL may increase their disability (Cocito et al., 2006).

With regards to quality of life and peripheral neuropathy in PLWHs, limited information is available in literature. According to the researcher only quality of life and peripheral diabetic neuropathy studies are available. Like all chronic pain, diabetic peripheral neuropathic pain (DPNP) takes a toll on patients' quality of life. One small study found that quality of life was significantly ($p < .01$) more impaired among patients with DPNP than among diabetic patients without neuropathy (Benbow, Wallymahmed & Mcfarlane, 1998). Another study of 105 patients with DPNP reported high levels of interference with sleep and enjoyment of life and moderate interference with mobility, employment, and recreational and social activity (Galer, Giana, & Jensen, 2000). Furthermore, in an earlier study of diabetic patients with chronic pain, pain was associated with reduction in sleep, walking and ability to perform domestic duties (Benbow et al., 1998).

Chronic painful symptoms can have a considerable impact on an individual's life and may be associated with anxiety, depression, loss of mobility and independence (Benbow et al., 1998). In addition, painful peripheral neuropathy has been shown to play an important negative role in physical and psychological functioning as well as in the overall quality of life of people living with HIV/AIDS (Breitbart et al., 1998). Also, Pandya et al. (2005) found that HIV-related neurological syndromes, including neuropathy, significantly reduce quality of life. Thus, increased and improved surveillance for HIV-associated peripheral neuropathy will allow earlier interventions to improve quality of

life and prevent severe toxicities. Griswold et al. (2005) examined coping strategies of HIV patients with peripheral neuropathy and found that these strategies may differ according to age, gender and ethnic background in those living with HIV.

2.6 SUMMARY

This chapter has described the general overview of HIV/AIDS worldwide, including Rwanda. Relevant literature on peripheral neuropathy amongst and quality of life of people living with HIV/AIDS has been reviewed. The literature reviewed showed that DSPN remains one of the most common neurological complications associated with HIV infection or its treatment and poses enormous limitations related to functional status, activity levels, and physical comfort. The spectrum and the frequency of this complication are expected to change with continued experience and introduction of new antiretroviral drugs, an aging HIV-infected population, and the emergence of other long-term complications of HIV and/or its treatment. Additionally, the assessment of QoL is now acknowledged as a central component of health care and healthcare research. It is essential that initial and ongoing assessment address symptom management to improve the individual's quality of life.

CHAPTER THREE

METHODOLOGY

3.1 INTRODUCTION

This chapter outlines the methods used in the study. It explains the rationale for the study, the design chosen and describes the research setting. The population, the sampling method, data collection and analysis are described. Finally, the ethical considerations regarding the study are described.

3.2 RESEARCH SETTING

This study was carried out in the Rulindo, a district located in the Northern Province, 40 kilometers from Kigali city, in Rwanda. The Republic of Rwanda is a small, land-locked country in East Africa with one of the highest population densities in the world at 344 people per square kilometer. Most recent statistics indicate a population size of 9,241,661 (National Institute of Rwanda (NISR), 2007). In addition, the prevalence of people living with HIV/AIDS was estimated at 190,000, of which 160,000 were adults (UNAIDS, 2007). According to Furth et al. (2006), Rwanda has made remarkable strides in antiretroviral therapy and care of opportunistic infections which occur as a result of HIV. By the end of September 2004, a total of 6,230 clients had started ARVs. Furthermore, UNAIDS/WHO/UNICEF (2007) indicated that in Rwanda, the estimated number of people receiving antiretroviral therapy was 34,000 in 2006.

The study was based at Rutongo Hospital in Rulindo District in Rwanda. This is a District Hospital to which most patients from 16 Primary Health Care Centers around the

District are referred for HIV/AIDS services and other health services. The hospital has an average 100 beds and five out-patients clinic consultations per week and each PLWH comes twice per month. This site was chosen because it offers HIV care (Anti-retroviral drug, Voluntary Counseling and HIV testing, and other medical routine care). At Rutongo Hospital, PLWHs are sent to the ARV service provider where they are examined and a CD4 count is ordered.

3.3 STUDY DESIGN

A cross-sectional descriptive design using quantitative research method was used in the study. Thyer (2001) indicated that descriptive studies summarise the relationships between or among two or more variables aiming at quantifying the extent of the problem. A cross-sectional study involves examining the responses of different groups of participants at one point in time. It has the advantage of collecting information in a short time frame (Mertens & Mc Laughlin, 2004). Therefore; it was an appropriate study design, to collect data relating to the prevalence of peripheral neuropathy amongst and the quality of life of adults living with HIV/AIDS attending the out-patient clinic at Rutongo Hospital in this study at a given point in time.

3.4 STUDY POPULATION AND SAMPLING

Approximately 800 people living with HIV/AIDS have attended Rutongo hospital; more than 600 of these are adults. Approximately 35 adults living with HIV/AIDS attend this setting once a week to receive medication. The study was conducted over a 6 week period. A time constrained sample of 185 people living with HIV/AIDS attending this

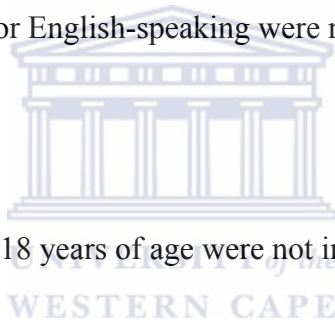
setting was therefore recruited to participate in the study. Participants in this study were adults confirmed to have HIV/AIDS infection. The patients attending the out-patient clinics included those who were receiving HAART and those who needed assessment of their CD4 counts not receiving medication. Only those participants attending the out-patient clinics at the time of data collection were included in the study.

3.4.1 Inclusion criteria

Only HIV-positive males and females who are: over 18 years, receiving AIDS-related care at Rutongo Hospital in Rulindo District in Rwanda, able to provide informed consent and fluent in the Kinyarwanda or English-speaking were recruited.

3.4.2 Exclusion criteria

HIV-positive patients less than 18 years of age were not included in the study.



3.5 INSTRUMENTS

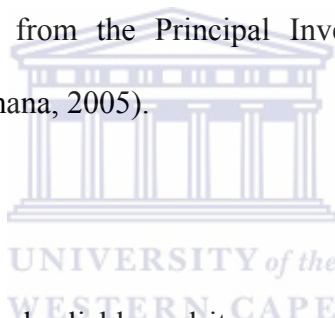
Two validated instruments were used to collect data. The Subjective Peripheral Neuropathy Screen (SPNS) (Appendix J) was used to screen for the presence of peripheral neuropathy and the World Health Organization Quality of Life, short form (WHOQOL BREF) (Appendix L) to assess quality of life.

1. Symptoms of peripheral neuropathy were measured using the Subjective Peripheral Neuropathy Screen (SPNS) (McArthur, 1998). This instrument is a brief self-report tool that was designed as a screening instrument for painful or nonpainful sensory in HIV-

infected subjects. SPNS has six questions which cover the following symptoms: “pain, aching or burning”, “pins and needles” (parasthesias) and “numbness”. Each of these six different symptoms was rated either as never occurring or occurring. If present at time of data collection, the severity of the symptoms was scored on a scale from 01 (mild) to 10 (most severe). The symptom receiving the highest severity assessment (1-10) was converted into a categorical “severity grade” by means of the following raw scores are: 1 to 3, 4 to 6 and 7 to 10 and the corresponding clinical severity grade was 1, 2, and 3 respectively. This grade was called the subjective peripheral neuropathy grade.

2. The World Health Organization Quality of Life, short form (WHOQOL BREF) was used in this study to determine quality of life of the participants. The WHOQOL BREF consists of 26 items. These items are distributed in four domains of QOL, physical health and level of independence with seven items, psychological well being with eight items, social relationship with three items, and environment with eight items. There are also two items that are examined separately; one for the overall quality of life and another for general health. Each item uses a Likert-type five-point scale. Most scores are scaled in a positive direction where higher scores denote higher quality of life. Three items are not scaled in a positive direction but were scaled in negative direction (e.g. physical pain, negative feelings, dependence on medication), meaning that for these items higher scores do not denote higher quality of life. Participants were questioned regarding their experience relating the above domains in the previous two weeks. Summation and calculation of the mean score for each domain was calculated. Because the numbers of items are different for each domain as mentioned above, all domain scores were

calculated by taking the mean score for all items included in each domain and multiplying by a factor of 4. The first transformation method converts scores to range between 4-20, comparable with the WHOQOL-100. The second transformation method converts domain scores to a 0-100 scale. Where more than 20% of data is missing from an assessment, the assessment should be discarded. Where an item is missing, the mean of other items in the domain is substituted. Where more than two items are missing from the domain, the domain score should not be calculated (with the exception of domain 3, where the domain should only be calculated if < 1 item is missing). The instrument used in the current study was available in Kinyarwanda version. In addition, permission to use this instrument was obtained from the Principal Investigator of WHOQOL BREF Kinyarwanda version (Hakuzimana, 2005).



3 .5.1 Reliability

The SPNS instrument was found reliable and it possesses both construct and criterion-related validity. Using Cronbach's alpha test the internal consistency of the SPNS was high (0.86) (McArthur, 1998). The WHOQOL-BREF questionnaire has been shown to have a good internal consistency with Cronbach's alpha acceptable for overall quality of life and health satisfaction. Two week test-retest reliability shows intraclass correlation coefficients p for domain scores to be less than $p < 0.05$ for all domains indicating good correlation between test and retest values with Cronbach's alpha acceptable in physical and psychological domains (Hakuzimana, 2005).

3.5.2 Validity

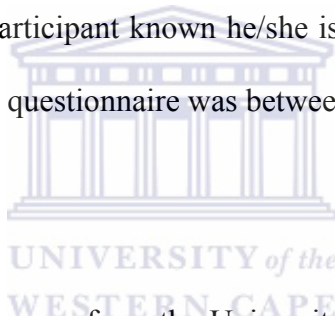
The test can discriminate between the symptoms of parasthesias, numbness, and lower extremity pain ($p < 0.05$). In addition, it has been demonstrated that the SPNS assess differences in symptoms severity ($p < 0.05$). Significant correlations were demonstrated for SPNS results and other tests like a neurologic examination, vibratory quantitative sensory testing, and severity measures. Sensitivity and specificity analysis indicates that numbness of the lower extremities is the symptoms reported by the SPNS that most correctly classifies painful sensory neuropathy. Further, the SPNS has appeared to be a useful tool for screening HIV-associated sensory neuropathies; it has a high specificity (83%) and a good positive predictive value (70%) (Venkataramana, Skolasky, Creighton, & McArthur, 2005). Finally, the content validity of the SPNS was established, since it was developed by a group of neurologists with experience and expertise in the area of painful sensory neuropathy. Fang et al. (2004) in their study on validation of the World Health Organisation quality of life instrument in patients with HIV infection concluded that the WHOQOL-BREF would be a useful tool in assessing quality of life in patients with HIV infection.

3.5.3 Translation

The Subjective Peripheral neuropathy screen (SPNS) (Appendix K) was translated from English to Kinyarwanda by a professional translator. In order to ascertain if the translated version into Kinyarwanda relay to the intended meaning in the English version, two other translators assisted back translation of this instrument to the English. The back translated version was the same as the original English version with no changes needed

3.6 PILOT STUDY

The aim of the pilot study was to identify how well respondents understood the questions and how long it took to answer the questions. Ten patients with HIV/AIDS who satisfied the inclusion criteria at Rutongo Hospital were interviewed for the pilot study after written consent was obtained from them. These patients were not included in the main study. Balnaves & Caputi (2001) indicated that performing a pilot study assists in the identification of problems and benefits associated with the questionnaire design. The necessary changes to the instrument were made after piloting. For example, the question requesting for how long has the participant known he/she is HIV positive, was changed into how many years has the participant known he/she is HIV positive. The time it took for respondents to complete the questionnaire was between twelve and fifteen minutes.



3.7 PROCEDURE

After obtaining the ethical clearance from the University of the Western Cape's Senate Research Committee, ethical approval was sought from the Minister of state in charge of HIV/AIDS and other epidemics in the Ministry of Health (APPENDIX B). In addition, permission to conduct the study was obtained from the Director of Rutongo Hospital. One physiotherapist and one counselor were recruited as research assistants; they were explained their role in the study, the aim and the nature of the study, as well as all ethical issues. The sample consisted of patients who were attending the Rutongo Hospital for out-patient services. The patients were approached and invited to partake in the study while waiting to be attended to by the doctors, where the aims and objectives of the study were explained. All subjects who volunteered to participate provided written informed

consent. The researcher completed SPNS and WHOQOL-BREF. Demographic data including age, gender, level of education, occupation, marital status and the length of time participants known their-HIV status was also collected from the participants.

3.8 DATA ANALYSIS

Responses to the questionnaires were entered and analysed in the Statistical Package for the Social Sciences (SPSS) for Window Version software 15.0. Descriptive statistics (i.e. means, standard deviations, frequencies and percent) were used to examine demographic characteristics of the sample, prevalence of peripheral neuropathy and WHOQOL BREF domain scores. One-way Analysis of variance and Independent sample T-tests were performed to determine a significant difference between quality of life domain scores and demographic characteristics. Chi-square Tests were used to demonstrate association between demographic characteristics and severity of peripheral neuropathy.

3.9 ETHICAL CONSIDERATION

The researcher obtained permission to conduct the study from the Higher Degrees Committee of the University of the Western Cape and ethical permission from the Research and Study Grant Committee of the University of the Western Cape. Secondly, permission was sought from the Minister of state in charge of HIV/AIDS and other epidemics in the Ministry of Health in Rwanda. The researcher obtained permission from the Director of Rutongo Hospital. The researcher explained the aim and objectives of the study to participants prior to their participation. Written consent was sought from the participants and they were informed of the voluntary nature of the study and their right to

withdraw from the study at any time if they so wished. In addition, participants were assured of respect, confidentiality and anonymity. For those who reported PN, advice such as avoiding walking long distances, standing for long periods of time, or wearing restrictive shoes was given to them. The results of the study will be availed to the director of Rutongo, the head of ARV service and to those interested participants.

3.10 SUMMARY

This chapter described the methodology used in this study. It explained the research setting and the whole procedure of how the data was collected and analysed. Finally, the chapter explained how ethical considerations were applied in this study. The findings of the study are presented in the next chapter.



CHAPTER FOUR

RESULTS

4.1 INTRODUCTION

In this chapter the results of the study are described. The results are described under various headings which reflect the general picture of the prevalence of peripheral neuropathy symptoms among adults living with HIV/AIDS attending the out-patient clinic at Rutongo Hospital in Rulindo District in Rwanda, by giving types, area and severity of symptoms. The quality of life of adults living with HIV/AIDS in Rulindo District is also presented.

4.2 DEMOGRAPHIC CHARACTERISTICS OF THE STUDY SAMPLE

A total of 185 participants completed the two questionnaires from December 2007 to January 2008. The participants' mean age was 38.70, with a standard deviation of 9.538. The ages ranged from 19 years to 73 years. The majority of the sample fell into the age range of 31-40 years. The study sample consisted of more female 131 (70.8 %) than males 54 (29.2%). In the present sample, the majority of the participants 160 (86.5%) were farm workers, while 3 (1.6 %) were self-employed. Approximately half of the participants 94 (50.8%) were married while the remaining part did not have a partner as they were single or widowed. Only three of the participants had university education, whereas most participants had a primary level of education. The majority of participants 110 (59.5%) had known their HIV-positive status for a period of 2 to 4 years. Table 4.1 below illustrates these results.

Table 4.1: Demographic characteristics of the study sample (n=185)

Demographic variables	Characteristics	Frequency	Percentage
Age	Less than 30	35	18.9
	31-40	79	42.7
	41-50	49	26.5
	51-60	16	8.6
	More than 60	6	3.2
Gender	Female	131	70.8
	Male	154	29.2
Occupation	Farm workers	160	86.5
	Unemployed	12	6.5
	Public or private employed	10	5.4
	Self employed	3	1.6
Marital status	Married	94	50.8
	Widowed	53	28.6
	Separated	24	13.0
	Single	12	6.5
	Cohabiting	2	1.1
Level of education	Primary	112	60.5
	Secondary	15	8.1
	University	3	1.6
	Not at all	55	29.3
Time elapsed since HIV diagnosis	< 2 years	54	29.2
	2 to 4	110	59.5
	5 to 7	12	6.5
	8 to 10	7	3.8
	> 10 years	2	1

4.3 PERIPHERAL NEUROPATHY

This section includes the prevalence and type of peripheral neuropathy symptoms as well as severity of those symptoms.

4.3.1 Prevalence of peripheral neuropathy symptoms

A total of 185 adults living with HIV/AIDS attending out-patient clinic at Rutongo Hospital received and completed the Subjective Peripheral Neuropathy Screen (SPNS) (Appendix A). Peripheral neuropathy was defined as being present if an individual described responses on both the presence and severity of each of three types of symptoms (“pain, aching, or burning”; “pins and needles”; and “numbness”). The overall prevalence of peripheral neuropathy in the sample of people living with HIV/AIDS attending out-patient clinic at Rutongo Hospital was 75 (40.5%). Figure 4.1 illustrates the overall prevalence of peripheral neuropathy symptoms of the participants.

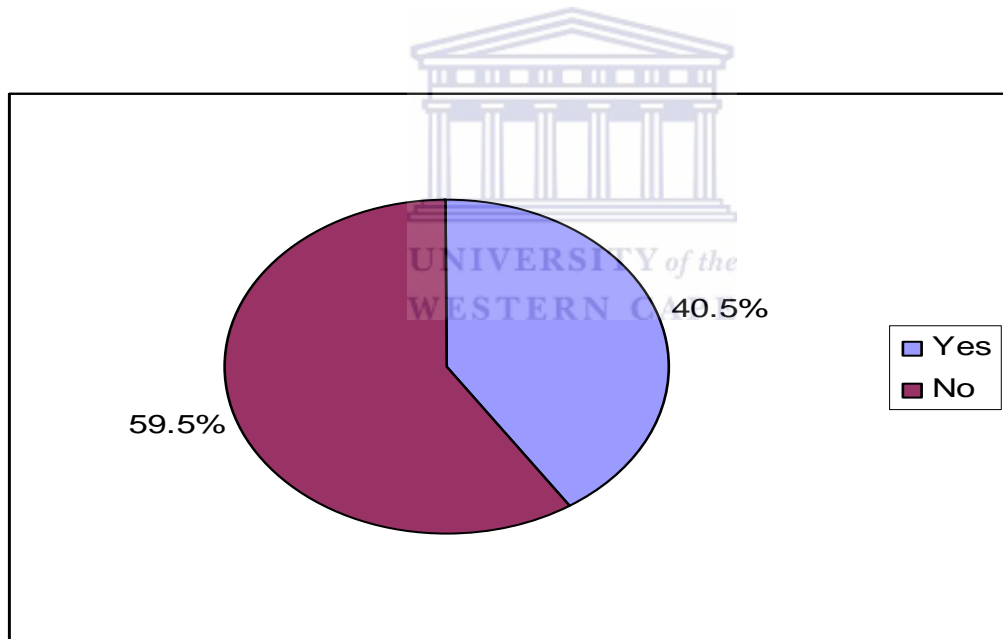


Figure 4.1: Overall prevalence of Peripheral neuropathy symptoms (n=185)

4.3.2 Type and area of peripheral neuropathy

Three types of symptoms “pain, aching or burning”, “pins and needles” (parasthesias) and “numbness” were assessed. Each of these three types of symptoms was assessed in

terms of two body locations such as hands or arms versus feet or legs. Thus, six different symptoms depending on type and location were assessed. The most common reported symptoms were pain, aching or burning while the least common reported symptoms were pins and needles in feet and legs. The symptoms reported in this study showed that the upper extremities were more commonly affected than lower extremities (Figure 4.2).

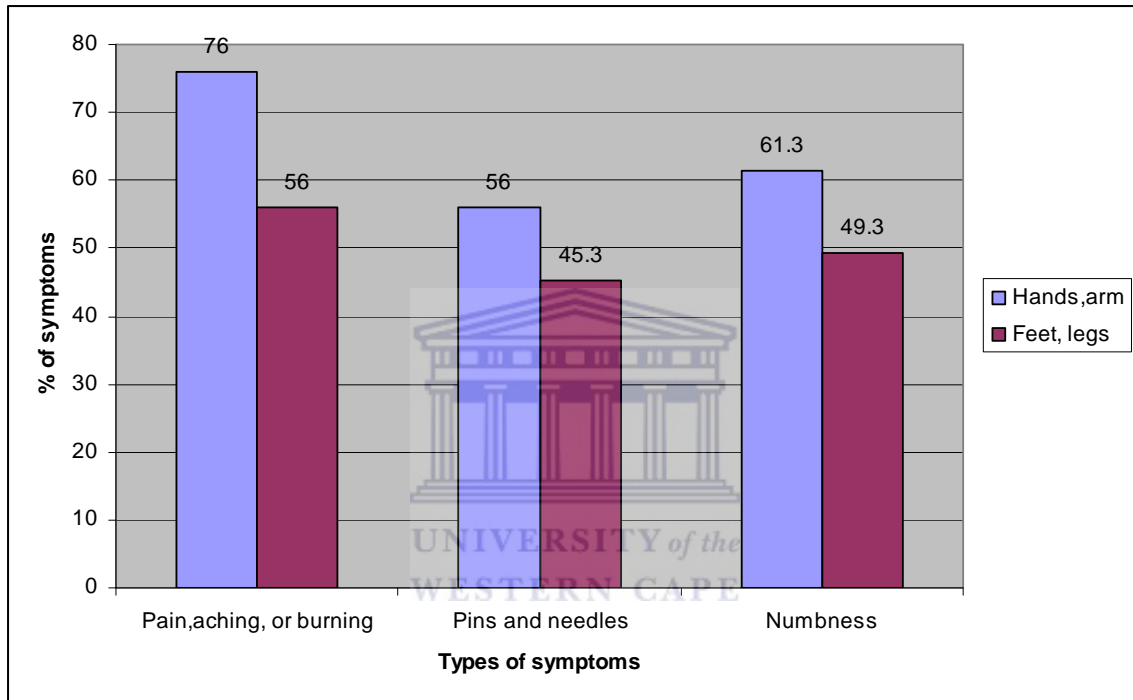


Figure 4.2 Types of peripheral neuropathy symptoms for PLWHs (n=75)

4.3.3 Severity of symptoms

The severity of the symptoms is determined by calculating the Subjective Peripheral Neuropathy Grade. The Subjective Peripheral Neuropathy Grade is determined by using the symptom with highest score between 1 and 10. These were then categorised into three groups. A Subjective Peripheral Neuropathy Grade of 1 illustrated a mild peripheral

neuropathy, 2 moderate and 3 severe. A symptom scored between 1 and 3 equal a clinical grade of 1, 4 and 6 a clinical grade of 2 then 7 to 10 a clinical grade of 3.

In the present study, Subjective Peripheral Neuropathy mean was 1.69, with a standard deviation of 0.885. Figure 4.3 below shows that out of 75 participants who reported symptoms at the time of data collection, 44 (58.7 %) were in grade 1 whereas 10 (13.3 %) were in grade 2 and 21 (28 %) in grade 3. This study found that they were 21 male and 54 female living with HIV/AIDS with peripheral neuropathy.

Chi-square test was conducted to analyse the difference between the genders of the participants living with HIV/AIDS with peripheral neuropathy in relation to Subjective Peripheral Neuropathy Grade. There was no significant difference in the severity of PN between males and females ($\chi^2=0.909$, $P=0.635$).

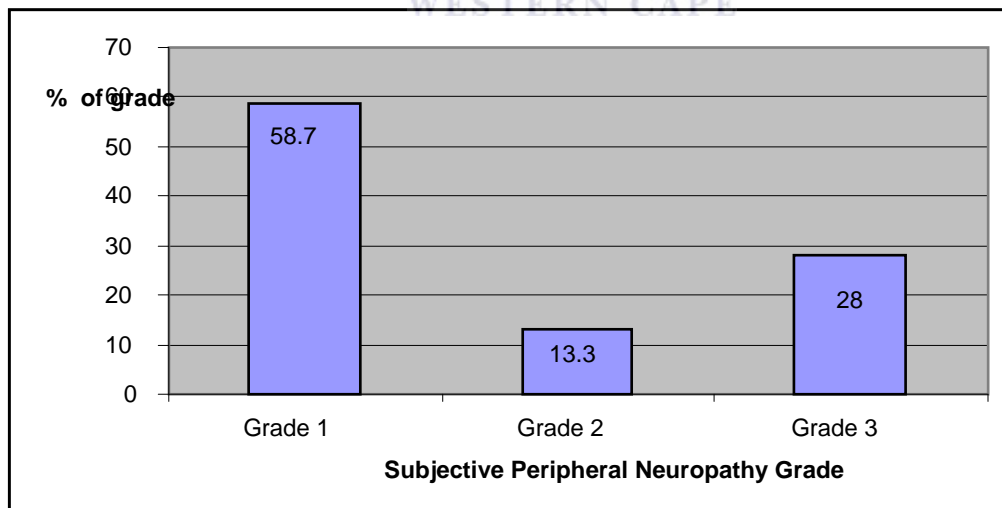


Figure 4.3: Distribution of participants according to the Subjective Peripheral Neuropathy Grade. (n=75)

Fig 4.4 illustrates Subjective Peripheral Neuropathy Grade by age. The majority of patients reported symptoms at the time of data collection fell into the age range of 31-40 years, followed by the age range of 41-50 years; while few patients fell in age group of more than 60 years. Chi-square Tests were used to demonstrate association between age and Clinical Severity Grade. There was a significant association ($p=0.000 < 0.005$).

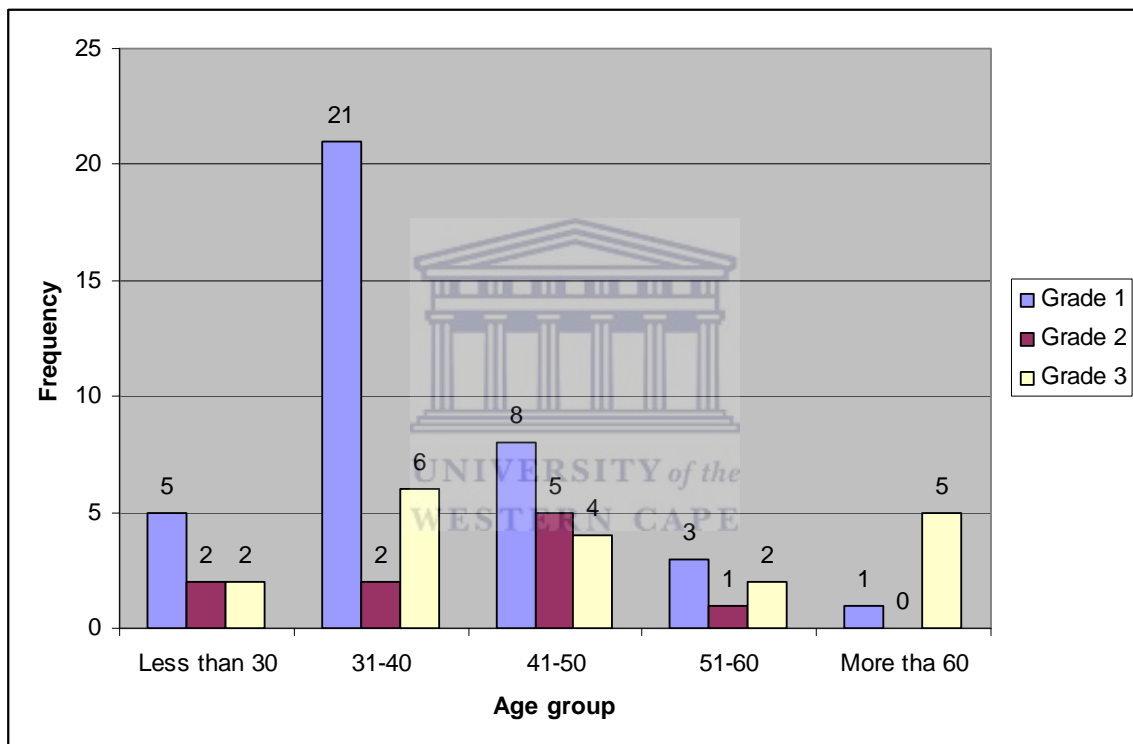


Fig 4.4: Representation according to age group versus Subjective Peripheral Neuropathy Grade (n=75)

4.4 QUALITY OF LIFE

This section includes the mean quality of life scores, demographic information and mean scores of quality of life domains and their respective mean differences.

4.4.1 Mean quality of life domain scores

The mean score in four domains of quality of life was the highest for the psychological domain followed by the social domain, physical health domain and environmental. Figure 4.5 illustrates the mean quality of life scores.

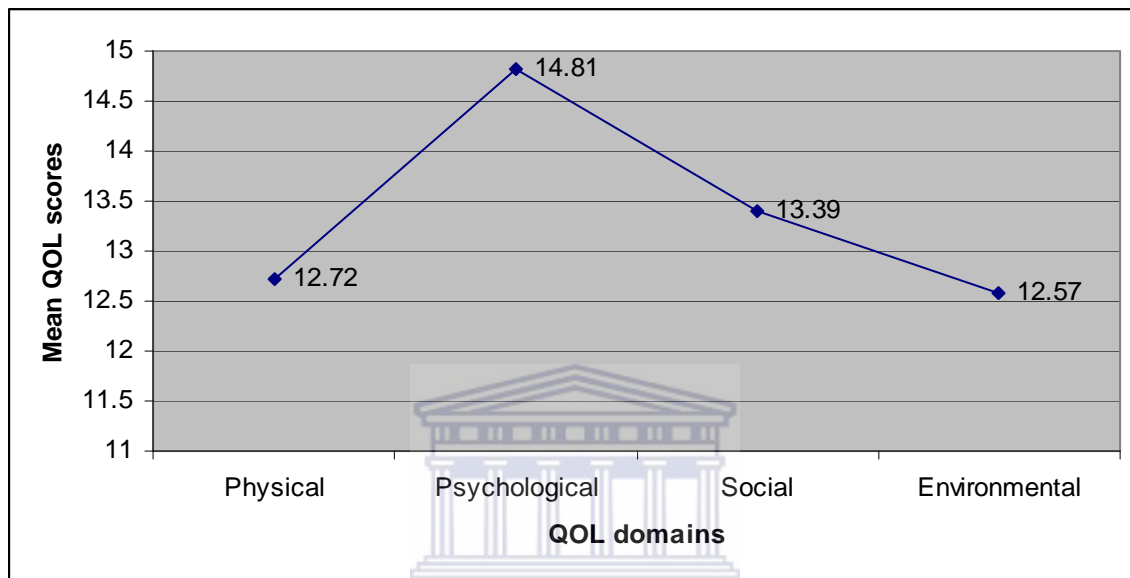


Figure 4.5: Quality of life domain scores

4.4.2 Quality of life according to different demographic characteristics

Table 4.3 shows demographic information and mean scores of quality of life domains and their respective mean differences. Multiple comparisons of means were performed using Tukey's test. The results from the Student's t-test and one-way analysis of variance (ANOVA) showed that a significant difference was observed with respect to the ages of the participants in the psychological domains ($P=0.028$). Lower scores were seen among subjects who were older than 60 years compared to those who were less than 30 years old. However, there was no significant difference of quality of life in the physical, social and environmental domains amongst the different age groups. The comparison of the

mean raw scores of quality of life in men and women showed that there is a statistically significant difference in the social relationships domains ($P=0.033$) with lower scores for women in this domain. In the present study, there was no significant difference between quality of life and occupation.

One way analysis of variance (ANOVA) was also performed to determine if there was a significant difference between scores of the different domain and marital status. There were no statistically significant differences between quality of life domains according to the marital status. In the social relationships domain, there was however a statistically significant difference ($P=0.030$) for the subjects who were cohabiting when compared to those who were widowed with subjects who were cohabiting having better scores. Comparisons of mean scores of quality of life revealed significant differences in the physical health ($P=0.000$), psychological ($P=0.000$), social relationships (0.033) and environment domains (0.040) and level of education; scores were lower for those who did not attend school compared to those with primary, secondary and tertiary level of education. The mean scores were lower in the physical domain for who did not attend school. The variable relating to time since HIV diagnosis indicated that subjects who knew their HIV status for two to four years had higher mean scores in the social relationships domain when compared to those knew about their status for less than two years.

Table 4.2 Relationship between quality of life scores and demographic characteristics (n=185).

Demographic characteristics	Mean quality of life scores			
	Physical health	Psychological health	Social relationships	Environment
Age				
< than 30 years	13.06	15.17*	13.60	12.51
31-40	13.04	14.90	13.58	12.57
41-50	12.31	14.92	13.49	12.59
51-60	12.44	14.00	12.00	12.44
> than 60 years	10.83	12.83*	12.50	13.17
Gender				
Male	12.59	14.74	13.91*	12.52
Female	12.78	14.84	13.18 *	12.60
Occupation				
Public or private employed	12.90	15.10	14.00	12.70
Self-employed	13.00	15.00	15.00	13.33
Unemployed	12.17	14.42	13.92	11.58
Farming or livestock	12.75	14.82	13.28	12.63
Marital status				
Married	12.57	14.81	13.46	12.50
Single	13.25	14.58	13.08	12.08
Separated	12.46	14.21	12.29	12.54
Cohabiting	12.50	16.00	14.00 *	12.00
Widowed	13.00	15.09	13.81 *	12.85
Education				
Not at all	11.60 *	13.87 *	12.71 *	12.09 *
Primary	12.93 *	15.13 *	13.62 *	12.82 *
Secondary	13.21	15.60	14.07	12.40
University	14.00	16.00	14.00	13.00
Time elapsed since HIV diagnosis				
< 2 years	12.70	14.48	12.78 *	12.26
2 to 4	12.69	14.96	13.78 *	12.67
5 to 7	13.58	15.50	13.67	13.08
8 to 10	12.29	14.14	12.43	12.57
> 10 years	11.50	13.50	10.00	12.50

*P< 0.05

4.4.3 Distribution of the population studied according to the presence and absence of peripheral neuropathy symptoms and quality of life scores

Independent samples T-Test was performed to determine if significant differences existed between quality of life domain (physical, psychological, social and environmental) of participants with and without peripheral neuropathy symptoms. Quality of life in PLWHs with peripheral neuropathy showed significantly lower scores in the physical ($p=0.013$) and psychological ($p=0.020$) domains. There was no statistically significant difference between the two groups with regards to the social and environmental domains. The quality of life domain scores have been summarized in Figure 4.6.

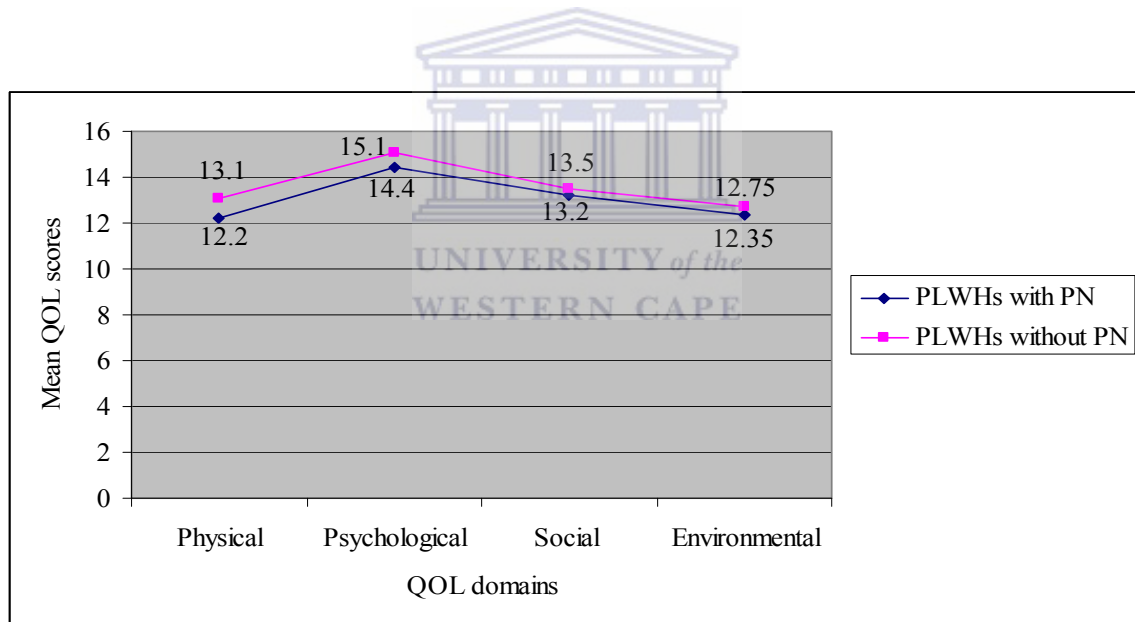


Figure 4.6 QoL domain scores between participants with and without peripheral neuropathy symptoms (PLWHs with PN, n=75; PLWHs without PN, n=110).

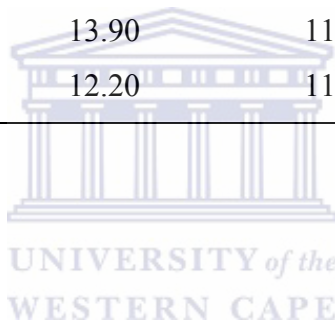
One way analysis of variance was performed for finding out significance between quality of life domain scores and subjective peripheral neuropathy grade. The physical,

psychological and social domain scores showed significant differences in participants with grade 1 and grade 3 scores in participants with peripheral neuropathy; lower scores were seen among subjects with grade 3 scores when compared to those with grade 1 scores. The description of one way Analysis of variance (ANOVA) between quality of life domain scores and clinical severity grade is detailed in Table 4.3.

Table 4.3 Quality of life domain scores and subjective peripheral neuropathy grade (n=75)

Domains for QOL	Grade 1	Grade 2	Grade 3	P value
Physical	12.93*	11.30	11.14*	0.006
Psychological	14.98*	14.50	13.19*	0.004
Social relationship	13.68*	13.90	11.95*	0.008
Environmental	12.64	12.20	11.30	0.284

*P< 0.05



4.6 SUMMARY

This chapter highlighted the findings of the study. The results showed that the 31 to 40 years old age group had a high prevalence of people living with HIV/AIDS with peripheral neuropathy symptoms, while the mean score of quality of life domains was lowest for environmental domain, followed closely with physical health domain. The study identified also contributing factors for quality of life in PLWHs. The discussion of these results will be presented in chapter five.

CHAPTER FIVE

DISCUSSION

5.1 INTRODUCTION

The aim of the study was to determine the prevalence of peripheral neuropathy amongst and the quality of life of adults PLWHs attending the out-patient clinics at Rutongo Hospital in Rwanda. In this chapter, the significant findings of the study will be discussed. The limitations of the study are also highlighted.

5.2 DEMOGRAPHIC STATUS OF PLWHs

In this study, the majority of the participants were female (70.8%). These results are similar to those of Jelsma, Maclean, Hughes, Tinise and Darder (2005). The predominance of women is due to more women attending clinic as in 2007, 46 % only of people living with HIV/AIDS (15.4 million) were women worldwide (UNAIDS 2007). According to Calderon (1997), biological, socio-economic and cultural factors make women more vulnerable to HIV infection. The same author stated that women are affected by gender imbalance; they do not have equal opportunities to education, on-going training and jobs as men and tend to be excluded from the formal economy. It was further indicated that HIV infection was six times more prevalent in women than in men (Population Council Epidemiology, 2002). Thus, the high prevalence of women participation in the current study could be explained by the fact that at the time of data collection women were the most participants attending Rutongo hospital.

The findings of this study revealed that the majority of the sample fell into the age range of 31-40 years. This proportion indicates that the prevalence of HIV could be high among youths and young adults in the population studied. This is not surprising because people in this age range tend to be more sexually active, hence causing them to be at high risk of HIV infection. The similar age range was found in a previous study conducted in Nigeria on relationship between depression and quality of life in persons with HIV infection (Adewuya et al., 2008).

The present study showed that approximately half of the participants (50.8%) attending the out-patients clinics at Rutongo hospital were married. A similar result was found in previous study on perceived psychosocial needs, social support and quality of life in subjects with HIV/AIDS (John, Ndebbio, & Udoma, 2003). Additionally the current study found a high percentage (28.6%) of widowed people compared to an earlier study conducted in Zambia on quality of life of men and women living with HIV/AIDS, where the percentage of widowed was 9% (Mweemba, 2008). This might be related to the 1994 Rwandan genocide and marital separation due to HIV. In addition, the reason explaining this occurrence is because of the high mortality rate among PLWHs. Their males may be dying due to AIDS.

5.3 PERIPHERAL NEUROPATHY

The diagnosis of peripheral neuropathy can generally be made by a healthcare provider who is experienced in the treatment of HIV disease based on a history of the symptoms and a comprehensive physical examination which includes testing of the reflexes and

evaluation of the sense of vibration, touch, pressure, and pain in the extremities (Swanson et al., 1998). Different prevalence rates of peripheral neuropathy in people living with HIV/AIDS have been reported in the literature. This may be due to different methodology of studies, defining criteria, and patient populations.

In the present study, the diagnosis of peripheral neuropathy was established by a researcher based on the subjects' responses from subjective peripheral neuropathy screen (SPNS). Pain, paresthesias, and numbness were the three symptoms that differentiated those with peripheral neuropathy from those without.

Using the subjective peripheral neuropathy screen (SPNS) the overall prevalence of peripheral neuropathy in the sampled participants of the study was 75(40.5%) out 185 adults PLWHs attending out-patients clinic at Rutongo Hospital. This result was similar to findings in studies conducted internationally and in Africa. Mbuya et al. (1996) found peripheral neuropathy rates in Kenya to be 15 (37.5%) out of PLWHs; Skopelitis et al. (2006) found peripheral neuropathy rates in United Kingdom (UK) to be 36 (36%) out 100 PLWHs, Smyth et al. (2007) found 42% in Melbourne; Parry et al. (1997) found 44% in Zimbabwe, Schifitto et al. (2002) found 135 (36%) of 375 in Etats-Unis. The lowest prevalence 329 (13.1%) of 2515 PLWHs was reported in a previous study conducted in Etats-Unis on modification of the incidence of drug-associated symmetrical peripheral neuropathy by host and disease factors in the HIV outpatients study (Lichtenstein et al., 2005). This study was aimed at identifying factors associated with the clinical diagnosis of symmetrical peripheral neuropathy during the era of highly active antiretroviral

therapy. These conflicting figures compared to the findings of this study are due to differences in the minimum criteria for making a diagnosis, sample size and exclusion criteria. As documented recently, clinical tools aimed at measuring peripheral neuropathy in HIV/AIDS have been developed (Cherry et al., 2005; McArthur, 1998; Venkataramana et al., 2005).

According to the findings of the present study, 41.3% of participants with peripheral neuropathy were in the age group of 31-40 years. This is in disagreement with a study that has found increasing age as a predictor of developing peripheral neuropathy (Lopez et al., 2004). Peripheral neuropathy is a recognized side effect of certain antiretroviral therapy and can be caused by advanced HIV disease (Nicholas et al., 2007). The present study did not assess the clinical stages of the HIV infection and under which ARV drugs participants were subjected. Therefore the factors that could influence the presence of peripheral neuropathy were not known.

Individuals with HIV/AIDS experiencing DSPN may present with a number of different complaints. The earliest symptoms of peripheral neuropathy are pain, numbness, and tingling in the hands and feet in the classic "sock and glove" distribution (Delakas, 2001; Simpson & Cikurel, 2006). The results of this study showed that the most symptoms were pain, aching or burning, followed by numbness while the least symptoms were pins and needles. These results are comparable to the findings of McArthur (1998) and Nicholas et al. (2002) studies indicating that these symptoms acceptably identified most people with peripheral neuropathy in HIV/AIDS. A contradictory result was found in a previous study

(Konchalard, Wangphonpattanasiri, 2007) where numbness was the dominant symptom in all patterns of HIV-related neuropathy. Harrison and McArthur (1995) have suggested, the pain and parasthesias could be early phenomena, which as the neuropathy “burns” out, leave numbness as the more prominent symptom.

Severity of peripheral neuropathy in people living with HIV/AIDS can range from mild discomfort to a debilitating condition, robbing a person of the ability to walk or even to stand (Herrmann et al., 2001; Schifitto et al., 2002). In addition, many people with early or mild peripheral neuropathy do not experience any symptoms and, again, the worst symptoms generally occur in people with more advanced immunosuppression (lower CD4 cell counts) (Simpson & Cikurel, 2006). Participants in this study were adults confirmed to have HIV/AIDS infection and receiving HAART. The presence of PN in this sample can result from the direct infection of neurons with human immunodeficiency virus (HIV), opportunistic infection of neurons because of generalized immunosuppression, or from highly active antiretroviral therapy (HAART) (Hurst, 1999; Moyle and Sadler, 1998).

The study indicated that the majority of people living with HIV/AIDS with peripheral neuropathy were in grade 1 compared to grade 2 and grade 3. This indicates that peripheral neuropathy was mild in the majority of people living HIV/AIDS attending out-patients clinics at Rutongo Hospital. This may indicate that the physical health domain of quality of life of those subjects was affected moderately in terms of ability to walk, work, and participate in activities of daily living. Previous studies of quality of life among

persons with HIV have suggested that as the disease progresses, individuals experience more symptoms and more problems with physical function, and role functioning (de Boer, Van Dam & Sprangers, 1995; Franchi & Wenzel, 1998). The physical discomfort and pain resulting from these symptoms may make it difficult to conduct basic daily activities. In addition, among HIV-positive patients, disease progression is related to decreasing energy and increasing difficulties with daily activities and pain (Sousa et al., 1999).

5.4 QUALITY OF LIFE OF PLWHs

Living with HIV/AIDS remains a severe strain for those afflicted, due to a variety of reasons. These include physical and psychological effects of HIV-related symptoms, toxicity of HAART, the hardship of having to adhere to a rigid medication regimen, implications of the HIV-infection for the patient's relationships and sex life, stigmatization and the fear of dying from the illness (Pierret, 2000). This section discusses specific aspects of QoL including physical, psychological, social relationship, environment and contributing factors for the QoL in PLWHs.

5.4.1 Physical health domain

The physical health domain assesses the impact of the disease on the activities of daily living, dependence on medical substances, a lack of energy and initiative, restricted mobility and the capacity to work (Skevington, 2002). In the present study, the mean score fell in intermediate level (12.72) in the physical domain of QoL. As noted in the literature, research has shown that nearly one third of PLWHIV reported problems with

mobility, limitation of usual activity and pain or discomfort (Hughes et al., 2004). These problems might also have contributed to the large number of subjects who rated lower scores in the physical domain of WHOQOL BREF in the present study.

As acknowledged by previous studies physical health quality of life deteriorated with HIV progression (Burgess et al., 1993; Liu et al., 2006), while the side effects of HAART may cause as much physical discomfort as the symptoms of the illness including peripheral neuropathy, nausea, vomiting, anemia, headache, skin rashes, neutropenia, diarrhea, and abdominal discomfort (Maenza & Flexner, 1998).

Moreover, the factors found to have significant affect on the physical health domain was the level of education. In the present study lower scores were seen among subjects who did not attend school compared to those with primary education in the present study. These results support the findings by Dos Santos et al. (2007) where lower scores were seen among subjects who did not attend school or completed middle school education compared to those with higher education. Furthermore, the results of this study observed no significant difference between quality of life domains and different occupations of the respondents. This could have been caused by the homogeneity of the sample regarding occupation where 86.5% of participants were farm workers. In contrast, Wig et al. (2006) reported that skilled workers and business persons had better physical health domain scores as compared to others.

5.4.2 Psychological health domain

The psychological domain accesses the patient's own thoughts about body image and appearance, negative feelings, positive feelings, self-esteem and person beliefs (Skevington, 2002). In addition, after being diagnosed, people confronted with their HIV-positive status are highly stressed and uncertain, despite the availability of HAART (Flowers, Duncan & Knussen, 2003) and their lives may be devastated by the need to deal with the new medical, personal and social situation (Green & Smith, 2004). In the current study the participants had quality of life scores in psychological domain close to the high level (between 15 and 20). This demonstrates that the majority of people living with HIV/AIDS were in the acceptance stage. According to Murphy and Melby (1999), during the acceptance stage people begin to take considerable control over their lives exercising self-determination and autonomy. Needs identified during this stage relate to the need for accurate information, education and knowledge. These results support the results found by Uwimana (2005), where most of the participants in Rwanda had received psychosocial support. This suggests that psychological needs were met to a certain extent. This might also indicate that there is a good service for meeting psychological needs of patients with the HIV disease.

This study further found that the level of education significantly affected the psychological domain of QoL. The observation of significant difference in the psychological domain in relation to the educational level of more than high school possibly suggests better coping attitudes towards disease. Contrary, in this study, beyond having some education, level did not seem to make any difference. According to

Ichikawa and Natpratan (2004) as the education of the patients increases, the better their psychological domains scores. It reflects that education enhances problem solving and active decision making and helps the patient to cope with the dread of the disease better, both emotionally and problem focused (Chesney & Folkman, 1999).

Furthermore, a significant difference was observed with respect to the ages of the participants in the psychological domains ($P=0.028$). Subjects who were less than 30 years had better scores in the psychological domain. This could indicate that young PLWHs are likely to cope with the disease better. Nonetheless, age has been associated with quality of life in a previous study (Piette, Wachtel, Mor, & Mayer, 1995), worse quality of life in the areas of physical and social functioning has been attributed to older age among people living with HIV/AIDS. These findings are similar to those among Zambian men and women with HIV/AIDS that showed younger persons reported more positive feelings, better cognitive functioning, higher self-esteem, more satisfaction with physical appearance and body image, and generally more satisfaction within the psychological domain of quality of life than older persons, confirming some reports in the literature (Mweemba, 2008). Additionally, young people are often diagnosed in an early stage of disease while older individuals are more likely to be diagnosed once experiencing later stages of HIV infection.

5.4.3 The social domain

Social domain assesses personal relationships, social support and sexual activity (Skevington, 2002). The mean score fell in intermediate level (13.39) in the social

relationships domain of QoL in this study, indicating that patients' social contacts and sexual activity were affected obviously to a reasonable extent. This trend seems consistent with the stigmatization of HIV/AIDS in the society. Research indicates that people still hold stigmatization attitudes towards those living with HIV and AIDS (PLWHs) confirms this expectation (Herek, Capitano, & Widaman, 2002).

The factors found to have significant affect on the social domain, were gender and marital status. The presence of significant association on the social domain in this study is in contrast with an earlier study which assessed the impact of HIV/AIDS on the quality of life (Wig et al., 2006), where there was a lack of any significant association on the social domain in relation to demographic variables.

Comparison of mean raw scores of quality of life in men and women showed a statistically significant difference in the social relationships domains with lower scores for women. This is in agreement with a previous study where women with HIV/AIDS had lower quality of life scores as opposed to men despite having less advanced disease (Nirmal, Divya, Dorairaj & Venkateswaran, 2008). Women with HIV/AIDS live longer and are likely to face a chronic disabling condition that is progressive (Hader, Smith, Moore, & Holmberg, 2001). Additionally, women often face more severe discrimination than men if they are known to be HIV-positive, they are more likely to sacrifice their own health for the welfare of their family and postpone treatment or because they have low income or perhaps they drop out of schools early. This can lead to physical abuse and the loss of economic stability if their partners leave them. Moreover, the latter can reflect

stigma and discrimination associated to difficulties to disclose their HIV status in social settings (work, family, and friends) and for comfortable sex life. Furthermore, as the number of women with HIV disease increases, and with no cure in immediate sight, understanding how HIV positive women adapt psychologically and socially has acquired a new importance (Nannis, Patterson, & Semple, 1997). The same authors stated that the psychosocial response of women to HIV infection might have implications for disease progression and quality of life.

Cohabiting subjects had better social domain scores compared to divorced subjects in the present study; this suggests that divorced people living with HIV/AIDS are less able to actively engage in social activities such as visiting with friends or close relatives and less able to perform work-related tasks in job, home, and educational settings. According to Mweemba (2008), marital status influences quality of life; subjects who are married or in relationships, reported a higher level of quality of life for the social relationships domain. Those in relationships may enjoy better social support. Moreover, a number of HIV-infected individuals are in long-term relationships with HIV-infected individuals, from whom they may derive additional stability and support. Those in a long-term relationship also need only disclose their serostatus to one person, their partner, thus alleviating some of the anxiety felt while revealing HIV-positive status.

The variable time elapsed since HIV diagnosis indicated that subjects who knew their HIV status for two to four years, had mean higher scores than those who knew it less than two years in the social relationships domain in the present study. In contrast, Sakthong,

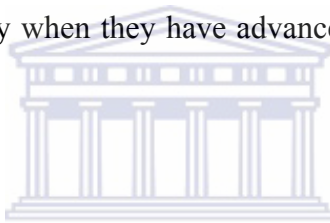
Schommer, Gross, Sakulbumrungsil and Prasithsirkal (2007) found that patients who had been diagnosed with HIV infection for a long time were more likely to have lower psychological domain. Although, the other domains of quality of life were not significantly associated with years since HIV diagnosis in the present study, meaning that there was no difference in domain scores in relation to the duration of disease. This indicates that subjects who knew their HIV status for two to four years may have been living with the illness longer and therefore may have had more time to develop adaptive coping strategies, or they may have had more experience with and more time to adjust to their medication regimes, which may have resulted in them feeling better. Based on the findings of this study, this suggests that the development of strategies to increase the self-esteem of HIV positive individuals and support them to protect their own health by avoiding new sexual transmissible infection is the most important, in order to meet the particular needs and concerns of new infected in immediately time following an HIV diagnosis.

5.4.4 Environmental domain

Environmental domain assesses influences of factors like financial resources, the work environment, accessibility to health and social care, freedom, security and participation and opportunities for leisure activities on the QoL. In this study the environmental domain had the minimum QoL score (12.57) of the four QoL domains. The number of items that contributed to the deterioration of the environmental domain includes the lack of information regarding a number of issues like protective measures for transmission of the HIV infection, the progression of the disease and ARV therapy. Lack of money to

meet the needs and transportation were identified as other contributory factors. Similar results were obtained in a previous study that assessed the impact of HIV/AIDS on quality of life (Wig et al., 2006).

The findings were not surprising as the research setting was situated in rural areas. Additionally, the road network and communication facilities of the rural hospitals are poor. These factors have contributed to the fact that only a few health facilities have adequate trained personnel to distribute antiretroviral therapy to HIV positive persons. The long distances to health centers and lack of transport have contributed to people seeking health care late, usually when they have advanced HIV disease (Phalazde et al., 2005).



The level of education significantly affected the environmental domain of QoL in PLWHs in this study. Lower scores were seen among subjects who did not attend schools compared to those with primary, secondary and university education. These results confirm the findings of previous studies (Holmes et al., 1997; Eriksson, et al., 2000), where the level of education was associated with quality of life of PLWHs. These findings support those reported by O'Connell, Skevington and Saxena, (2003) who found a large difference for the environment domain by education level.

In earlier study on the impact of HIV/AIDS on the quality of life, family support and occupation significantly affected the environmental domain of quality of life in PLWHs (Wig et al., 2006). The same authors stated that the effect of family support on the

environmental domain was a significant observation. They further urged that family is usually the most important component of the immediate environment of the patient. Also the family of the patient can be a major support, in terms of not only financial support, but also safety and security while a good and supportive home environment can help a patient feel better. In the same study, skilled workers and business persons had better scores in environment domain scores. Therefore, improving the all round environment surrounding of HIV infected individuals, will lead to a better quality of life.

5.5 LIMITATIONS OF STUDY

There are a number of limitations to this study:

- No medical investigations or assessment tools for identifying peripheral neuropathy were used. Therefore, peripheral neuropathy and quality of life were based on self-report.
- In the present study, the critical indicators of disease progression, such as CD4 count and viral load, were not assessed. Thus conclusions could not be made as to the relationship between the progression of the HIV infection and peripheral neuropathy as well as quality of life.
- This study is limited by being a cross-sectional assessment, which limits contributory assumptions about the ways in which peripheral neuropathy might affect physical health, psychological and social relationship domains of adults PLWHs at Rutongo Hospital.
- The study population was not a random sample of people living with HIV/AIDS in Rulindo District. The participants were those who were actively seeking routine medical care. Those who did not schedule or keep regular clinic visits were not included and

consequently, the results of this study might not be generalized to all HIV patients in Rulindo District.

5.6 SUMMARY

The discussion dealt with the major findings of the study. Similarities with other studies were found with regard to the prevalence of peripheral neuropathy and quality of life of people living with HIV/AIDS. The summary of the study, conclusion and recommendations based on the findings will be explained in the next chapter.



CHAPTER SIX

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

6.1 SUMMARY

The aim of the study was to determine the prevalence of peripheral neuropathy amongst and the quality of life of adults living with HIV/AIDS in Rulindo District in Rwanda.

Out of 185 adult people living with HIV/AIDS who have completed the subjective peripheral neuropathy screen (SPNS) at Rutongo hospital, 75 (40.5%) reported at least one of the six symptoms of peripheral neuropathy. Out of 75 (40.5%) participants who reported symptoms at the time of data collection, 44 (58.7%) were in grade 1 whereas 10 (13.3%) were in grade 2 and 21 (28%) in grade 3. While they had quality of life scores in the physical health, psychological, social relationship and environmental domains fell in intermediate level (between 10 and 14.9). The mean score of domains was highest for the psychological health (14.81), followed by social domain (13.39), then physical domain (12.72), and lowest for environmental domain (12.57). Additionally, this study found that education significantly affected physical health domain scores. Age and education influence psychological domain scores. Gender, marital status, education and time elapsed since HIV diagnosis significantly affected social domain. The level of education significantly affected the environmental domain of quality of life. The findings suggest that the assessment of both peripheral neuropathy and quality of life be included in the intervention programmes designed for people living with HIV/Aids.

6.2 CONCLUSION

A total of 75 (40.5 %) out 185 adults PLWHs attending out-patients clinic at Rutongo Hospital in Rulindo District in Rwanda experienced peripheral neuropathy in varying grades. These findings confirm that peripheral neuropathy remains a prevalent problem among PLWHs. Those PLWHs who are experiencing peripheral neuropathy symptoms should work closely with their medical providers to find the combination of medical treatment and supportive therapies that works best for them. Additionally, the assessment of QoL is now acknowledged as a central component of health care and healthcare research. In the present study, PLWHs had quality of life scores in the physical health, psychological, social relationship and environmental domains which fell in intermediate level; physical and environment domains are the ones which are most impaired in people living with HIV/AIDS attending out-patient clinic at Rutongo Hospital. With regard to the environmental domain, it is impossible to know how much of the environmental problems experienced are due to HIV or due to living in an impoverished area, a comparison with WHOQOL Bref scores for the general population would have been very useful. The study findings also demonstrate that socio-demographic characteristics such as age, education, marital status and gender influence quality of life of adults PLWHS. Therefore, the results could allow health care providers to screen these factors so that they can intervene to improve quality of life and better care.

6.3 SIGNIFICANCE OF THE STUDY

The results from this study will contribute to the knowledge of the prevalence and severity of peripheral neuropathy among adults living with HIV/AIDS and its relationship on quality of life. In addition, the results could be used in Rwanda by health care providers to design programmes that manage the peripheral neuropathy that could negatively affect the quality of life of adults living with HIV/AIDS. Physiotherapists should be encouraged to screen PLHWs who are referred to them using a basic tool such as the SPNS. If necessary they would then be able to include the treatment of peripheral neuropathy when managing these patients.

6.4 RECOMMENDATIONS

Based on the results of the study, the following recommendations for managing peripheral neuropathy and for improving quality of life were made:

- The prevalence of peripheral neuropathy was high in adults PLWHs attending out-patients clinic at Rutongo hospital. Healthcare providers should assess for this common problem so that appropriate intervention and follow up can be offered to patients as this condition can impair functional ability and limit physical activity.
- Future studies are warranted with regard to the impact of improved peripheral management on people living with HIV/AIDS and their quality of life.
- While quality of life may change in the fullness of time, a longitudinal study could demonstrate better the relationships between effects of the disease progression and impact of PN on quality of life domains.

- Furthermore, it is essential that initial and ongoing assessment address symptom management to improve the individual's quality of life.
- Thus, future research should attempt to address gender issues in relation to quality of life of HIV- infected individuals as identification of gender issues may assist in the design of gender -specific interventions to improve quality of life.



REFERENCES

Adewuya, A., Afolabi, M.O., Ola, B.A., Ogundele, O.A., Ajibare, A.O., & Oladipo, B.F., et al. (2008). Relationship between depression and quality of life in persons with HIV infection in Nigeria. *MedicineInternational Journal of Psychiatry in Medicine*, 38, 43-51.

Agnoletto, V., Chiaffarino, F., Nasta, P., Rossi, R., & Parazzini, F. (2003). Reasons for complementary therapies and characteristics of use among HIV-infected people. *International Journal of STD and AIDS*, 14, 482-486.

Alonzo, A. A., & Reynolds, N. R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science Medicine*, 41, 303-315.

Armstrong, T. (2000). Peripheral neuropathy: Causes, assessment and diagnostic work-up. Symposium conducted at the meeting of the ONS Foundation, symptom management: Peripheral neuropathy, Dallas, TX.

Auer-Grumbach, M., Mauko, B., Auer-Grumbach, P., & Pieber, T.R. (2006). Molecular genetics in sensory neuropathies. *Neuromolecular Medicine*, 8, 147-158.

Aversa, S., Kimberlin, C.L. & Segal, R. (1998). The Medication Attribution Scale: Perceived effects of antiretrovirals and quality of life. *Quality of Life Research*, 7,205-214.

Backonja, M. (2002). Use of anticonvulsants for treatment of neuropathic pain. *Neurology*, 59, S14-S17.

Badia, X., Podzamezer, D., Casado, A., Lopez-Lavid, C. C., & Garcia, M. (2000). Evaluating changes in health status in HIV-infected patients: Medical outcomes study HIV and multidimensional quality of life-HIV quality of life questionnaires. *AIDS*, 14(10), 1439-1447.

Balnavaz, M., & Caputi, P. (2001). Introduction to quantitative research method. An investigative approach. London. Sage Publications.

Bastardo, Y.M., & Kimberlin, C.L. (2000). Relationship between quality of life, social support and disease-related factors in HIV-infected persons in Venezuela. *AIDS Care*, 12,673-684.

Benbow, S.J., Wallmahmed, M.E., & Mcfarlane, I.A. (1998). Diabetic peripheral neuropathy and quality of life. *Quarterly Journal of Medicine*, 91,733-737.

Blalock, A.C., McDaniel, J.S., & Farber, E.W. (2002). Effect of employment on quality of life and psychological functioning in patients with HIV/AIDS. *Psychosomatics*, 43, 400-404.

Blum, A.S., Dal Pan, G.J., Feinberg, J., Raines, C., Mayjo, K., & Cornblath, D.R. (1996). Low-dose zalcitabine-related toxic neuropathy: frequency, natural history, and risk factors. *Neurology*, *46*(4), 999-1003.

Bormann, J., Shively, M., Smith, T.L., & Gifford, A. L. (2001). Measurement of fatigue in HIV-positive adults: reliability and validity of the Global Fatigue Index. *Journal of the Association of Nurses in AIDS Care*, *12*, 75-83.

Brashers, D. E., Neidig, J. L., Cardillo, L. W., Dobbs, L. K., Russell, J. A., & Haas, S. M. (1999). "In an important way I did die": Uncertainty and revival in persons living with HIV or AIDS. *Journal of the Association of Nurses in AIDS Care*, *11*(2), 201-219.

Breitbart, W. & Dibiase, L. (2002). Current perspectives on pain in AIDS, *Oncology*, *16*, 964-972.

Brimbow, D.L., Cook, J.S., & Seaton, R. (2003). Stigma and HIV/AIDS: Stigma and HIV/AIDS: A review of the literature. Retrieved September 15, 2005, from <http://hab.hrsa.gov/publications/stigma/front.htm>.

Brooks, R. A., & Klosinski, L. E. (1999). Assisting persons living with HIV/AIDS to return to work: Programmatic steps for AIDS service organizations. *AIDS education and prevention*, *11* (3), 212-223.

Bullinger, M., & Von Mackensen, S. (2004). Assessment of quality of life outcomes. *Haemophilia*, 10 (Suppl.1), 9-16.

Burgess, A., Dayer, M., Catalan, J., Hawkins, D. & Gazzard, B. (1993). The reliability and validity of two HIV-Specific health-related Quality of Life measures: A preliminary Analysis. *AIDS*, 7(7), 1001-1008.

Burgoyne, R.W., & Saunders, D.S. (2001). Quality of life among urban Canadian HIV/AIDS clinic outpatients. *International Journal of STD and AIDS*, 12, 505-512.

Calderon, R. (1997). The HIV/AIDS Multidimensional Model, AIDSCAP, Arlington 48.

Casado, A. (2005). Measurement of quality of life of HIV individuals: Perspective and future directions. *Indian Journal of Medical Research*, 112, 282-284.

Cella, D.F. & Tulsky, D.S. (1990). Measuring Quality of Life Today: Methodological Aspect. *Oncology*, 4(5), 29-38.

Cherry, C.L., Wesselingh, S.L., Lal, L., & McArthur, J.C. (2005). Evaluation of a clinical screening tool for HIV-associated sensory neuropathies. *Neurology*, 65, 1778-1781.

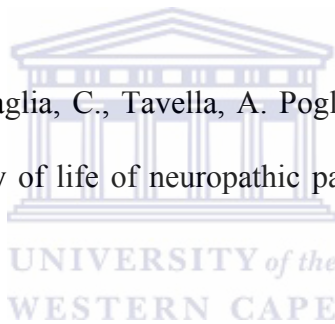
Chesney, M.A. & Folkman, S. (1994). Psychological impact of HIV disease and implications for intervention. *Psychiatric Clinics of North America*, 17, 163-182.

Chesney, M.A., & Folkman, S. (1999). Sexually transmitted diseases. 3rd ed, Ch72, 987-92.

Chin, J. (2007). The AIDS Pandemic: the collision of epidemiology with political correctness. Oxford: Radcliffe Publishing.

Cleary, P.D., Fowler, F.J., Weissman, J., Massagli, M.P., Wilson, I., & Seage, G.R., et al. (1993). Health-related quality of life in persons with acquired immune deficiency syndrome. *Medical care*, 31 (7), 569-580.

Cocito, D., Paolasso, L., Pazzaglia, C., Tavella, A. Poglio, F., & Ciaramitaro, P., et al. (2006). Pain affects the quality of life of neuropathic patients. *Journal of Neurological Sciences*, 27, 155–160.



Cohen, C., Revicki, D. A., Nabulsi, A., Sarocco, P. W., Jiang, P. & Advanced HIV Disease Ritonavir Study Group (1998). A randomized trial of the effect of ritonavir in maintaining quality of life in advanced HIV disease. *AIDS*, 12 (12),1495-1502.

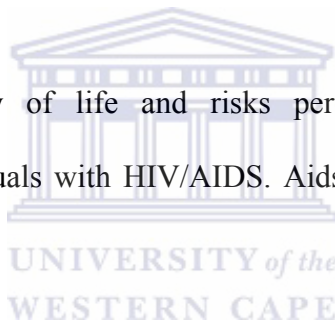
Crystal, S., Fleishman, J.A., Hays, R.D., Shapiro, M.F., & Bozzette, S.A. (2000). Physical and role functioning among persons with HIV: results from a nationally representative survey. *Medical Care*, 38,1210-1223

Cornblath, D.R., & McArthur, J.C. (1988). Predominantly sensory neuropathy in patients with AIDS and AIDS-related complex. *Neurology*, 38, 794-796.

De Boer, J.B., van Dam F.S., & Sprangers, M.A. (1995). Health-related quality-of-life evaluation in HIV-infected patients. A review of the literature. *Pharmacoeconomics*, 8(4), 291-304.

Delakas, M. C. (2001). Peripheral neuropathy and antiretroviral drugs. *Journal of the Peripheral Nervous System*, 6, 14-20.

Demmer, C. (2001). Quality of life and risks perception among predominantly heterosexual, minority individuals with HIV/AIDS. *Aids patient care and STDs*, 15(9), 481-489.



Dieterich, D. T. (2003). Long-term complications of nucleoside reverse transcriptase inhibitor therapy. *AIDS Reader*, 13, 176- 184.

Dorsey, S. G., & Morton, P. G. (2006). HIV peripheral neuropathy: Pathophysiology and clinical implications. *AACN Clinical Issues*, 17, 30-36.

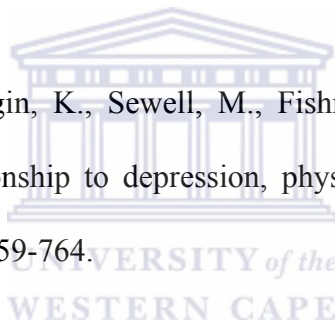
dos Santos, E.C.M., Junior, I.F., & Lopes, F. (2007). Quality of life of people living with HIV/AIDS in Sao Paulo, Brazil. *Rev Saude Publica*, 41(Supl.2),1-7.

Eriksson, L.E., Nordstrom G., Berglund, T., & Sandstrom, E. (2000). The health related quality of life in a Swedish sample of HIV-infected person. *Journal of Advanced Nursing*, 32(5), 1213-1223.

Fan, H.Y., Conner, R.F., & Villareal, L.P. (2004). *AIDS science and society*. 4th ed. Boston: Jones and Bartlett Publishers.

Farinpour, R., Miller, E.N., & Satz, P. (2003). Psychosocial risk factors of HIV morbidity and mortality: Findings from the Multicenter AIDS Cohort Study (MACS). *Journal of Clinical and Experimental Neuropsychology*, 25, 654-670.

Ferrando, S., Evans, S., Goggin, K., Sewell, M., Fishman, B., & Rabkin, J. (1998). Fatigue in HIV illness: relationship to depression, physical limitations, and disability. *Psychosomatic Medicine*, 60, 759-764.



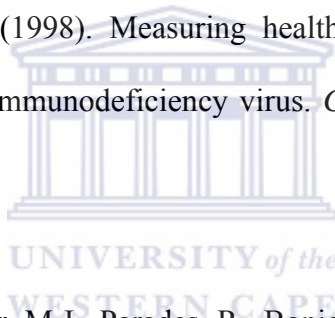
Ferrari, S., Vento, S., Monaco, S., Cavallaro, T., Cainelli, F., & Rizzuto, N. et al. (2006). Human immunodeficiency virus– associated peripheral neuropathies. *Mayo Clinic Proceedings*, 81, 213-219.

Figg, W.D. (1991). Peripheral neuropathy in HIV patients after isoniazid therapy. *Annals of Pharmacotherapy*, 25(1), 100-101.

Fleishman, J.A., Sherbourne, C.D., Crystal, S., Collins, R.L., Marshall, G.N., & Kelly, M., et al. (2000). Coping, conflictual social interactions, social support, and mood among HIV-infected persons. *American Journal of Community Psychology*, 28, 421- 453.

Flowers, P., Duncan, B., & Knussen, C. (2003). Re-appraising HIV testing: an exploration of the psychosocial costs and benefits associated with learning one's HIV status in a purposive sample of Scottish gay men. *British Journal of Health Psychology*, 8,179-194.

Franchi, D. & Wenzel, R.P. (1998). Measuring health-related quality of life among patients infected with human immunodeficiency virus. *Clinical Infectious Diseases*, 26, 20-26.



Fumaz, C.R., Tuldra, A., Ferrer, M.J., Parades, R., Bonjoch, A., & Jou, T., et al. (2002). Quality of life, emotional status, and adherence of HIV-1 infected patients treated with efavirenz versus protease inhibitor-containing regimens. *Journal Acquired Immune Deficiency Syndrome*, 29 (3), 244-253.

Furth, R., Gass, R., & Kagubare, J. (2006). Rwanda Human Resources Assessment for HIV/AIDS scale-up. Summary Report. *Operations Research Results*. Published for the U.S. Agency for International Development by the Quality Assurance Project.

Gale, J. (2003). Physiotherapy intervention in two people with HIV or AIDS-related peripheral neuropathy: Case report. *Physiotherapy Research International*, 8(4), 200-209.

Galer, B.S., Gianas, A., Jensen, M.P. (2000). Painful diabetic polyneuropathy: epidemiology, pain description and quality of life. *Diabetes Research and Clinical Practice*, 47,123-128.

Gill, C.J., Griffith, J.L., Jacobson, D., Skinner, S., Gorbach, S.L., & Wilson, I.B. (2002). Relationship of HIV viral loads, CD4 counts, and HAART use to health-related quality of life. *Journal of Acquired Immune Deficiency Syndrome*, 30 (5), 485-492.

Globe, D.R., Hays, R.D., Cunningham, W.E. (1999). Association of clinical parameters with health related quality of life in hospitalised persons with HIV disease. *AIDS Care*, 11,71-86.

Government of Rwanda and William John Clinton Foundation (2003). Five years HIV/Aids treatment and care plan (2003-2007). [Online] Available:<http://www.google.com> [4/15/07].

Green, G., & Smith, R. (2004). The psychosocial and health care needs of HIV-positive people in the United Kingdom: a review. *HIV Medicine*, 5(Suppl. 1), 5-46.

Griffin, K.W., Rabkin, J.G., Remien, R.H., Williams, J.B. (1998). Disease severity, physical limitations and depression in HIV- infected men. *Journal of Psychosomatic Research*, 44(2), 219-227.

Griswold, G.A., Evans, S., Spielman, L., & Fishman B. (2005). Coping strategies of HIV patients with peripheral neuropathy. *AIDS Care*, 17(6), 711-720.

Hader, S., Smith, D., Moore, J., & Holmberg, S. (2001). HIV infection in women in the United States: Status at the Millennium. *Journal of American Medical Association*, 285, 1186-1192.

Hakuzimana, A. (2005). *Quality of life assessment in adults with HIV infection in the treatment and research aids center (TRAC) HIV Clinic of Kigali: A cross-sectional study*. Unpublished. Thesis. National University of Rwanda, Kigali, Rwanda.

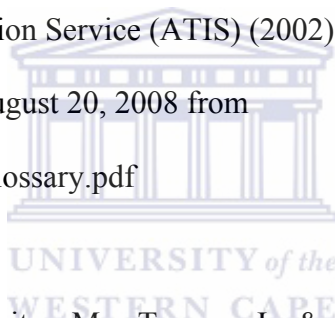
Harrison, M.J.G. & McArthur, J.C. (1995). *AIDS and neurology*. Edinburgh: Churchill Livingstone.

Heckman, T.G., Somlai, A.M., Sikkema, K.J., Kelly, J.A., & Franzoi, S.L. (1997). Psychosocial predictors of life satisfaction among persons living with HIV infection and AIDS. *Journal of Association Nursing in AIDS Care*, 8, 21-30.

Herek, G., Capitano, J.P., & Widaman, K.F. (2002). HIV-related knowledge in the United States: Prevalence and trends, 1991-1999. *American Journal of Public Health, 92*, 371-377.

Herrmann, D., DeMarcaida, J., Akowah, K. (2001). Epidermal nerve fiber density, quantitative sensory testing, and virologic and immunologic measures as predictors of symptomatic HIV associated distal symmetrical polyneuropathy. *Annals Neurology, 50* (Suppl.1), S 33.

HIV/AIDS Treatment Information Service (ATIS) (2002). Glossary of HIV/AIDS-related terms, 4th Edition. Retrieved August 20, 2008 from <http://www.hiv.gov.gy/edocs/glossary.pdf>



Holmes, W.C., Bix, B., Meritz, M., Turner, J. & Hutelmyer, C. (1997). Human immunodeficiency virus (HIV) infection and quality of life: the potential impact of Axis I psychiatric disorders in a sample of 95 HIV seropositive men. *Psychosomatic Medicine, 59*, 187-192.

Hughes, J., Jelsma, J., Maclean, E., Darder, M., & Tinise, X. (2004). The health-related quality of life of people living with HIV/AIDS. *Disability and Rehabilitation, 26*, 371-376.

Hurst, M. (1999). Stavudine: An update of its use in the treatment of HIV infection. *Drugs*, 58, 919-949.

Ichikawa, M., & Natpratan, C. (2004). Quality of life among people living with HIV/AIDS in northern Thailand: MOS-HIV health survey. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*, 13(3), 601-610.

Janssen, R.S. (1997). Epidemiology and neuroepidemiology of human immunodeficiency virus infection. In: Berger JR, Levy RM, eds. *AIDS and the nervous system, 2nd ed.* Philadelphia: Lippincott-Raven 1997,13-37.

Jelsma, J., Maclean, E., Hughes, J., Tinise, X., & Darder, M. (2005). An investigation into the health-related quality of life of individuals living with HIV who are receiving HAART. *AIDS Care*, 17, 579-588.

John, M.E., Ndebbio, T.J., & Udoma, E.J. (2003). Perceived psychosocial needs, social support and quality of life in subjects with HIV/AIDS. *Global Journal of Medical Sciences*, 2 (2), 171-175.

Kayirangwa, E., Hanson, J., Munyakazi, L. & Kabeja, A. (2006). Current trends in Rwanda's HIV/AIDS epidemic. *Sexually Transmitted Infections*, 82, 27-31.

Kemppainen, J. K. (2001). Predictors of quality of life in AIDS patients. *JANAC: Journal of the Association of Nurses in AIDS Care*, 12(1), 61-70.

Keswani, S.C., Pardo, C.A., Cherry, C.L., Hoke, A., & McArthur, J.C. (2002). HIV-associated sensory neuropathies. *AIDS*, 16(16), 2105-2117.

Kohli, R.M., Sane, S., Kumar, K., Paranjape, R.S., & Mehendale, S.M. (2005). Modification of medical outcome study (MOS) instrument for QOL assessment and its validation in HIV infected individuals in India. *Indian Journal of Medical Research*, 122, 297-304.

Konchalar, K. & Wangphonpattanasiri, K. (2007). Clinical and Electrophysiologic Evaluation of Peripheral Neuropathy in a Group of HIV-Infected Patients in Thailand. *Journal of the Medical Association of Thailand*, 90 (4), 774-81.

Lichtenstein, K.A., Armon, C., Baron, A., Moorman, A.C., Wood, K.C., & Holmberg, S.D. (2005). HIV Outpatient Study Investigators. Modification of the incidence of drug associated symmetrical peripheral neuropathy by host and disease factors in the HIV outpatient study cohort. *Lichtenstein Clinical Infection Disease*, 40,148-157.

Liu, C., Ostrow, D., Detels, R., Hu, Z., Johnson, L., & Kingsley, L., et al. (2006). Impacts of HIV infection and HAART use on quality of life. *Quality of Life Research*, 15, 941-949.

Lopez, O.L., Becker, J.T., Dew, M.A., & Caldararo, R. (2004). Risks modifiers for peripheral sensory neuropathy in HIV infection/AIDS. *European Journal of Neurology*, 11, 97-102.

Lubeck, D.P., & Fries, J.F. (1997). Assessment of quality of life in early stage HIV-infected persons: data from the AIDS time-oriented health outcome studies. *Quality of Life Research*, 6, 494-506.

Maenza, J. & Flexner, C. (1998). Combination antiretroviral therapy for HIV infection. *American Family Physician*, 57 (11), 2789-98.

Manji, H., & Miller, R. (2004). The neurology of HIV infection. *Journal of Neurology, Neurosurgery and Psychiatry*, 75(1), 29-35.

Maschke, M., Kastrup, O., Esser, S., Ross, B., Hengge, U., & Hufnagel, A. (2000). Incidence and prevalence of neurological disorders associated with HIV since the introduction of highly active antiretroviral therapy (HAART). *Journal of Neurology, Neurosurgery and Psychiatry*, 69 (3), 376-380.

Mbuya, S.O., Kwasa, T. O., Amayo, E.O., Kioy, P.G., & Bhatt, S. M. (1996). Peripheral neuropathy in AID'S patients at Kenyatta national hospital. *East African medical journal*, 73 (8), 538-540.

McArthur, J., Cohen, B & Selnes, O. (1989). Low prevalence of neurological and neuropsychological abnormalities in otherwise healthy HIV1-infected individuals: results from the Multicenter AIDS cohort study. *Annals of Neurology* 26, 601-611.

McArthur, J.H. (1998). The reliability and validity of the subjective peripheral neuropathy screen. *Journal of the Association of Nurses in AIDS Care*, 9(4), 84-94.

Mertens, M.D., & McLaughlin, A.J. (2004). *Research and evaluation methods in special education*. Thousand Oaks, California. Corwin Press.

Ministry of Health, Government of the Republic of Rwanda. Health Indicators: HIV/AIDS and other epidemics. [Online]. http://www.moh.gov.rw/health_indicator.html. Accessed June 3, 2007

Molassiotis, A., Callaghan, P., Twinn, S.F. & Lam, S.W. (2001). Correlates of quality of life in symptomatic HIV patients living in Hong Kong. *AIDS Care*, 13(3), 319-334.

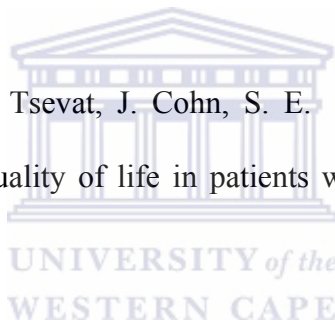
Morgello, S., Estanislao, L., Simpson, D., Geraci, A., DiRocco, A., & Gerits, P., et al. (2004). HIV-associated distal sensory polyneuropathy in the era of highly active antiretroviral therapy: The Manhattan HIV Brain Bank. *Archives of Neurology*, 20(61), 546-551.

Moore, R.D., Wong, W.M., Keruly, J.C., & McArthur, J.C. (2000). Incidence of neuropathy in HIV-infected patients on monotherapy versus those on combination therapy with didanosine, stavudine and hydroxyurea. *AIDS, 14*, 273-278.

Moyle, G.J., & Gazzard, B.G. (1999). A risk-benefit assessment of HIV protease inhibitors. *Drug Safety, 20*, 299-321.

Moyle, G.J., & Sadler, M. (1998). Peripheral neuropathy with nucleoside antiretrovirals: risk factors, incidence and management. *Drug Safety, 19*, 481-494.

Mrus, J. M., Williams, P. L., Tsevat, J. Cohn, S. E. & Wu, A. W. (2005). Gender differences in health-related quality of life in patients with HIV/AIDS. *Quality of Life Research, 14*, 479-491.



Murphy, M., & Melby, V. (1999). Psychological needs of patients with HIV disease: reviewing the literature using Nicholas' (1985) Adjustment Reaction Modal as a framework. *Journal Psychiatric and Mental Health Nursing, 6*, 101-106.

Mweemba, P. (2008). *Quality of life among rural and urban Zambian men and women with HIV/AIDS*. Unpublished. Dissertation. Kent State University, Zambia.

Nannis, E., Patterson, T., & Semple, S. (1997). Coping with HIV disease among seropositive women: psychosocial correlates. *Women and Health, 25*(1), 1-22.

National Institute of statistics of Rwanda (NISR) (2007). Republic of Rwanda Millennium Development Goals: towards sustainable social and economic growth. Country report 2007.

Nicholas, P. K., Kemppainen, J. K., Holzemer, W. L., Nokes, K. M., Eller, L. S., & Corless, I. B., et al. (2002). Self-care management for neuropathy in HIV disease, *AIDS Care, 14*, 763-771.

Nicholas, P.K., Mauceri, L., Slate Ciampa, A., Corless, I.B., Raymond, N., & Barry, D.J., et al. (2007). Distal sensory polyneuropathy in the context of HIV/AIDS. *Journal of the Association of Nurses in AIDS Care, 18(4)*, 32-40.

Nicholas, P.K., Kemppainen, J.K., Canaval, G.E., Corless, I.B., Sefcik, E.F., & Nokes, K.M., et al. (2007). Symptom management and self-care for peripheral neuropathy in HIV/AIDS. *AIDS Care, 19(2)*, 179-189.

Nieuwker, P.T., Gisolf, E.H., Colebunders, R., Wu, A.W., Danner, S.A., & Sprangers, M.A. (2000). Quality of life in asymptomatic and symptomatic HIV infected patients in a trial of ritonavir/saquinavir therapy. The Prometheus Study Group. *AIDS, 14 (2)*, 181-187.

Nirmal, B., Divya, K.R., Dorairaj, V.S., & Woran, K.V. (2008). Quality of life in HIV/AIDS patients: A cross-sectional study in South India. *Indian Journal of Sexually Transmitted Diseases*, 29, 15-7.

O'Connell, K., Skevington, S., & Saxena, S. (2003). Preliminary development of the World Health Organization's Quality of Life HIV Instrument (WHOQOL-HIV): analysis of the pilot version. *Social Science Medicine*, 57, 1259-75.

Pallela, F.J., Delaney, K.M., Moorman, A.C., Loveless, M.O., Fuhrer, J., & Satten, G.A., et al. (1998). Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. *The New England Journal of Medicine*, 338, 853-860.

Pandya, R., Krentz, H.B., Gill, M.J., & Power, C. (2005). HIV-related neurological syndromes reduce health-related quality of life. *Canadian Journal of Neurological Sciences*, 32, 201-204.

Pardo, C. A., McArthur, J. C., Griffin, J. W. (2001). HIV neuropathy: Insights in the pathology of HIV peripheral nerve disease. *Journal of the Peripheral Nervous System*, 6, 21-27.

Parsons, T.D., Braaten, A.J., Hall, C.D., & Robertson, K.R. (2006). Better Quality of Life with Neuropsychological Improvement on HAART. *Health and Quality of Life Outcome*, 4(11),1-7.

Pascuzzi, R.M. (2003). Peripheral neuropathies in clinical practice. *Medical Clinics of North America*, 87, 697-724.

Patrick, D.L., & Eriksson, P. (1993). *Health Status and Health Policy: Quality of Life in Health Care Evaluation and Resource Allocation*. New York: Oxford University Press.

Parry, O., Mielke, J., Latif, A.S., Rays, S., Levy, L.F., & Sizya, S. (1999). Peripheral neuropathy in individuals with HIV infection in Zimbabwe. *Acta neurologica scandinavica*, 96, 218-222.

Phaladze, N.A., Human, S., Dlamini, S.B., Hulela, E.B., Hadebe, I.M., & Sukati, N.A., et al. (2005). Quality of Life and the Concept of “Living Well “With HIV/AIDS in Sub-Saharan Africa. *Journal of Nursing Scholarship*, 37(2), 120-126.

Phillips, K. D., Skelton, W. D., & Hand, G. A. (2004). Effect of acupuncture administered in a group setting on pain and subjective peripheral neuropathy in persons with human immunodeficiency virus disease. *Journal of Alternative and Complementary Medicine*, 10, 449-455.

Pierret, J. (2000). Every day life with AIDS/HIV: Survey in the social sciences. *Social Sciences in Medicine*, 50, 1589-1598.

Piette, J., Wachtel, T.J., Mor, V., & Mayer, K. (1995). The impact of age on the quality of life in persons with HIV infection. *Journal of Aging and Health, 7*, 163-178.

Remien, R. H., Halkitis, P. N., O'Leary, A., Wolitski, R. J., & Gomez, C. A. (2005). Risk perception and sexual risk behaviors among HIV-positive men on antiretroviral therapy. *AIDS and Behavior, 9*(2), 167–176.

Revicki, D. A., Sorenson, S., Wu, A. W. (1998). Reliability and validity of physical and mental health summary scores from the medical outcomes study HIV health survey. *Medical Care, 36*(2), 126-137.

Rosenfeld, B., Breitbart, W., McDonald, M.V, Passik, S.D, Thaler, H., & Portenoy, R.K. (1996). Pain in ambulatory AIDS patients. II: Impact of pain on psychological functioning and quality of life. *Pain, 68*(2), 323-328.

Rusch, M., Nixon, S., Schilder, A., Braitstein, P., Chan, K., & Hogg, R.S. (2004). Impairments, activity limitations and participation restrictions: Prevalence and associations among persons living with HIV/AIDS in British Columbia. *Health and Quality of Life Outcomes, 2*(46), 1477-752.

Sacktor, N. (2002). The epidemiology of human immunodeficiency virus associated neurological disease in the era of highly active antiretroviral therapy. *Journal of NeuroVirology, 8* (Suppl 2), 115–121.

Schag, C. A. C., Ganz, P. A., Kahn, B., Petersen, L. (1992). Assessing the needs and quality of life of patients with HIV infection: development of the HIV overview of problems-evaluation system (HOPES). *Quality of Life Research*, 1, 397-413.

Sakthong, P., Schommer, J.C., Gross, C.R., Sakulbumrungsil, R., & Prasithsirkal, W. (2007). Psychometric Properties of WHOQOL BREF-TAI in patients with HIV/AIDS. *J Med Ass Tai*, 90 (11), 2499-2460.

Sarna, L., van Servellen, G., Padilla, G., & Brecht, M. (1999). Quality of life in women with symptomatic HIV/AIDS. *Journal of Advanced Nursing*, 30(3), 597-605.

Schifitto, G., McDermott, M. P., McArthur, J. C., Marder, K., Sacktor, N., & Epstein, L., et al. (2002). Incidence of and risk factors for HIV-associated distal sensory polyneuropathy. *Neurology*, 58, 1764-1768.

Schifitto, G., McDermott, M. P., McArthur, J. C., Marder, K., Sacktor, N., & McClernon, D. R., et al. (2005). Markers of immune activation and viral load in HIV associated sensory neuropathy. *Neurology*, 64, 842-848.

Sherbourne, C.D., Hays, R.D., Fleishman, J.A., Vitiello, B., Magruder, K.M., & Bing E.G., et al. (2000). Impact of psychiatric conditions on health-related quality of life in persons with HIV infection. *American Journal of Psychiatry*, 157, 248-254.

Simpson, D.M., Tagliati, M. (1995). Nucleoside analogue-associated peripheral neuropathy in human immunodeficiency virus infection, *Journal Acquired Deficiency Syndrome Human Retrovirology*, 9, 153-161.

Simpson, D. M., Olney, R., McArthur, J. C., Khan, A., Godold, J., & Ebel-Frommer, K. (2000). A placebo-controlled trial of lamotrigine for painful HIV-associated neuropathy. *Neurology*, 54, 2115-2119.

Simpson, D. M., McArthur, J. C., Olney, R., Clifford, D., So, Y., Ross, D., et al. (2003). Lamotrigine for HIV-associated painful sensory neuropathies. *Neurology*, 60, 1508-1514.

Simpson, D. M., & Cikurel, K. (2006). Neurologic and psychiatric adverse effects of antiretroviral agents. In *Neurologic aspects of effects of antiretroviral agents*. In *Neurologic aspects of HIV/AIDS: New insights and management advances*. Retrieved August 28, 2006, from <http://www.clinicaloptions.com/neuroaids>

Simpson, D. M., Kitch D., Evans, S. R., McArthur, J. C., Asmuth, D. M., & Cohen, B., et al. (2006). HIV neuropathy natural history cohort study: assessment measures and risk factors. *Neurology*, 66 1679-1687.

Skevington, S.M. (2002). Advancing cross-cultural research on quality of life. Observations drawn from WHOQOL development. *Quality of life Research*, 11, 135-144.

Skopelitis, E. E., Kikotis, P. I., Kontos, A. N., Panayiotakopoulos, G. D., Konstantinou, K., & Kordossis, T., et al. (2006). Distal sensory polyneuropathy in HIV-positive patients in the HAART era: An entity underestimated by clinical examination. *International Journal of STD & AIDS*, *17*, 467-472.

Smith, K. W., Avis, E. N., Mayer, K. H., Swislow, L. (1997). Use of the MQoL-HIV with asymptomatic HIV-positive patients. *Quality of Life Research*, *6*, 555-560.

Snider, W.D., Simpson, D.M., Nielsen, S., Gold, J.W., Metroca, C.E., Posner, J.B. (1983). Neurological complications of immune deficiency syndrome: analysis of 50 patients. *Annals of Neurology*, *14*, 403-418.

So, Y., Holtzman, D., Abrams, D., & Olney, R. (1988). Peripheral neuropathy associated with acquired immunodeficiency syndrome prevalence and clinical features from a population-based survey. *Archives of Neurology*, *45*, 945–948.

Sousa, K. H., Holzemer, W. L., Henry, W. L., & Slaughter, R. (1999). Dimensions of health-related quality of life in persons living with HIV disease. *Journal of Advanced Nursing*, *29*, 178-187.

Sowell, R.L., Seals, B.F., Moneyham, L., Demi, A., Cohen, L., & Brake, S. (1997). Quality of life in HIV-infected women in the south-eastern United States. *AIDS Care*, *9*, 501-512.

Steenburgen, A.K., & Rogers, S. (1997). Health promotion: An essential component of rehabilitation for persons with chronic disabling conditions. *Advances in Nursing Science, 19*, 1-20.

Stokes, M. (2004). *Physical Management in Neurological Rehabilitation*. University of Southampton, Southampton, UK.

Swanson, B., Zeller, J.M., & Paice, J.A. (1998). HIV-associated distal symmetrical polyneuropathy: Clinical features and nursing management. *The journal of the Association of Nurses in AIDS Care, 9*(2), 77-80.

Swindells, S., Mohr, J., Justis, J.C., Berman, S., Squier, C., & Wagener, M.M., et al. (1999). Quality of life in patients with human immunodeficiency virus infection: impact of social support, coping style and hopelessness. *International Journal of STD and AIDS, 10*, 383-391.

Tagliati, M., Grinnel, J., Godbold, J., Simpson, D.M. (1999). Peripheral nerves function in HIV infection. *Archives of Neurology, 56*, 84-89.

Taylor, S. E., Kemeny, M. E., Reed, G. M., Bower, J. E., & Gruenewald, T. L. (2000). Psychological resources, positive illusions, and health. *American Psychologist, 55*(1), 99-10.

Testa, M.A., Simonson, D.C. (1996). Assessment of quality-of-life outcome. *The New England Journal of Medicine*, 334 (13), 835-840.

TRACT (2004). Distribution of Anti-retroviral drugs in Rwanda. Report from Treatment, Research AND Aids Care (TRACT). [Online] Available: <http://www.tract.rw.gov>> [8/20/07]

UNAIDS (2002, January 28-31). HIV/AIDS in sub-Saharan Africa: An overview. Paper presented at the Fourth Meeting of the Follow-up Committee on the Implementation of the DND and ICPD-PA, Yaoundé, Cameroon.

UNAIDS (2005). AIDS Epidemic update: December 2005 UNAIDS/04.16E.

UNAIDS/WHO (2006). AIDS epidemic update, Retrieved on October 2, 2007 from http://www.unaids.org/en/HIV_data/epi2006/default.asp

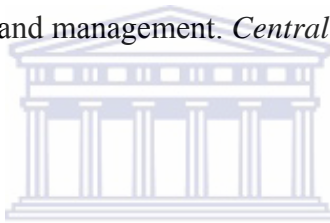
UNAIDS (2007). AIDS Epidemic update: December 2007 UNAIDS/07.27E.

UNAIDS/WHO. (2007). AIDS epidemic update, Policy document, UNAIDS, Geneva. Retrieved on August 20, 2007 from <http://data.unaids.org/pub/factsheet/2008/epi07-fs-regional-summary-subafrica-en.pdf>

Uwimana, J. (2005). *Met and unmet palliative care needs for people living with HIV/AIDS in selected areas in Rwanda*. Unpublished. Masters Thesis. University of the Western Cape, Cape Town, South Africa.

Venkataramana, A.B., Skolasky, R.L., Creighton, J.A., & McArthur, J.C. (2005). Diagnostic utility of the subjective peripheral neuropathy screen in HIV-infected persons with peripheral sensory polyneuropathy. *AIDS Read*, 15(7), 341-344.

Verma, S., Estanislao, L., & Simpson, D. (2005). Controlling neuropathic pain in HIV: Epidemiology, pathophysiology and management. *Central Nervous System drugs*, 19, 325-334.



Vetter, C.J., & Donnelly, J.P. (2006). Living long-term with HIV/AIDS: Exploring impact in psychosocial and vocational domains. *IOS Press*, 27(3), 277-286.

Vosvick, M., Gore-Felton, C., Koopman, C., Thoresen, C., Krumboltz, J., & Spiegel, D. (2003). Relationship of Functional quality of life to strategies for coping with the stress of Living with HIV/AIDS. *Psychosomatics*, 44, 51-58.

Wachtel, T., Piatt, J., Mor, V., Stein, M., Fleishman, J., Carpenter, C. (1992). Quality of life in persons with human immunodeficiency virus infection: Measurement by the Medical Outcome Study instrument. *Annals of Internal Medicine*, 116,129-137.

Watson, A., Samore, M.H., & Wanke, C.A. (1996). Diarrhea and quality of life in ambulatory HIV-infected patients. *Digestive Diseases and Sciences*, 41, 1794-1800.

Weinfurt, K.P., Willke, R.J. Glick, H.A. Freimuth, W.W. & Schulman, K.A. (2000). Relationship between CD4 count, viral burden, and quality of life over time in HIV-1-infected patients. *Medical care*, 38(4), 404-10.

WHO, Department of Mental Health. (1999). Annotated bibliography of the WHO Quality of Life Assessment Instrument-WHOQOL. Second revision. Geneva: WHO.

WHOQOL-HIV Group. (2003a). Initial steps to developing the World Health Organizations Quality of Life Instrument (WHOQOL) module for international assessment of HIV/AIDS, *AIDS Care*, 15(3), 347-357.

WHOQOL-HIV Group. (2003b). Preliminary development of the World Health Organisation's quality of life HIV instrument (WHOQOL HIV): analysis of the pilot version. *Social Science Medicine*, 57, 1259-1275.

Wig, N., Lekshmi, R., Pal, H., Ahuja, V., Mittal, C.H., & Agarwal, S.K. (2006). The impact of HIV/AIDS on Quality of Life: A cross-sectional study in North India. *Indian Journal of Medical Sciences*, 60 (1), 1-11.

World Health Organisation Quality of life Group. (1995). the World Health Organisation Quality of Life Assessment: Position paper from the World Health Organisation. *Social science and Medicine*, 41(10), 1403-1409.

Wu, A. W., Revicki, D. A., Jacobson, D., & Malitz, F. E. (1997). Evidence for the reliability, validity and usefulness of the Medical Outcomes Study HIV Health Survey (MOS-HIV). *Quality of Life Research*, 6, 481-493.

Wu, A.W. (2000). Quality of life assessment comes of age in the era of highly active antiretroviral therapy. *AIDS*, 14, 1449-1451.

Wulff, E.A., Wang, A.K., & Simpson, D.M. (2000). HIV-associated peripheral neuropathy: Epidemiology, pathophysiology and treatment. *Drugs*, 59(6), 1251-60.

Yen, C.F., Tsai, J.J., Lu, P., Chen, Y., Chen, T., Chen, P. & Chen, T.P. (2004). Quality of Life in HIV/AIDS male outpatients receiving highly active antiretroviral therapy in Taiwan. *Psychiatry and Clinical Neurosciences*, 58, 501-506.

Zanneti, C., Manzano, G.M., & Gabbai, A.A. (2004). The frequency of Peripheral Neuropathy in a group of HIV positive patients in Brasil. *Arq. Neuro-Psiquiatr*, 62(2-A), 253-256.



A. POPULATION CHARACTERISTICS

A.1	Gender	1. Male	1
		2. Female	2

A.2	How old are you?	Age completed in years	
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A.3	What is your employment status?	1. Employed	1
		2. Self employed	2
		3. Student	3
		4. Unemployment	4
		5. Farmer	5

A.4	What is your marital status?	1. Married	1
		2. Single	2
		3. Divorced	3
		4. Cohabiting	4
		5. Widowed	5

A.5	What is your level of Education?	1. Not at all	1
		2. Primary	2
		3. Secondary	3
		4. University	4

A.6	For how long have you known you are HIV positive?	Time completed in years	
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B. SUBJECTIVE PERIPHERAL NEUROPATHY SCREEN (SPNS)

1. INSTRUCTION FOR RECORDING SUBJECTIVE PATIENT-ELICITED SYMPTOMS:

Ask the patient to rate the severity of each symptom (a-f) on a scale of 01 (mild)-10 (most severe). Enter the severe score for each symptom in the column marked Presence/Severity.

If symptom has been present in the past, but not since the last visit, enter “00”/ Currently Absent. If the symptom has never been present, enter “11”/Always Been normal.

Always Been normal	Currently Absent	Mild.....Severe									
11	00	01	02	03	04	05	06	07	08	09	10

Symptom(s)	Presence/Severity
a. Pain, aching, or burning in hands, arms:	<input type="text"/> <input type="text"/>
b. Pain, aching, or burning in feet, legs:	<input type="text"/> <input type="text"/>
c. “Pins and needles” in hands, arms:	<input type="text"/> <input type="text"/>
d. “Pins and needles” in feet, legs:	<input type="text"/> <input type="text"/>
e. Numbness (lack of feeling) in hands, arms:	<input type="text"/> <input type="text"/>
f. Numbness (lack of feeling) in feet, legs:	<input type="text"/> <input type="text"/>

2. INSTRUCTION FOR GRADING SUBJECTIVE PATIENT-ELICITED SYMPTOMS:

Use highest severity score recorded in (a-f) above to obtain a subjective peripheral neuropathy grade:

- Presence/Severity score of: 01-03 = Grade of 1
- 04-06 = Grade of 2
- 07-10 = Grade of 3
- 11 or 00 = Grade of 00

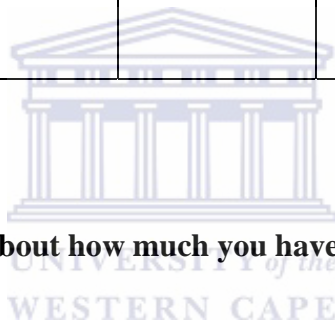
1. Subjective peripheral neuropathy grade?.....

C. WHOQOL-BREF

After reading each question, assess your feelings, and circle the number on the scale for each question that gives the best answer.

		Very poor	Poor	Neither poor nor good	Good	Very good
1(G1)	How would you rate your QOL?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2(G4)	How satisfied are you with your life?	1	2	3	4	5



The following questions ask about how much you have experienced certain things in the last two weeks.

		Not at all	A little	moderate amount	Very much	An extreme amount
3(F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4(F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5(F4.1)	How much do you enjoy life?	1	2	3	4	5
6(F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	moderate	Very much	Extremely
7(F5.3)	How well are you able to concentrate?	1	2	3	4	5
8(F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9(F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last 2 weeks

		Not at all	A little	Moderately amount	Mostly	Completely
10(F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11(F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12(F18.1)	Have enough money to meet your needs?	1	2	3	4	5
13(F20.1)	How available to you is information that you need in your day-to – day life?	1	2	3	4	5
14(F21.1)	To what extent do you have opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15(F9.1)	How were you able to get around?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16(F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17(F10.3)	How satisfied are you with your ability to perform your daily activities?	1	2	3	4	5
18(F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19(F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20(13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21(F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22(F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23(F17.3)	How satisfied with the conditions of your living place?	1	2	3	4	5
24(F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25(F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26(F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

THANK YOU FOR YOUR HELP.

