

**QUALITY OF LIFE OF PEOPLE LIVING WITH HIV AND AIDS  
IN SWAZILAND WHO ARE ON ANTIRETROVIRAL  
THERAPY**

by

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Submitted in accordance with the requirements  
for the degree of

**DOCTOR OF LITERATURE AND PHILOSOPHY**

in the subject

**HEALTH STUDIES**

at the

**UNIVERSITY OF SOUTH AFRICA**

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September 2012

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## **DECLARATION**

I declare that **QUALITY OF LIFE OF PEOPLE LIVING WITH HIV AND AIDS IN SWAZILAND WHO ARE ON ANTIRETROVIRAL THERAPY** is my own work and that all sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any institution.

**SIGNATURE: .....**

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**(Theresa T. Ntshakala)**

# **QUALITY OF LIFE OF PEOPLE LIVING WITH HIV AND AIDS IN SWAZILAND WHO ARE ON ANTIRETROVIRAL THERAPY**

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## **Abstract**

This study was done to assess the quality of life (QOL) of people living with HIV and AIDS (PLWHA) in Swaziland who are on antiretroviral therapy (ART). No study has been done on QOL of PLWHA in Swaziland who are on ART since it started to be administered in Swaziland in 2001.

A qualitative, exploratory, descriptive, and contextual design was used to assess QOL of PLWHA in Swaziland who are on ART. Twenty-four PLWHA were purposely selected to participate in the study. Methods of data collection used were semi-structured individual in-depth interviews, focus group discussions, and observations. The data (tape-recorded interviews and discussions, and field notes) were transcribed verbatim for data analysis. Data analysed was done using Tesch's framework of data analysis as described in Creswell (2002:256-283).

The research findings are reflected, with the six domains of QOL identified through a literature review and validated by nurses' expertise. These domains are the physiological, psychological, spiritual, socio-economic, cognitive, and environmental domains.

The study revealed that PLWHA in Swaziland are faced with many challenges concerning ART, namely: inability to meet their nutrition needs, non-adherence to

ART, experience of disfiguring side effects of ARVs, inconsistent condom use, experience of stigma and discrimination, depression, difficulty in accepting and coping with ARVs, lowered self-esteem, a negative influence of some religions on ART, a lack of financial support, poor support systems, poor understanding of ARVs, negative thoughts about HIV and AIDS and ART, an unsatisfactory health care delivery system, a negative influence of culture on ART, and violation of the rights of PLWHA. These challenges negatively influence the QOL of PLWHA and hence the study concluded that PLWHA in Swaziland who are on ART have a poor QOL.

Conclusions drawn from the data analysis reveal that PLWHA in Swaziland are powerless to deal with the above challenges and improve their QOL. The researcher, therefore, developed guidelines to empower PLWHA to deal with these challenges and adhere to ART, thus improving their QOL. Recommendations were made with regard to nursing practice, nursing education, and further nursing research.

**KEYWORDS:** quality of life (QOL), people living with HIV and AIDS (PLWHA), antiretroviral therapy (ART), voluntary counseling and testing (VCT), guidelines.

# ACKNOWLEDGEMENTS

*"It always seems impossible until it is done."* Nelson Mandela

At first, it seemed like an impossible journey. This thesis was made possible with the contributions of some individuals. It is not possible to mention all those who contributed to the success of this study. However, I wish to express my sincere gratitude to the following people:

First and foremost, I thank God the Almighty, who gave me the strength and determination to complete this study.

In addition, my sincere thanks go to my promoters, Prof. T.R. Mavundla and Dr B. Dolamo, for the unreserved support, patience, and assistance that they showed me during the course of this study.

I also wish to thank the following parties:

- My employer, the Nazarene College of Nursing (NCN), for allowing me to pursue my study.
- The University of South Africa (UNISA), for its financial support, in the form of a bursary.
- Ms. Phumzile Shongwe, for her patience in typing this manuscript.
- Mr. Anthony E Sparg, for his expertise and patience in editing and formatting this document.
- The UNISA and NCN library staff, for their assistance in locating literature sources.
- My mother, for her continual encouragement.
- My two beautiful girls, Khosi and Lindo, for their enduring love and support.
- Lastly, but not least, all the participants, for their willingness to participate in the study.

## **DEDICATION**

This thesis is dedicated to my late father, whose departure left a vacuum in my life. He believed that “all things are possible for all those that trust in the Lord”. I am also dedicating this thesis to all the HIV and AIDS survivors in the world, hoping that someday our prayers will be answered, and a cure for HIV will be found.

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## List of abbreviations

ABCDE	Anthropometric, biochemical, clinical, dietary, and environmental measures
AGOA	African Growth Opportunity Act
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral drug
CDC	Center for Disease Control
CIRA	Center for Interdisciplinary Research on AIDS
CMTC	Crisis Management and Technical Committee
DENOSA	Democratic Nursing Organisation of South Africa
DOT	Directly Observed Treatment
d4T	Stavudine
FAO	Food and Agricultural Organization
GALEN	Global AIDS Learning and Evaluation Network
GDP	Gross Domestic Product
GIPA	Greater Involvement of People Living with HIV and AIDS
HAART	Highly active antiretroviral therapy
HIV	Human Immunodeficiency Virus
HSRP	Health Sector Response Plan
IEC	Information, education and communication
KS II	King Sobhuza II
MDGs	Millennium Development Goals
MOH	Ministry of Health
MOHSW	Ministry of Health and Social Welfare
MOHSEC	Ministry of Health Scientific Ethics Committee
NDS	National Development Strategy
NERCHA	National Emergency Response Council on HIV and AIDS
NSF	National Strategic Framework
PHC	Primary Health Care
PLWHA	People living with HIV and AIDS
PRSAP	Poverty Reduction Strategy and Action Plan
PSMP	Public Sector Management Program
QOL	Quality of Life
RFMH	Raleigh Fitkin Memorial Hospital
RHM	Rural Health Motivators
SADC	Southern African Development Community
SDHS	Swaziland Demographic and Health Survey
SNAP	Swaziland National AIDS Programme

SNPP	Swaziland National Pharmaceutical Policy
SSEC	Swaziland Scientific Ethics Committee
SWANNEPHA	Swaziland Network of People Living with HIV and AIDS
TB	Tuberculosis
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session
UNISA	University of South Africa
UNISA HSREC	University of South Africa Health Studies Research and Ethics Committee
VCT	Voluntary counseling and testing
WFP CFSAM	World Food Programme Crop and Food Security Assessment Mission
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life

## CHAPTER 1

### ORIENTATION TO THE STUDY

#### 1.1 INTRODUCTION

The prevalence of HIV infection in Swaziland increased from 3.9% in 1992 to 26.1% in 2007, and by September 2008, 30,337 of those infected with HIV were receiving antiretroviral therapy (ART) (Multisectoral Strategic Framework for HIV and AIDS 2009-2014:23). The assumption has been made that as long as antiretroviral drugs prolong life, quality of life (QOL) will be improved.

QOL is a conceptual model intended to represent the perspective of the patient (Kinghorn & Gamlin 2002:245). QOL is becoming increasingly important in nursing as an outcome measure of health care (Bowling 1995:1447). It is, therefore, essential to utilise the concept of QOL when evaluating the health status of people living with various diseases, including HIV and AIDS.

Schalock (2000:121) defines QOL as “a concept that reflects a person’s desired conditions of living related to eight core dimensions of one’s life: emotional wellbeing, rights, interpersonal relationships, material wellbeing, personal development, physical wellbeing, self-determination and social inclusion”. The above confirms that one’s QOL entails a number of essential dimensions that should be considered when assessing QOL.

Apart from being multidimensional in nature, ChingSuet (2001:219) defines QOL as “the concept representing individual responses to the physical, mental and social effects of illness on daily living that influence the extent to which personal satisfaction with the life circumstances can be achieved”. This implies that the utilisation of the multidimensional

concept when assessing QOL may help to capture the nature of the individual's feelings and perceptions that prevail as a result of the effects of HIV and AIDS and ART.

Although ART improves the physical life of persons living with HIV and AIDS (PLWHA), the concern is the social, psychological, sexual, and spiritual aspects of their lives, which, when taken together, make up their QOL. According to Snoek (2000:25), it takes more than improving people's physical circumstances to enhance their subjective QOL. It is therefore essential to find out what other experts say about QOL and ART.

## **1.2 BACKGROUND**

HIV and AIDS is today among the most pressing concerns facing health providers worldwide. There is still no cure for HIV. This means that once one has become infected, one will always be infected. HIV is now regarded as a chronic and manageable illness. In 2005, it was estimated that 40 million people worldwide were living with HIV (UNAIDS 2006). This number includes adults and children. Of the 40 million people infected with the virus, 28 million were from sub-Saharan Africa (UNAIDS 2006).

In Swaziland, the first case of AIDS was identified in 1986. The prevalence of HIV infection has increased sharply, from 3.9% in 1992 to 26.1% in 2007 among people aged 15-49 years (Multisectoral Strategic Framework for HIV and AIDS 2009-2014:23). Swaziland is considered to be one of the countries most affected by HIV, with about one in three adults infected (UNDP 2002). By 2005, there were approximately 220,000 people living with HIV in Swaziland (UNAIDS 2006).

AIDS, the syndrome caused by the HIV, has killed more people worldwide than the two world wars combined (Calles & Schwardwald 2001:10). An estimated three million people have died of AIDS since the global epidemic started (UNAIDS 2006). Again, sub-Saharan Africa is in the lead, with 2.4 million deaths. In 2005, more than 16,000 adults and children died of AIDS in Swaziland (UNAIDS 2006). The most affected

population group is women between the ages of 20 and 24.

The epidemic is far more extensive than was predicted a decade ago, and the challenges that it poses vary from region to region. HIV, and AIDS, is still a challenge at personal, family, and community levels. The disease is still out of control. This is seen by the number of adults and children that are newly infected with HIV every year. In total, there were 4.9 million people worldwide that were newly infected with the virus in 2005 (UNAIDS 2006). Sub-Saharan Africa had 3.2 million new infections in the year 2005 (AIDS Epidemic Update, December 2005). Swaziland has a high HIV incidence rate, namely 3% (Multisectoral Strategic Framework for HIV and AIDS 2009-2014:23).

In 1999, His Majesty King Mswati III of Swaziland declared HIV and AIDS a “national disaster”. In response to the epidemic, the National AIDS Programme, within the Ministry of Health, was established. It was later renamed the “Swaziland National AIDS Programme (SNAP)”. The Cabinet Committee on HIV and AIDS and the Crisis Management and Technical Committee (CMTC) were set up to coordinate a national multisectoral response, and the CMTC developed the first national strategic plan for HIV and AIDS for 2000 to 2005. The National Emergency Council on HIV and AIDS (NERCHA) was established in 2001 to replace the CMTC. The National Multisectoral HIV and AIDS Policy was adopted in July 2006 to provide the framework, direction, and general principles for interventions. The policy was aimed at strengthening efforts to manage and coordinate the response, promote HIV and AIDS prevention interventions, provide effective treatment, care and support to PLWHA, and mitigate the impact of the epidemic.

The number of people receiving antiretroviral drugs (ARVs) in developing countries has more than doubled, from 400,000 in December 2003 to about 1 million in June 2005, according to reports released by WHO (2006) and UNAIDS (2006). In sub-Saharan Africa, as of June 2005, only 500,000 people were receiving the life-prolonging medication, yet 3.8 million people needed the treatment (WHO 2006 & UNAIDS 2006).

Swaziland has made enormous progress towards providing ARVs, guided by the Health Sector Response Plan for HIV and AIDS 2003-2005 and the Emergency Care and Treatment Implementation Plan. Both the public sector and non-governmental organisations offer ART. The public sector started providing ART in 2001 at the Mbabane Government Hospital. By September 2008, 30,337 of those infected with HIV in Swaziland (or 48% of those infected) were receiving ART (Multisectoral Strategic Framework for HIV and AIDS 2009-2014:23). This represented insufficient ART coverage, as 36,000 HIV-infected people were in need of the treatment (WHO 2006). An effort to scale up ART provision in Swaziland was made through the 3 by 5 Initiative. This is an initiative aimed at providing antiretroviral drugs to 3 million people by the year 2005. Scaling up ART was a necessity in Swaziland, in order to prolong and improve the lives of PLWHA. Hence, this study is conducted to assess whether ART improves the QOL of PLWHA.

ARVs have been provided free of charge since November 2003, so as to meet the Free by Five campaign. The Free by Five is an advocacy campaign that calls for free health care for HIV and AIDS and ARVs in Africa and other developing regions. The 2006 National Guidelines for Antiretroviral Treatment and Post-Exposure Prophylaxis for Adults and Adolescents are used.

Although ART may be regarded as a saviour by many people, QOL of people on ART remains a concern. According to Carr, Gibson and Robinson (2001:1240), health care is changing, and the two driving factors for this change are the recognition of the importance of the social consequences of disease, and the acknowledgement that medical interventions aim to increase the length and quality of survival. Consequently, to increase the length and quality of survival of PLWHA who are on ART, it is essential that an evaluation of their QOL first be done, because in most instances, in illness, QOL becomes more important than quantity of life.

Furthermore, regarding healthcare intervention, Addington-Hall and Kalra (2001:1417) state that “one of the reasons behind the rapid development of QOL measures in health care has been the growing recognition of the importance of understanding the impact of healthcare interventions on patients’ lives rather than their bodies”. It seems, therefore, that it is important to realise that ART is for the holistic improvement of PLWHA, not only the physical aspect of the person infected. Holistic improvement requires consideration of the fundamental components of QOL.

According to Cella (1992), as cited in Kinghorn and Gamlin (2002:245), there are two fundamental components of QOL. These are subjectivity and multidimensionality. Subjectivity, according to Cella (1992), refers to the fact that QOL can only be determined by the patient, and only by asking the patient directly can the subjective component be assessed. It is important, therefore, that QOL comes from the subjective responses of PLWHA, since they are the ones who have “walked the walk”, and they are considered to be the “masters of their own destinies”.

On expanding on the issue of the multidimensionality of QOL, Cella (1992), as cited in Kinghorn and Gamlin (2002:245), states that “multidimensionality refers to the psychometric tradition of health status measurement which includes physical, functional, emotional and social wellbeing”. According to the Quality of Life Research Unit at the University of Toronto (1994), a human being is made up of three domains, each having three subdomains. There is the “being domain”, the “belonging domain”, and the “becoming domain”. The being domain is subdivided into the physical, the psychological, and the spiritual domains. The belonging domain is subdivided into physical belonging, social belonging, and community belonging. The becoming domain is made up of practical becoming, leisure, and growth becoming. It therefore follows that in evaluating the QOL of PLWHA who are on ART, their health status must be measured in accordance with the relevant domains.

The WHO (1948) defines health as “a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity”. It can be concluded that vital aspects to include when evaluating the QOL of PLWHA who are on ART are the physical, the mental, the spiritual, and the emotional concepts.

According to Calles and Schwarzwald (2001:111), most people taking ARVs will live longer than they would without this medication. Sharing the same sentiments about ARVs prolonging life, Shernoff (2002:25) asserts that the types of combination therapy that are currently being administered have brought numerous individuals back from the brink of death. He also goes on to state that so many seriously ill people with HIV disease have experienced significant improvements in their health as a result of ARVs. ARVs have been described as “Lazarus Drugs”, which produce the “Lazarus Syndrome”, that is, they bring people back from the dead. This is because ARVs slow down HIV replication to such an extent that the viral load in the blood is reduced to very low and even undetectable levels (Calles & Schwarzwald 2001:111). This reduces the chances of being attacked by opportunistic infections and cancers, and PLWHA who are on ART may live a near-normal life.

Although ART has significant benefits of controlling HIV disease and extending life, many researchers suggest that ARVs have unpleasant side effects that may erode QOL (Roberts & Dennilk 2006:191-197; Swaziland National VCT guidelines 2002:5-7; and Noble & Magee 2007) (<http://www.avert.org/conttrt.htm>). Many health carers are faced with the dilemma of extending life versus improving life. In agreement with the issue of this dilemma, Burgoyne and Tan (2008:469) assert that length of life and QOL in this age of highly active antiretroviral therapy (HAART) is a delicate system, difficult to keep in balance.

According to Shernoff (2002:25), being on ART means participating in what he calls “the largest uncontrolled clinical trial in the history of medical science”, because, according

to him, no one can say for sure what the long-term effects of the drugs will be. Against the above background, one is forced to question the issue of QOL of PLWHA who are on ART.

Dudgeon (1992) states that the ultimate goal of medicine (in chronic illnesses) is the improvement of the patient's QOL. Yet Fellow field (1992) in Mitchell (2002:245) states that the advancement in medical science appears to have led to a decline in the art of medical science and that medical intervention may result in states of life that are, in her opinion, worse than death. Mitchell (2002: 245) also suggests that the treatment of cancer, which is also a chronic illness, can be worse than the disease, and that there is no certainty that the sufferer will enjoy a longer life. This author is suggesting that treatment, cannot guarantee a good QOL.

Taking these medications is not simply a matter of popping pills a few times a day. Rather, according to Shernoff (2002:25), these drug regimes have radiating effects, which profoundly influence eating, sleeping, and work schedules, as well as day-to-day interactions with other people. All these factors have an important bearing on a person's QOL. This is what should matter to all health professionals.

ART may indeed prolong life, but may only do so at considerable cost to the QOL of PLWHA. Health workers should be concerned about quality, rather than quantity. Instead of being content that many people have been put on ART, the concern should be the QOL of these people. QOL is to be taken as an important indicator of the efficacy of ART, compared to other indicators, such as inpatient period, length of sick leave, side effects of drugs, and mortality. QOL challenges nurses to look beyond ART and adopt a holistic approach that includes all facets of life improving people's QOL.

### **1.3 PROBLEM STATEMENT**

Although ART prolongs life by delaying disease progression, it does not eradicate HIV infection. AIDS is now considered a chronic illness in Swaziland. PLWHA have to manage their chronic HIV illness by taking ARVs for the rest of their lives, in order to prolong their lives. This therefore means that QOL has become an important outcome measure. Previously, the response to ART was measured in terms of survival time and physician-rated toxicity. Today, QOL has emerged as an important assessment of the impact of ART.

This study grew out of the researcher's concern that no research has been done to assess the QOL of PLWHA in Swaziland who are on ART since the introduction of ART in 2001. It has been assumed that because ARVs reduce the viral load and improves the CD4 cell count, QOL will be improved. It has been assumed that the viral load and CD4 cell readings can be translated into day-to-day feelings of the person on ART.

Furthermore, the researcher has also noted that QOL of many people taking ART is measured by the presence or absence of side effects of ARVs. Hence it is believed that the presence of unpleasant symptoms will certainly lower the patient's QOL. Thus the absence of symptoms is assumed to suggest an improved QOL. The researcher is of the opinion that QOL of PLWHA needs to be assessed from the perspective of the people on ART, and no assumptions must be made.

### **1.4 RESEARCH QUESTIONS**

The study is aimed at answering the following questions:

- How is the concept of QOL conceptualised in general?
- What are the domains that are relevant to PLWHA in Swaziland who are on ART?
- How is the QOL of PLWHA in Swaziland who are on ART?

## **1.5 PURPOSE OF THE STUDY**

A goal or purpose indicates the dream, whereas objectives indicate steps for the actualisation of the dream (De Vos 2002:107). The main purpose of the study was to assess QOL of PLWHA in Swaziland who are on ART.

## **1.6 RESEARCH OBJECTIVES**

There are four objectives in this study, namely the following:

- Describe the concept of quality of life (phase 1).
- Validate the QOL domains that were obtained through literature review and be assured that they are relevant to PLWHA in Swaziland who are on ART (phase 2).
- Assess the QOL of PLWHA in Swaziland on ART (phase 3).
- Develop guidelines that will be used to empower PLWHA in Swaziland who are on ART (phase 4).

## **1.7 SIGNIFICANCE OF QUALITY OF LIFE ASSESSMENT IN NURSING**

In this section, the researcher discusses the significance of the study. The discussion answers the following questions: Why should healthcare professionals be concerned about QOL in general, and, in particular, the QOL of PLWHA who are on ART? Why is this study important to nursing and to the individuals infected and affected by HIV and the families and organisations involved in the care of PLWHA who are on ART?

Snoek (2000:25) is of the view that studies on QOL are basically performed for two reasons. First, they are conducted to evaluate the psychosocial functioning of patient groups and to identify specific problems and needs of patients at different stages of the disease process. Second, and more often the case, QOL studies are conducted to compare the impact of different treatment regimens on the patient's wellbeing and treatment satisfaction. Such studies may provide nurses with important information to

support decision making, taking both biomedical and psychosocial aspects into consideration. This shows the importance of considering how PLWHA feel and how satisfied they are with ART, which focuses on more than just their bodies, hence the quality, effectiveness, and efficiency of ART care should be evaluated by its impact on the QOL of PLWHA. This should be the focus of nursing.

One major reason that prompted the researcher to conduct this study was the recognition that QOL of many people taking ARVs is measured by the CD4 cell count and the presence or absence of side effects to treatment. It has been assumed that the presence of unpleasant symptoms will certainly lower the patient's QOL, thus absence of symptoms means a good quality of life. This is in contrast with a number of studies, which indicate that the seeking of medical attention is more closely related to how patients feel their condition has impacted on their lives, rather than the presence of symptoms per se. Furthermore, compliance with any treatment is dependent on how the condition has affected patients' lives.

Given the fact that there is still no cure for HIV and AIDS, nurses need to shift their focus from curative care to palliative care. The aim of palliative care, according to Kirton et al. (2001:173), is to address the physical, psychological, social, spiritual, and existential needs of clients with progressive life-threatening illness, with the overall goal of improving QOL of individuals and families. When a cure is not an option, caring becomes the primary objective (Mitchell 2002:252). When assessing QOL of PLWHA, nurses should focus on QOL domains to maintain the holistic philosophy of caring. It is also the duty of nurses to attend to patients holistically. This means attending to clients' physical, mental, psychosocial, and spiritual wellbeing, as advocated by the WHO's definition of health.

Lastly, nurses have to measure QOL of PLWHA on ART, because if QOL cannot be measured, it cannot be improved. QOL puts the patient at the centre of inquiry and gives due weight to their opinions. As pointed out by Orley, Sazena and Herman (1998),

in Berlin and Fleck (2003:2), “it responds to patients’ concern not to be treated as cases, but as human beings who have a life with many facets not connected to their disease”. This corresponds with the sentiments of Higginson and Carr (2001:1298), who are of the view that QOL measures ensure that treatment and evaluations focus on the patient, rather than the disease. According to Delate and Coons (2001:47), assessing QOL of persons infected with HIV is important, because these persons are concerned not only with the ability of the antiretroviral treatment to extend their lives, but also with the QOL that they are able to enjoy. This means that prolonging life may not matter as much as QOL. The researcher is of the opinion that a short life with quality is better than a long life without quality.

An important thing to note here is that QOL measures are not a substitute for measuring outcomes associated with the disease, but are an adjunct to them. For example, at the time of this study HIV-infected individuals are not treated with ARVs based on QOL scores only, but also based on laboratory tests. Together these results can give important information about the client. QOL assessment will mean that the client is taken as an expert in his or her own illness, and thus the illness will be assessed from the patient’s perspective, based on the holistic approach model, which is client-centred. Hence, human dignity will be preserved.

## **1.8 THE CONTEXT OF THE STUDY**

The Kingdom of Swaziland is a small landlocked Southern African country that has an area of 17,364 square km, extending 176 km north-south and 135 km east-west. The country shares borders with the Republic of South Africa in the north, south, and west, and with Mozambique in the east. The country is divided into four ecological and topographic regions, namely the Highveld, the Middleveld, the Lowveld, and the Lubombo Plateau. Administratively, the country is divided into four regions: Hhohho in the north, Lubombo in the east, Manzini in the centre, and Shiselweni in the south. The four regions are further divided into smaller administrative constituencies, known as

*tinkhundla*, which are made up of chiefdoms. There are 55 *tinkhundla* and approximately 360 chiefdoms. The chiefdoms are the lowest-ranked community-based administrative structures.

Swaziland has a dual system of governance characterised by the co-existence of both traditional and modern modes of life. It has a strong cultural identity, which permeates all forms of social, political, and economic interaction. The official languages of the country are siSwati and English.

Swaziland has a population of 1,173,900 people (UN 2006). About 40% of the population is under 14 years old, 56% percent is in the 15-65 year range, and 4% is over 65 years. The population growth rate is estimated at 0.25%, while life expectancy has decreased from an average of 54 years to 35 years. The literacy rate, which refers to those who have completed primary education, is estimated to be at 81.6% (UNDP 2002). About 77% of the population is rural and depends on subsistence farming for its livelihood. Only 23% of the population lives in urban and peri-urban areas. Approximately two-thirds of the urban population lives in unplanned townships. Women head 66% of households in the country.

The country's healthcare system consists of the formal sector and the informal sector. The informal sector is made up of traditional health practitioners and other unregulated service providers. The health service that is based on Western medicine is considered to be formal sector, and consists of public and private health services. The formal health sector is based on the concepts of Primary Health Care (PHC) and decentralisation. The PHC strategy was adopted in Swaziland in 1983 as a strategy for delivery of health services. The healthcare infrastructure consists of seven government hospitals, two mission hospitals, and one industry-supported hospital. There are also 8 public health units, 12 health centres, 76 clinics, and 187 outreach sites. In addition, there are 73 mission health facilities, 62 private clinics, and 22 industry-supported health centres and

clinics. About 85% of the Swazi population resides within eight km of a healthcare facility.

The success of the immunisation programme has resulted in a dramatic decrease in the incidence of vaccine-preventable diseases, such as diphtheria, neonatal tetanus, poliomyelitis, measles, and hepatitis B. Respiratory conditions account for more than a quarter of all outpatients' visits, having increased from 25.5% in 1995 to 26.6% in 2002. Of all health problems in the country, the HIV and AIDS epidemic poses the greatest challenge. According to the Swaziland Demographic and Health Survey (SDHS) (2006-2007:223), Hhohho Region has the highest HIV prevalence, at 28.9%. It is followed by Lubombo Region, at 26.2%, Manzini Region, at 24.9%, and Shiselweni Region, at 23.1%. It was also noted that the prevalence was higher in urban areas than in rural areas, and it was higher in females than in males.

Swaziland is a patriarchal monarchy. Kanduza (2003, paper presentation) states that patriarchy manifests itself in Swazi society, in ordaining the perpetual minority of women. This perpetual minority contributes towards increasing the vulnerability of Swazi women to HIV infection, by hindering women from adopting the "Abstain, Be Faithful, and Condomise (ABC)" approach to HIV prevention. Culture contributes to the spread of HIV and AIDS in Swaziland. Cultural practices which place Swazi people at risk include society's approval of multiple sexual partners for men, polygamy, arranged marriages, and widow inheritance.

## **1.9 THE PARADIGM EMPLOYED, AND IT'S APPLICATION IN THE CONTEXT OF THIS STUDY**

A paradigm is defined by Polit and Beck (2008:761) as a way of looking at natural phenomena that encompasses a set of philosophical assumptions and that guides one's approach to enquiry. Creswell (2007:19) defines a paradigm as "a basic set of beliefs

that guide action”. In addition to beliefs, Schwandt (2001:243) asserts that paradigms include commitments, values, and methods.

This research is situated in a naturalistic research paradigm which emphasises that reality is multiple, subjective and context bound (Polit & Beck 2008:14). The researcher believes that being on ART is an experience that is subjective and context bound with multiple interpretations.

Assumptions refer to basic principles that are believed to be true without proof or verification (Polit & Beck 2008:14). Assumptions influence the development and implementation of the research process. Botes (1995:17) states that no research is value-free. Consequently, the researcher has made explicit her meta-theoretical (ontological), theoretical (epistemological), and methodological assumptions in the following manner:

### **1.9.1 Meta-theoretical (ontological) assumptions**

Ontological assumptions relate to the nature of reality and its characteristics (Creswell 2007:16). In this study, the following ontological assumptions are made by the researcher:

#### **1.9.1.1 *The client/person***

The researcher believes that a person, or a client, is an open holistic being that is a composite of five interrelated variables – physiological, psychological, sociocultural, developmental, and spiritual – and is in constant interaction with the environment.

For this study, a “person” refers to a holistic person who is living with HIV and AIDS and is on ART. The researcher aimed at investigating the QOL of such a person, with the objective of developing guidelines that will be used to empower PLWHA in Swaziland

who are on ART. As QOL is multidimensional, the researcher used relevant context-specific domains to assess the QOL of PLWHA in Swaziland. These domains were obtained through a literature review, and were validated through a workshop strategy by a sample of expert nurses involved in the care of PLWHA in Swaziland on ART.

### ***1.9.1.2 The environment***

DuToit and Van Staden (2005:69) state that much of human existence is made up of social interaction, and that this always takes place in some or other social environment or context. Neuman (1995), as cited in George (2002:344), emphasises that environmental stressors may affect the client negatively or positively at any particular time. Conversely, the client may affect his or her environment. Not all stressors are necessarily harmful, as the client system has the ability to change the mode of response to environmental forces. As the client is viewed as an open holistic being the mechanisms of input, process outcome, and feedback between the client and the environment are considered to be circular in nature. The relationship between the client and the environment is considered to be complementary, or reciprocal, and therefore produces an outcome of correction or regulation of the system (Neuman, 1995, as cited in George 2002:344).

For this study, the environment includes all the internal and external factors or influences that affect the life and development of PLWHA who are on ART. Stressors for a person who is infected with HIV and is on ART include the effects of HIV on the body, side effects of ARVs, the client's thought content, and society's reaction towards HIV and AIDS and ART, which includes the stigma associated with HIV and AIDS, and discrimination against individuals infected with HIV and individuals suffering from AIDS.

### **1.9.1.3 Health**

Health is seen as a continuum ranging from wellness to illness. A person's health is therefore constantly in a state of change. Wellness constitutes the harmonious balance of all the subsystems and parts of the whole system. Neuman (1995) refers to wellness, or client system stability, as negentropy, when more energy than is needed is generated, and illness as entropy, when less energy than required is generated (George 2002:347).

When applied to this study, the term "health" means wholeness of PLWHA, as determined by the interrelationships of all five client variables (physiological, psychological, developmental, sociocultural, and spiritual). "Illness" is represented by disharmony of the above variables of the system, as a whole, resulting in poor QOL.

### **1.9.1.4 Nursing**

Nursing is "a unique profession concerned with all the variables affecting clients in their own environment" (Neuman 1995, as cited in George 2002:347). The major concern of nursing is to help the client system attain, maintain, or regain system stability (George 2002:347). Neuman views the nurse as an intervener in assisting the client to reduce the reaction to stressors. Neuman (1995) identifies three levels of prevention as intervention, namely primary, secondary, and tertiary prevention.

In caring for PLWHA, nursing is seen as a unique profession aimed at assisting individuals, families, and groups in attaining and maintaining a maximum level of QOL, by attending to all the variables affecting clients, and maintaining equilibrium between clients' internal and external environment.

### **1.9.2 Theoretical (epistemological) assumptions**

Theoretical assumptions reflect the researcher's view about what is considered true or valid knowledge in the theoretical framework that relates to her research subjects (Botes 1995:6). This author goes on to state that theoretical assumptions are testable and yield epistemic pronouncement, and provide structure that identifies and clarifies the whole person as she or he interacts with the environment. Creswell (2007:18) is of the view that with epistemological assumption, qualitative researchers try to get as close as possible to the participants being studied.

This study is based on Betty Neuman's Systems Theory, which is reflective of the whole-person philosophy. According to this philosophy, an individual is viewed as an open holistic being that is in comprehensive and continuous interaction with his or her internal and external environment. The internal environment consists of those influences within the client (intrapersonal), and the external environment consists of influences outside the client (Potter & Perry 2005:62). The environment is viewed as a stressor.

This paradigm also focuses on all the variables of the whole person. These variables are the physiological, psychological, sociocultural, developmental, and spiritual variables. To understand a human being means understanding all these variables together. Klein and White (1996), cited in Friedman, Bowden and Jones (2003:155), support the above idea in their statement that "understanding is only possible by viewing the whole". This is because a system has the vital element of interconnectedness and interrelatedness.

When applied to this study, the concept of holism emphasises that nurses must keep the whole person in mind and strive to understand how one area of concern relates to the whole person. A person who is infected with HIV and is on ART has all these variables affected.

### **1.9.2.1 Theoretical definitions**

This section provides definitions of concepts that are frequently used in this study.

- **Antiretroviral therapy**

This is a combination of antiretroviral drugs and supportive care given to people living with HIV or AIDS, to decrease or reverse immune system damage associated with HIV infection.

- **Guidelines**

The word “guideline” means a general rule, principle, or piece of advice (Concise Oxford English Dictionary 2002:632).

- **Nurse**

A nurse is an individual who has undergone training according to the specifications of the Swaziland Nursing Council (SNC) and can work as an independent practitioner.

- **Swaziland**

This is a small country in Southern Africa surrounded by the Republic of South Africa in the north, south, and west, and by Mozambique in the east. Swaziland had the highest HIV prevalence in the world in 2007, at 26.1%, and by September 2008, 30,337 people in this country (or 48% of those infected with HIV) were receiving ART (Multisectoral Strategic Framework for HIV and AIDS 2009-2014:23).

- **Quality of life**

The WHO (1946) defines QOL as “the individual’s perception of his or her position in life, within the cultural context and value system, his or her goals, expectations, parameters, and social relations, and is a broad-ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment”.

### **1.9.3 Methodological assumptions**

Methodological assumptions focus on analysis of the methods used for obtaining data (Cohen, Manion & Morrison 2000:22). Methodological assumptions concern the researcher’s view of the nature of the research process and the most appropriate methods, as these direct the research design (Mouton 2002:124). According to Morse (2003:189), the goal of social science is to understand the complexity of human behaviour and experience, and the task of the researcher is to describe and explain this complexity, which is limited by our research methods.

Morse (2003:189) goes on to state that by using more than one method, we are able to broaden the dimensions, and hence the scope, of our project. We are thus able to obtain a more complete picture of human behaviour and experiences, and we are thus able to hasten our understanding and achieve our research goals more quickly.

The aim of this research was to assess QOL of PLWHA in Swaziland who are on ART. QOL is a complex and multidimensional concept that needs to be studied using different approaches. The researcher triangulated her data collection methods to get a clear picture of the experiences of being on ART. Table 1.1 depicts a summary of the research phases, research methods, and reasoning strategies applied. This is an attempt to summarise the research methods for the reader. A comprehensive description of research methods used is given in Chapter 2.

**Table 1.1: A summary of research methods used in the study**

Phase	Research methods	Reasoning strategies
<b>Phase 1</b> A literature review and concept analysis of QOL	Descriptive and content analysis Contextual definition of the concept of QOL The domains of the concept of QOL were identified. Indicators for each domain were identified.	<ul style="list-style-type: none"> <li>• Analysis</li> <li>• Synthesis</li> </ul>
<b>Phase 2</b> Validation of the domains of QOL, obtained through an extensive literature review	<p><b>Sampling technique:</b> Purposive sampling</p> <p><b>Data collection method:</b> A workshop was held with expert nurses involved in ART care. Quality of life and quality of care of PLWHA were discussed extensively. Nurses presented their inputs.</p> <p><b>Data analysis:</b> Data was analysed using Tesch's (1990) framework of data analysis as described in Creswell (2002:256-283). Findings from the workshop were used to identify themes.            A literature control</p>	<ul style="list-style-type: none"> <li>• Bracketing</li> <li>• Intuition</li> <li>• Inductive reasoning</li> <li>• Deductive reasoning</li> <li>• Analysis</li> <li>• Synthesis</li> </ul>
<b>Phase 3</b> An assessment and description of the QOL of PLWHA on ART	<p><b>Sampling technique:</b> Purposive sampling</p> <p><b>Data collection method:</b> The researcher conducted in-depth semi-structured individual interviews and focus group discussions with PLWHA on ART who met the criteria to answer the question "How is your life since you started ART?"</p> <p><b>Data analysis method:</b> Data was analysed using Tesch's framework of data analysis as described in Creswell (2002:256-283). Findings from observations, individual interviews, and focus group discussions were used to identify themes. Member and peer checking.            A literature control</p>	<ul style="list-style-type: none"> <li>• Bracketing</li> <li>• Intuition</li> <li>• Inductive reasoning</li> <li>• Deductive reasoning</li> <li>• Analysis</li> <li>• Synthesis</li> </ul>
<b>Phase 4</b> Development and description of empowerment guidelines for PLWHA on ART	Dickoff, James and Wiedenbeck's (1968:420-423) framework for guideline development was used. Guidelines were evaluated using Chinn and Krammer's (1999:111) and Walker and Avant's (2005:160) strategies for theory evaluation. Guidelines received an external review from nine experts (three ART experts, three guideline development experts, and three potential users).	<ul style="list-style-type: none"> <li>• Deductive reasoning</li> </ul>

## **1.10 MEASURES OF ENSURING TRUSTWORTHINESS**

Since this is qualitative research, it concentrated on enhancing trustworthiness. Trustworthiness is ensured by applying Lincoln and Guba's (1985) model of assessing trustworthiness. The four criteria for assessing trustworthiness, according to Lincoln and Guba (1985), are credibility, transferability, dependability, and confirmability (Polit & Beck 2008:539). These are discussed in detail in Chapter 2.

## **1.11 ETHICAL CONSIDERATIONS**

Conducting nursing research requires not only expertise and diligence, but also honesty and integrity (Burns & Grove 2005:176). Investigating HIV and AIDS and ART is sensitive. PLWHA may easily break down when relating their experiences. Thus the researcher's counselling competency was very important. According to Thomas (2002:10), when doing research on the lived experience of a person living with AIDS, researchers must possess at least basic skills in HIV and AIDS counselling. Fortunately, the researcher is also a professional counsellor. The researcher used empathy, warmth, unconditional acceptance of PLWHA, and genuineness to help the participants reveal their experiences of being on ART. Ethical standards set by the Democratic Nursing Organisation of South Africa (DENOSA 1997), the UNISA Ethics Review Board (UNISA HSREC), and the Swaziland Scientific and Ethics Committee (SSEC) were adhered to in this study.

## **1.12 THE SCOPE OF THE STUDY**

This study endeavoured to assess QOL of PLWHA in Swaziland who are on ART. The study sample comprised 24 PLWHA who have been on ART for more than a year. The researcher used method triangulation to obtain credible findings. Data was first collected from 12 participants by means of semi-structured individual in-depth interviews. Two focus group discussions (FGDs) (each with six participants) were also

used as a means of data collection. One of the assumptions underlying the use of focus groups is that group dynamics can assist people to express and clarify their views in ways that are less likely to occur in a one-on-one interview. Data was collected by means of an interview guide that covered the contextualised domains of QOL. These domains were obtained through a literature review and were validated through a workshop strategy with nurses involved in the care of PLWHA who are on ART (Chapter 4). These nurses were considered experts in the field of ART. Empowerment guidelines were developed based on the study findings (Chapter 6).

Because the study was qualitative and exploratory, the sample of PLWHA who were on ART was small (24 PLWHA). Hence the findings of the study can only be contextualised among PLWHA in Swaziland who are on ART. A detailed description of the research methods used can be found in Chapter 2. Figure 1.1 illustrates the steps carried out by the researcher for the study.

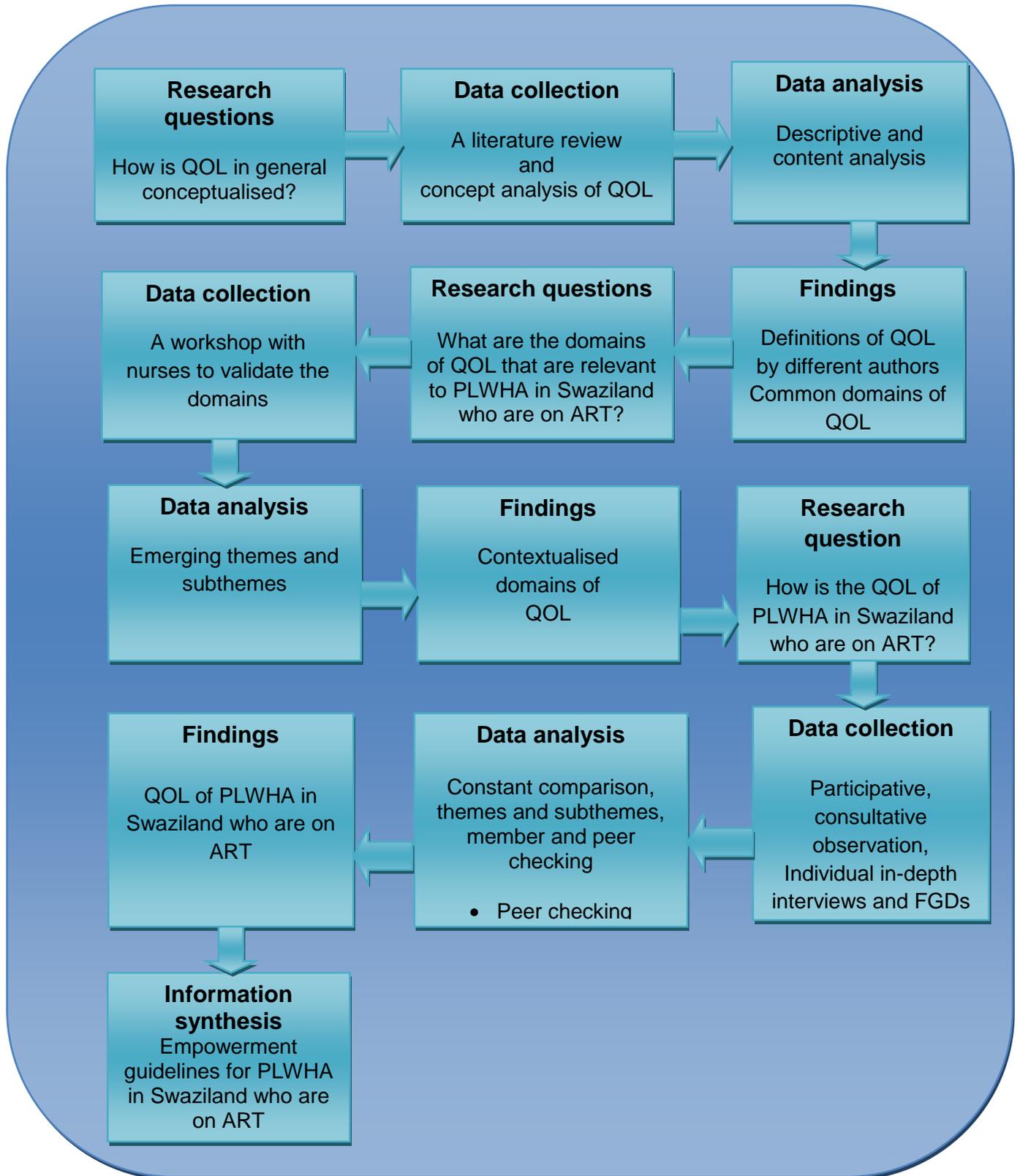


Figure 1.1 A flow diagram illustrating the research steps carried out by the researcher

### **1.13 OUTLINE OF THE THESIS**

**Chapter 1** Orientation to the study

**Chapter 2** Research design and methods

**Chapter 3** Literature review

**Chapter 4** Validation of the domains of QOL by a sample of expert nurses who are involved in the care of PLWHA who are on ART

**Chapter 5** Assessment of the QOL of PLWHA in Swaziland who are on ART

**Chapter 6** Development and description of guidelines for empowering PLWHA in Swaziland who are on ART

**Chapter 7** Presentation of recommendations for nursing practice, education, and research

### **1.14 CONCLUSION**

This chapter has given an overview of the study. It has outlined the background, purpose, problem statement, and objectives of the study. The significance of the study was clearly stated, with literature support. The next chapter contains a detailed description of the research design and methods used in the study.

## **CHAPTER 2**

### **RESEARCH DESIGN AND METHOD**

#### **2.1 INTRODUCTION**

The previous chapter gave the outline of the study. This chapter presents research methods in four phases as they are used by the researcher to answer her research questions mentioned in Chapter 1 of this thesis. Phase 1 describes the process followed in deriving the meaning of the concept QOL. Phase 2 details the steps followed by the researcher in validating and describing the relevant domains that need to be considered when assessing QOL of PLWHA in Swaziland who are on ART. In Phase 3, the researcher comprehensively describes methods of data collection and analysis used to describe the QOL of PLWHA in Swaziland who are on ART. In the last phase, Phase 4, the researcher describes how guidelines were formulated in order to empower PLWHA in Swaziland who are on ART.

#### **2.2 OVERALL AIM OF THE STUDY**

The overall aim of the study was to assess and describe the QOL of PLWHA in Swaziland who are on ART and to develop guidelines that will be utilised to empower PLWHA. In view of the above aim of the study, the researcher intended to achieve the following objectives:

- To describe the concept of QOL;
- To validate the domains of QOL that were obtained through literature review and be assured that they are relevant to PLWHA in Swaziland who are on ART (phase 2).
- To assess the QOL of PLWHA in Swaziland who are on ART; and
- To develop guidelines to empower PLWHA in Swaziland who are on ART.

## **2.3 RESEARCH DESIGN**

A research design is defined as a blueprint for conducting the study that maximises control over factors that could interfere with the validity of the findings (Burns & Grove 2005:223). A research design can also be defined as “the overall plan for obtaining answers to the questions being studied and for handling some of the difficulties encountered during the research process” (Polit & Beck 2008:66). According to Durrheim (1995), as cited in Terre Blanche and Durrheim (1999:29-30), a research design is a strategic framework for action that specifies how the research should be executed in a way that answers the research questions. The above authors go on to state that in developing a research design, the researcher must make a series of decisions along four dimensions, namely: 1) the purpose of the research; 2) the theoretical paradigm; 3) the context or situation within which the research is carried out; and 4) the research techniques employed to collect and analyse data (ibid.:33). In addition, the choice of a research design for this study must consider the sensitivity and emotive nature of HIV and the participants involved as they disclose their individual personal lived experience (QOL).

A qualitative, exploratory, descriptive, and contextual design was used for this study to assess the QOL of PLWHA in Swaziland who are on ART. Findings from the assessment were used to develop guidelines to empower PLWHA in Swaziland who are on ART. Each aspect of the design is described fully in the following sections.

### **2.3.1 Qualitative approach**

Qualitative research is a systematic, interactive, subjective approach used to describe life experiences and give them meaning (Burns & Grove 2005:747). Polit and Beck (2008:763) define qualitative research as “the investigation of phenomena, typically in an in-depth and holistic fashion, through the collection of rich narrative materials, using a flexible research design”.

The qualitative approach is based on a philosophical orientation that adopts a person-centred and holistic perspective (Burns & Grove 2005:24). Latimer (2003:27) describes qualitative research as part of a debate, an attempt to capture the sense that lies within a structure, and an exploration, elaborating the significance of a defined phenomenon. This research is an inductive, holistic, subjective, and process-oriented method used to understand, interpret, and describe the phenomenon of QOL of PLWHA in Swaziland who are on ART.

The study used a qualitative approach based on the exploratory nature of the phenomenon of the study. It was focused on assessing the QOL of PLWHA on ART, because QOL is a phenomenon that is subjective and unique to each individual (Ventegodt, Merrick & Andersen 2003:1032).

The qualitative approach is also applicable to this study because of its person-centredness. The researcher believes that any form of health intervention should put the person at the centre of care, because PLWHA are the ones who have experienced being HIV-positive and being on ART.

The qualitative research design was used for the following reasons:

- To validate the QOL domains by a sample of expert nurses involved in the care of PLWHA in Swaziland. The purpose of validation was to make sure that the domains were relevant to PLWHA in Swaziland; and
- To assess QOL of PLWHA in Swaziland who are on ART.

### **2.3.2 Exploratory approach**

One of the characteristics of qualitative research is that it is explorative. According to Brink and Wood (1998:312), the purpose of an exploratory research design is to study that which has not been previously studied, where the researcher is looking for new

knowledge, new insight, new understanding, and new meaning. Furthermore, Polit and Beck (2008:20) and Mouton and Marais (1991:43) state that exploratory research investigates the full nature of a phenomenon in the manner in which it is manifested and other factors to which it is related.

The aspect of the design was used in the study to assess the QOL of PLWHA in Swaziland who are on ART.

### **2.3.3 Descriptive approach**

Apart from the exploratory nature of qualitative research, it is important for the researcher to describe accurately the phenomenon being studied. Descriptive research studies are research studies that have as their main objective the accurate portrayal of the characteristics of persons, situations, or groups and/or the frequency with which certain phenomena occur (Polit & Beck 2008:752). The descriptive design was selected because there are elements in life that are best described in words, rather than numbers. QOL cannot be easily quantified and needs to be described in detail to get meanings.

The descriptive design was used for the following reasons:

- To describe the concept of QOL (Chapter 3);
- To validate the QOL domains that were obtained through literature review and be assured that they are relevant to PLWHA in Swaziland who are on ART(Chapter 4);
- To describe the QOL of PLWHA in Swaziland who are on ART (Chapter 5); and
- To develop and describe guidelines for the empowering of PLWHA in Swaziland who are on ART (Chapter 6);

### **2.3.4 Contextual aspect of the design**

Burns and Grove (2005:732) describe context as the body, the world, and the concerns unique to each person, within which the person can be understood. According to Babbie and Mouton (2003:272), context defines and describes the setting in which the research actions occur, the aim being to understand events within the context in which they occur.

This study was contextual in the sense that it was conducted within the Swazi urban context, and the findings were understood within this setting. The study setting was the Raleigh Fitkin Memorial Hospital Voluntary Counselling and Testing (VCT) Centre in the Manzini Region. This setting of the study was chosen for its accessibility to the researcher. As this setting is an urban setting, the research took into account the social, physical, and cultural values of the participants. The context was a naturalistic setting, and was thus free from manipulation.

## **2.4 REASONING STRATEGIES**

Reasoning strategies were utilised for the purpose of enriching this research project with some scientific logic. The researcher used the following reasoning strategies for the research: bracketing, intuition, induction, and deduction.

### **2.4.1 Bracketing**

According to Cohen, Kahn and Steeves (2000:7) and Polit and Beck (2008:228), bracketing refers to a process of holding in abeyance prejudices, personal commitments, preconceived beliefs, assumptions, and presuppositions to improve the research. Bracketing is a qualitative research technique of suspending or laying aside what is known about an experience being studied (Streubert Speziale & Carpenter 2007:457; Burns & Grove 2005:729).

For this study, bracketing meant the researcher's identification of any preconceived ideas about domains that sum up an individual's QOL and QOL of PLWHA who are in ART in Swaziland. These were bracketed out of consciousness by the researcher, by retaining a neutral stance regarding the revelations of participants' interviews and preventing personal beliefs from interfering with the description given by the participants. As ART is a new strategy for dealing with AIDS, a lot of research has been done internationally, and a lot has been said about it concerning its effect on QOL. The researcher suspended belief in all existing claims and assumed a neutral position, to avoid biases that may interfere with the credibility of the findings.

#### **2.4.2 Intuition**

Intuition occurs when researchers remain open to the meanings attributed to the phenomenon by those who have experienced it (Polit & Beck 2008:228), thus the researcher becomes immersed in the phenomenon under study, focusing all awareness and energy on participants being interviewed to increase insight into the phenomenon (Streubert Speziale & Carpenter 2007:85).

In order to achieve intuition, the researcher was open to all participants' responses, ensured absolute concentration, and was absorbed during in-depth interviews and FGDs and during data analysis, in order to get the full picture of QOL of PLWHA in Swaziland who are on ART.

#### **2.4.3 Inductive reasoning**

The various features of qualitative studies, such as naturalism, insider perspective, and thick description, are an inductive approach (Babbie & Mouton 2003:273; Nieswiadomy 2008:95). It means that the researcher begins with immersion in the natural setting,

describing events as accurately as possible as they occur, or have occurred, and slowly but surely building second-order constructs (Babbie & Mouton 2003:273).

The inductive approach was applicable to this study, since little was known about QOL of PLWHA in Swaziland who are on ART, and the researcher was immersed in data collection and data analysis to obtain the relevant domains of QOL, and, in particular, the QOL of PLWHA in Swaziland who are on ART.

#### **2.4.4 Deductive reasoning**

The deductive approach is the process of developing specific predictions from general principles, in other words, moving from the general to the particular (Burns & Grove 2005:8; Polit & Beck 2008:13). Polit and Beck (2008:13) emphasise that the deductive approach is not itself a source of new information, but rather an approach to illuminating relationships as one proceeds from the general to the specific.

During the literature review, there were many definitions of QOL that were identified. These definitions have their specific domains. The researcher noted that these domains were just general domains, and none of them were specific to PLWHA. The deductive approach was applied to this study, when the researcher validated the domains obtained during the literature review and contextualised them to PLWHA in Swaziland who are on ART. Deductive reasoning was also used during the interviews and FGDs, and empowerment guidelines were developed for PLWHA who are on ART.

## **2.5 RESEARCH METHODS**

Research methods are the techniques used to structure a study and to gather and analyse information relevant to the research question in a systematic fashion (Polit & Beck 2008:15). This chapter describes the methods used in obtaining, organising, and

analysing data. The purpose of this discussion about research methods is therefore to communicate exactly what the researcher did to solve the research question.

### **2.5.1 Phase 1: Description of the concept of QOL**

In this phase, the researcher was engaged in concept analysis of QOL. The purpose of concept analysis is to distinguish between defining and non-defining relevant attributes of a concept, to arrive at precise operational definitions of concepts, and to accurately reflect the theoretical base of a study (Walker & Avant 2005:64). The researcher did concept analysis to obtain a concise operational definition of quality, life, and QOL.

### **2.5.2 Phase 2: Validation of the domains of QOL by a sample of expert nurses who are involved in the care of PLWHA who are on ART**

This phase deals with the validation and description of the relevant domains necessary for assessing the QOL of PLWHA in Swaziland who are on ART. The domains were obtained through an extensive literature review. They are the physiological, psychological, spiritual, and social domains. The process of validation was undertaken through a workshop strategy with expert nurses involved in ART care. This phase is described under the following subsections.

#### ***2.5.2.1 Purpose of the workshop***

A workshop is a period of discussion and practical work on a particular subject in which a group of people share their knowledge and experiences (Oxford Advanced Learner's Dictionary 2005:1699).

The workshop strategy was efficient, because the researcher was able to bring expert nurses involved in the care of PLWHA to one venue at the same time and was able to obtain the viewpoints of these experts in a timely manner. The whole workshop lasted

six hours. The researcher was able to get information from 16 participants, and thus was able to validate the domains of QOL that were obtained through the literature review.

The workshop strategy proved to be effective. Through the interactive group sessions, members stimulated each other and reacted to what was said by others, thereby leading to a richer, or deeper, expression of opinion. The researcher was able to get rich information, which was needed to validate the QOL domains.

The strategy was an excellent way of disseminating information after getting clarifications from participants. It was an easy process, since it was done there and then, thus the process of data transcription was speeded up. Since the researcher is employed in one of the institutions where data from PLWHA was collected, it was easy to organise a venue in one of the institution's conference rooms. The venue was purposely selected for easy data collection using video recordings.

The main purpose of the study was to assess the QOL of PLWHA in Swaziland who are on ART. The researcher is of the view that knowledge generated from people's lived experiences is invalid when pre-existing measurement scales are used. Research aimed at understanding the lived experience of individuals in a situated context is undermined if the data collection tools are developed in some other context with a unique local reality (Fielden, Rusch, Masinda, Sands, Frankish & Envoy 2007:116; Jakobson & Rugelay 2007:23; Parrado, McQuinston & Flippen 2005:206; Propp 2003:130; Rosas & Camphausen 2007:126). It is important, therefore, that assessment of the QOL of PLWHA in Swaziland needs to be done using the relevant contextual domains of QOL. Through the literature review, the researcher was able to identify four domains of QOL that she considered relevant in the assessment of PLWHA. These domains were the physiological, psychological, spiritual, and social domains.

The purpose of the workshop was therefore to validate the above four QOL domains that were obtained through the literature review and to be assured that they are relevant, exhaustive, and context-specific to PLWHA in Swaziland who are on ART. The workshop was also aimed at identifying other evidence-based information concerning each of the identified domains. The refined validated information facilitated the process of interviews with PLWHA on ART, which is Phase 3 of this research.

### ***2.5.2.2 Sampling***

Participants were recruited from one referral hospital and one clinic in the Manzini Region. These institutions, the Raleigh Fitkin Memorial Hospital (RFMH) and the King Sobhuza II (KSII) Clinic, were purposely selected because they render ART services.

Eight departments from RFMH were purposely selected, since they offer ART services. Letters of request were written to the selected departments, including KSII Clinic, stating fully the nature of the workshop (Annexure A). The programme of the workshop was attached to each requesting letter (Annexure B). Permission was granted verbally by the supervisors of the selected departments. The supervisors, in liaison with the researcher, used a purposive sampling technique to recruit candidates who are considered to be experts in ART care to attend the workshop. In total, 16 registered nurses from RFMH and two nurses from KSII agreed to attend and participate in the workshop. After obtaining verbal consent from the participants, the researcher spent about 20 minutes with each participant, familiarising them with the workshop and explaining the overall purpose of the workshop.

Of the 18 nurses that agreed to participate, 16 nurses availed themselves for the workshop. This sample size was adequate to elicit sufficient information to validate the domains of QOL which were identified by the researcher through the literature review.

### **2.5.2.3 Workshop process**

It was made clear to participants that the role of the researcher was to facilitate the discussions, but not to contribute. This was done to ensure neutrality, based on the principles of bracketing. The researcher was responsible for establishing a supportive, non-threatening climate for participation. The workshop commenced with welcoming remarks and a workshop objective explanation by the researcher. The objectives of the workshop were:

- To discuss the concepts of quality of life and quality of care.
- To discuss the comprehensive quality of care of PLWHA on ART.
- To solicit nurses' lived experiences of quality of care of PLWHA on ART.

First, there was discussion of the concept of QOL. This was followed by a brief discussion of the quality of care of PLWHA who are on ART in Swaziland. The purpose of these discussions was to stimulate the thought content of participants, so as to enable them to share their experiences of working with PLWHA on ART. In accordance with the process of bracketing, the domains of QOL obtained through the literature review were not disclosed to the participants, thereby enhancing their ability to discuss their experiences adequately, without being influenced by the researcher's knowledge of the subject. Bracketing is the process of identifying and holding in abeyance any preconceived beliefs and opinions about the phenomenon under study (Polit & Beck 2008:748). The researcher was assisted in the facilitation of the workshop by a qualified researcher, who is an expert in qualitative research.

- **Division into groups**

Since the participants were a homogeneous group, it was easy to divide them into two groups of eight participants per group. All the participants had a similar background of having more than a year's experience of caring for PLWHA who are on ART. The group was small enough for each member to participate.

The two groups chose their leader, a secretary, and a presenter. The leader was responsible for coordinating the group activities and focusing the group. The secretary was responsible for documenting the group's inputs, and the presenter presented on behalf of the group. They were required to reflect on their experiences of caring for PLWHA and to discuss the QOL of PLWHA in Swaziland who are on ART. Discussions focussed on QOL, care given to PLWHA and their QOL.

After one and a half hours of deliberation, each group was requested to present their inputs. Presentations were made with the aid of flip charts, notes, and the whiteboard and were video-recorded for purposes of authenticity and data analysis. The researcher documented all the participants' inputs. After each presentation, the researcher made a summary of major themes identified. This was to ensure that important issues were not missed and were captured correctly. Presentations for both groups lasted one and a half hours. With the participants' discussions, the researcher was able to validate the domains of QOL that are considered relevant to PLWHA in Swaziland who are on ART.

#### ***2.5.2.4 Debriefing***

Debriefing means communication with study participants after participation is complete regarding various aspects of the study (Polit & Beck 2008:182). Debriefing ensures credibility of the research findings. In qualitative research, credibility of the information must be ensured. Credibility is considered by Lincoln and Guba (1985) as an "overriding goal of qualitative research" (Polit & Beck 2008:539). The researcher had to undertake the process of debriefing as a technique of demonstrating the credibility of the workshop findings. Furthermore, debriefing addresses the following questions: Is there evidence of researcher bias? Has the researcher been sufficiently reflexive? Do the gathered data adequately portray the phenomenon? If there are important omissions, what strategies might remedy this problem? Are there any apparent errors of fact? Are there possible errors of interpretation? Are there competing interpretations, or parsimonious

interpretations? Have all the themes been identified? Are the themes and interpretations knitted together into a coherent, useful, and creative conceptualisation of the phenomenon? (Polit & Beck 2008:549).

At the end of the presentations, there was a debriefing session with participants for 30 minutes. Debriefing was done to ensure that important information was captured. This helped to develop a clear picture of the participants' inputs. Participants were given the opportunity to ask questions and give more input on the information captured by the researcher. The findings of the validated domains are presented in Chapter 4.

### **2.5.3 Phase 3: Assessment of the QOL of PLWHA in Swaziland who are on ART**

In this phase the researcher describes the process of gaining entry into the research field, the population, the sample and how she selected it, the overall plan that she used for data collection, the data analysis itself, the steps that she took to minimise bias, and what she did to protect the rights of the participants.

#### ***2.5.3.1 Gaining entry and access***

One of the critical steps in any study is gaining entry into the area being studied (Burns & Grove 2005:561). In order to gain entry to the study site, the researcher had to identify and seek permission from the gatekeepers of the study field. The identified gatekeepers were the Swaziland Ministry of Health Scientific and Ethics Committee (MOH SEC), the hospital administration, and the sister in charge of the study VCT clinic. Permission was sought verbally and in writing. The researcher encountered some hurdles in gaining permission from the MOH SEC. The problems are outlined in Chapter 5, section 5.2. After meeting the requirements of the gatekeepers, permission was granted.

### **2.5.3.2 Population and sampling**

The researcher deliberated on these two concepts, as they are important, because it is through them that the researcher described clearly what the population for the assessment of QOL is and how the participants were selected. The two concepts are discussed below.

- **Population**

Population refers to the entire set of individuals or objects having some common characteristics (Polit & Beck 2008:761). The target populations for this study were adult PLWHA in Swaziland who have been on ART for more than a year. The researcher believed that this period offered sufficient evidence that the participant had enough experience on ART to participate in the study.

- **Sampling**

A sample is a subset of the population that is selected to participate in the study (Polit & Beck 2008:750). In qualitative research, the adequacy of the sample refers to information adequacy, which means that data is collected until no new information is obtained from participants. This is called data saturation. Information adequacy is not ensured by the number of participants interviewed, but by the quality of information gathered.

In qualitative research, the focus is on quality of information obtained from the person, situation, or event sampled, rather than the size of the sample (Patton 2002, as cited, in Burns & Grove 2005:358). In addition, explorative, descriptive designs require a small number of people and a small geographical or circumscribed setting. Against the above background, the researcher and the research assistant selected 24 participants (PLWHA) who were on ART by purposive sampling for individual interviews and FGDs.

The research assistant was requested for assistance since she is an expert in research and has been working at the ART clinic for more than five years. The participants (PLWHA) that were sampled were among those present in the health clinic at the time of the data collection.

- **Sampling technique**

Purposive sampling was used to include participants in the study. Purposive sampling is also referred to as judgemental sampling and involves the conscious selection of participants by the researcher (Burns & Grove 2005:747).

The reasoning that underlies the purposive selection of a sample in qualitative research is to identify information-rich participants who can supply the information required to answer the research questions. Participants are selected to participate in qualitative research based on their first-hand experience with a culture, social process, or phenomenon of interest (Streubert Speziale & Carpenter 2007:29).

For this study, PLWHA on ART who were willing to talk about their experiences of being on this treatment met the criteria and were selected to participate.

- **Sampling criteria**

Sampling criteria are a list of the characteristics essential to membership in the target population (Burns & Grove 2005:750). The sampling criteria were based on the research problem, research purpose, and research design. The sampling criteria for this study were as follows:

- Adult (at least 18 years of age, according to the constitution of Swaziland);

- Living with HIV and AIDS and is on ART for more than a year. Should not be on any other chronic illness medications that may interfere with QOL, for example, tuberculosis, hypertension, diabetes, and cancer medication;
- Is willing to participate of their own free will; and
- Is able to speak siSwati, isiZulu, or English, because the researcher and research assistant will be able to communicate clearly and meaningfully in these languages.

There was no discrimination of the participants in terms of being on first-line or second-line ARV treatment.

- **Sample description**

The characteristics below were compiled from the participants' biographical data. The sample consisted of more women (n=13) than men (n=11). According to the Swaziland Demographic and Health Survey (SDHS) (2006-2007:10), there are more women (53%) than men (47%) in Swaziland. This sample characteristic also reflects the fact that HIV prevalence is higher among women than among men in Swaziland (SDHS 2006-2007:221). The participants' ages ranged from 20 to 60 years, with a mean age of 36 years. According to SDHS (2006-2007:22), HIV prevalence in Swaziland is highest in the age group 15-49 years. The sample consisted mostly of those who were married (n=11), followed by those who were single (n=8), divorced (n=3), and widowed (n=2). This mirrors the HIV prevalence in Swaziland, where HIV is higher among married people than unmarried people (SDHS 2006-2007:221).

With regard to formal education, the majority of the participants had a junior certificate (n=10), followed by those that had only a primary certificate (n=6), those that had completed high school (n=5), and those that had no formal education (n=3). It was essential to determine the participants' employment status to determine how this could influence QOL. The majority of participants were not employed (n=11), followed by

those that were employed (n=7), and those that were self-employed (n=6). This parallels the employment status in Swaziland, where a third of the labour force is unemployed (<http://www.gov.sz/home.asp?pid>). During the interviews, it became evident that employment status does affect QOL, as those who were not employed had difficulty supporting themselves and their families.

The sample characteristic of religious background corresponds with the religious situation in Swaziland. In Swaziland, the major religion is Christianity, followed by other religions. The sample consisted of participants who were Christians (n=22), one who was a Muslim (n=1), and one that had no religious affiliation (n=1). (Table 2.1 provides a summary of the biographical information of the study participants).

**Table 2.1: Demographic characteristics of the study participants (n=24)**

AGE	SEX	EMPLOY- MENT	EDUCA- TIONAL LEVEL	MARITAL STATUS	YEARS ON ART	RELIGION	NO. OF CHIL- DREN	NO. OF DEPEN- DANTS
20	F	N	FORM 3	S	3	Christian	1	2
21	M	E	FORM 3	S	2	Christian	1	2
22	F	N	FORM 1	S	4	Christian	2	4
25	F	S	FORM 1	W	2	Christian	3	4
25	F	S	FORM 3	M	3	Christian	3	5
28	M	S	O LEVEL	M	1	Christian	1	6
28	M	N	FORM 3	M	1	Christian	2	4
30	M	N	STD 3	W	1	Christian	3	6
30	F	E	FORM 3	M	3	Christian	2	4
32	M	N	STD 1	M	1	Christian	2	6
33	F	E	STD 4	S	2	Christian	1	4
35	F	N	STD 4	M	2	Christian	3	5
35	M	N	NIL	S	1	Christian	4	7
37	M	S	O LEVEL	M	4	Muslim	0	4
39	M	E	O LEVEL	D	4	Christian	5	10
40	F	N	NIL	M	6	Christian	1	3
41	M	E	O LEVEL	S	2	Christian	1	5
44	F	E	O LEVEL	S	8	Christian	2	4
44	F	N	STD 5	M	3	Christian	3	8
48	M	S	STD 1	M	1	Christian	9	11
48	M	S	STD 1	D	9	Christian	6	10
52	F	E	FORM 3	D	1	Christian	2	3
53	F	N	STD 4	S	2	Christian	5	7
60	F	N	NIL	M	2	None	8	10

**Key: Employment:**      **N – not employed**  
                                  **E – employed**  
                                  **S – self-employed**

**Marital status:**        **M – married**  
                                  **S – single**  
                                  **D – divorced**  
                                  **W – widowed**

### **2.5.3.3 Data collection**

The overall approach to data collection used by the researcher was method triangulation. This involves using multiple methods of data collection for the same phenomenon, in order to develop a comprehensive understanding of it and to evaluate the extent to which it yields a consistent and coherent picture of the phenomenon (Polit & Beck 2008:543). QOL, HIV and AIDS and ART are complex phenomena. In order for

these phenomena to be fully understood, use of multiple data sources was necessary. As such, the researcher is confident of the research findings.

The researcher used a combination of participant observation, semi-structured in-depth individual interviews, and FGDs with PLWHA in Swaziland who were on ART. This ensured credibility of the research findings. The researcher spent two months in the field collecting data. For the first month, the researcher was engaged in participant observation only, and for the second month the researcher used participant observation, together with individual interviews and FGDs. These are discussed separately in the following sections.

#### **2.5.3.3.1 Participant consultative observation**

This is a method of collecting data through participation and observation of a group or culture (Polit & Beck 2008:761). It forces the observer to familiarise herself with the subject and it allows previously unnoticed or ignored aspects to be seen, as people's actions are probably telling more than their verbal accounts (Kelleher 1993, as cited in Babbie & Mouton 2003:295). The researcher spent a month at the centre where data was collected, familiarising herself with the setting, staffing, clinic interactions and being engaged in the routine of the clinic. The reason was to understand the phenomenon of QOL of PLWHA within the concrete, natural context in which ART services are offered to clients. This is because one understands the events against the background of the whole context and how such a context confers meaning to the events concerned, so that one can truly claim to understand the events (Babbie & Mouton 2003:272).

De Vos, Strydom and Fouche (2005:284) contend that there may be problems in participant observation, such as the participants not acting naturally, because of the presence of an outsider. This problem was not noted with this research, since the researcher is a nurse and is well known at the institution, and, as such, she was not regarded as an outsider.

The researcher made field notes in order to get a comprehensive understanding of the QOL of PLWHA in Swaziland who are on ART, and it enabled her to have confidence in the findings of this study. What was observed was the physical setting, staffing, participants, activities, interactions, and organisational procedures. These field notes were used to help fill in gaps in the data obtained during the individual interviews and the FGDs, and to triangulate the data (in chapter 5). (See annexure O for a summary of the researcher's field notes).

- ***Pilot study***

Behind every successful piece of completed research stands a pilot study (Lackey & Wingate 1995, as cited, in Brink & Wood 1998:375). According to Polit and Beck (2008:213), a pilot study is a small version or trial done in preparation for a major study. It serves the purpose of identifying any problems with the design, sequence of questions, and procedure for recording responses.

The researcher conducted a pilot study with two participants similar to those who were used in the study. The results of this pilot did not form part of the actual study. However, the pilot enlightened the researcher as to the duration of each interview and the appropriateness of the setting and allowed the researcher to try out particular data analysis techniques.

#### **2.5.3.3.2 Semi-structured in-depth individual interviews**

The researcher conducted semi-structured in-depth open-ended interviews with PLWHA who were on ART. In semi-structured interviews, researchers prepare in advance a guide of written topics, which is a list of areas or questions to be covered with each participant (Polit & Beck 2008:394). This technique ensures that researchers will obtain all the information required. It gives people the freedom to respond in their own words to

provide as much detail as they wish, and to offer illustrations and explanations (Polit & Beck 2008:394). This form of interviewing was ideal for investigating the personal experience of being on ART from the subjective perspective of each participant. (See Annexure C and D for the questions that were asked.)

Individual semi-structured interviews were conducted on every Wednesday and Friday of each week, because these are ART refill days and the researcher had a large population to purposely select from. Twelve participants were recruited, by the researcher and the research assistant using a purposive sampling technique after the patients had collected their ARV medications. The participants were kindly requested to participate in the research. They were given informed consent forms to sign. (See Annexure L for a consent form signed by a participant.)

A doctor's consultation room was used for the individual interviews, since it was vacant on Wednesdays and Fridays. Data was obtained through individual face-to-face interviews with PLWHA, using a semi-structured interview guide using siSwati (see Annexure D). This siSwati version of the questionnaire was translated by a professional translator from English (see Annexure C) into siSwati. The interview guide was composed of a list of 15 open-ended questions. These questions addressed the six domains of QOL relevant to PLWHA in Swaziland who are on ART. These domains were the physical, psychological, spiritual, socio-economic, cognitive, and environmental domains. These domains were identified after an extensive literature review on QOL and were validated by expert nurses involved in ART services.

The interview guide provided the researcher with some control over the interview process and ensured uniformity during the interviews. The face-to-face interview technique enabled the researcher to seek clarifications and probe deeper when necessary, thereby increasing the researcher's understanding of the interviewees' responses. The interviews were audio-recorded by means of a tape recorder, after permission had been obtained from the participants. Taping the interviews ensured

accuracy and clarity in transcription of the interviews and it allowed the researcher to make notes about the responses of the participants, without missing important information.

Responses were then translated into English for easy transcribing and coding. Interview notes were transcribed and analysed immediately following the first interviews. A summary of the interview was written, with notes for further clarification, and questions were developed following the transcription and initial analysis. Transcription of the interview notes immediately after the interview ensured the accuracy of the interview data, aided by the memory of the researcher of any events that occurred during the interview process (Gillham 2005:123). Follow-up questions that were identified during the transcription were asked during subsequent interviews with PLWHA. The researcher was able to conduct only three interviews per day, because of time constraints.

Each individual interview took approximately 45 to 60 minutes. Bracketing was done throughout the interview process to control any biases and preconceptions of the researcher on HIV and AIDS and ART so that these did not influence the information supplied by the participants. Data saturation was reached after 12 interviews. Interviews were conducted for four days. Participants were given R20.00 (US\$3.00) each as a token of appreciation for their time and participation. They were not informed of this token of appreciation before they agreed to participate in the interviews, in order to avoid any unintentional coercion.

#### **2.5.3.3.3 Focus group discussions (FGDs)**

In addition to individual interviews, FGDs were also held with participants. The reasons for using focus groups is based on the assumption that group dynamics can assist people to express and clarify their views in ways that are less likely to occur in a one-on-one interview, and the group may give a sense of safety in numbers to those who are wary of researchers or those who are anxious (Burns & Grove 2005:542). The focus

group is also effective in that researchers can obtain the viewpoints of many individuals in a short time, and members react to what is being said by others, leading to a richer and deeper expression of opinion (De Vos et al. 2005:300). The interaction of participants may stimulate a richer response, or new and valuable thoughts, and group pressure will be valuable in challenging the thinking of participants and illuminating conflicting opinions (Polit & Beck 2008:395).

Concerning the issue of the sample size for focus groups, Greeff (2005:305), states the following:

Focus groups usually include six to ten participants. A group this size allows everyone to participate, while still eliciting a range of responses. In making decisions about size, it is useful to think concretely about how much time each participant will get to talk in the group. Smaller groups (four to six) are preferable when the participants have a great deal to share about the topic or have intense or lengthy experiences related to the topic of discussion.

Morgan and Krueger (1998), as cited in De Vos et al. (2005:306), state that deciding on the right number of participants means striking a balance between having enough people to generate a discussion, but not having so many people that some feel crowded out.

Concerning what is an adequate number for focus groups, Morgan and Krueger (1998), as cited in De Vos et al. (2005:306), are of the view that there is no hard-and-fast rule on the number of focus groups that should be conducted. The determining factor for the number of focus groups is data saturation. It is for this reason that the researcher conducted two focus groups of six participants per group. Information-rich participants were purposely selected by the researcher and the research assistant, using the same strategy as for individual interviews. The first group consisted of two females and four males, and the second group had three males and three females. The fact that the

groups had individuals of different genders did not interfere in any way with the quality of the data that was collected.

Although pilot testing is a cardinal rule for research, it presents special problems when it comes to focus groups (De Vos et al. 2005:309). It is for this reason that the researcher did not conduct a pilot for the FGDs, as De Vos et al. (2005:306) state that the true pilot test is the first focus group.

The same room that was used for the individual interviews was used for the FGDs. The purpose of the research was explained to the group. A biographical profile of the participants was first created. Ground rules were set to ensure that the discussions ran smoothly. Ground rules were laid down relating to issues of confidentiality and permission to opt out of the group. It was agreed that every member would contribute, that every member would be listened to, and that all ideas would be analysed and every contribution considered vital.

The seating arrangement was circular, so that every member could see each other and the researcher was able to communicate with every member of the group. Due to the small size of the room, the researcher was not able to move around, but was part of the circle. Since the researcher is a lecturer and is familiar with group discussions, it was easier to manage the group. An independent person (the research assistant) took detailed notes of what every member said, so that “data collection should not interfere with the coordination of the group” (Burns & Grove 2005:544). The research assistant was properly oriented as to the process of focus group data collection. She focused on observing and taking notes, while the researcher concentrated on asking questions, facilitating the group interactions, following up on ideas, and making smooth transitions from one issue to another.

In order to make sure that all the relevant domains of QOL were deliberated on, the same comprehensive interview guide that was used for the individual interviews was

used for the FGDs. One question was asked at a time, and every member was given a chance to respond to it, and the researcher summarised after every question, so that what was captured by the researcher and the research assistant was what the participants had actually said. Participants were permitted to hear one another's responses and to make additional comments beyond their own original responses as they heard what the other participants said. The researcher made sure that every member contributed and that no two individuals dominated the discussions. The interviews were audiotaped with the permission of the participants. One FGD was conducted per day. FGDs lasted for about two hours for the first group, and for one and a half hours for the second group. The FGDs produced a range of insightful responses concerning the experience of being on ART in Swaziland. Data saturation was reached with the second FGD. Participants were paid a sum of R20.00 (US\$3.00) each for their time and contribution. The research assistant was paid a sum of R200.00 (US\$30.00) for the two FGDs.

In both the individual interviews and the FGDs, to protect participants from being identified as the individual who provided specific information in the study, the participants were assigned numbers, from Participant Number 1 to Participant Number 6. The participants' information was kept on a secure computer flash drive and personal computer. The identity of the participants was not revealed to anyone. Research information was reported in an aggregate report, using only the numbers that identified the participants.

- **The role of the researcher in the individual interviews and the FGDs**

The role of the researcher was the same for the individual interviews and the FGDs. In qualitative research, the researcher is a primary data-collecting tool (Morse & Field 1997:57). In order for the interviews to elicit genuine data, the researcher started the discussions by asking the research participants the following central question:

### ***How is your life since you started ART?***

The researcher relaxed the atmosphere by explaining that the participants should feel free to express their opinions while participating in the study. Some facilitative techniques include becoming immersed in the phenomenon under investigation and becoming aware of each participant. The researcher facilitated discussions by the use of facilitative communication techniques. This helped the participants to speak freely during the discussion process. Discussions were flexible, objective, empathic, and persuasive. Some of the communication techniques that were used by the researcher during the interviews include the following:

***Probing:*** Polit and Beck (2008:429) state that the purpose of probing is to elicit more useful information from the participants than was volunteered during the first reply. Probing may also be used when the researcher realises that the participant does not understand the question (Bryman 2004:122). Bernard (2000:198-225) identifies seven types of probes intended to communicate to the participant that they should continue. These are:

- ***The silent probe:*** This consists of remaining quiet and waiting for the participant to continue.
- ***The echo probe:*** In this probe, the researcher repeats the last thing said by the interviewee.
- ***The “uh-huh” probe:*** The participant is sometimes encouraged to continue by the interviewer making affirmative comments such as “uh-huh”, “OK”, or “I see”.
- ***The “tell me” probe:*** This is a commonly used probe where the researcher invites participants to say more.
- ***The long question probe:*** When the researcher needs a long answer, she often uses this probe.
- ***Probing by leading:*** Leading questions are often discouraged in qualitative research, however long provocative questions are sometimes asked.

The participants were helped to describe their experiences of being on ART. Probing also helped the participants to engage more constructively in the following communication techniques:

**Paraphrasing:** This refers to the researcher repeating in her own words the participants' expressed feelings and opinions to ensure that she understands correctly.

**Summarising:** This technique involves tying together into one statement several of the views and opinions of the participants at the end of an interview or discussion.

**Minimal response:** The researcher assumes a less active role, allowing the participants more time to talk. Interviews were audiotaped and transcribed verbatim.

- **Field notes**

Apart from discussions, the researcher also used observations in the form of field notes. Polit and Beck (2008:754) defines field notes as "the notes taken by researcher to record the semi-structured observations made in the field and the interpretations of those observations".

The researcher paid attention to non-verbal cues, which included gestures, movement, tone of voice, repetition, stammering, as well as other mannerisms that the participants displayed. In support of the above, Burns and Grove (2005:540) state that observations during interviews need not be in a structured form to allow spontaneous participation by the participants. In addition, observations carried out while watching and listening are valuable to the qualitatively oriented researcher, because what is being observed is what the participant is actually experiencing.

To obtain supportive information, field notes are essential in qualitative research, because they provide the researcher with a system for remembering observations gained during the interview process and, more importantly, these field notes can be retrieved and analysed when need be. Bryman (2004:307) asserts that field notes are used to supplement the data collected through the tape-recorded interviews. The researcher collected various forms of notes, namely observational notes, theoretical notes, methodological notes, and personal notes.

### ***Observational notes (ON), or descriptive notes***

These are objective descriptions of observed events and conversations, and information about actions, dialogue, and context (Polit & Beck 2008:406). Walsh (2002:89) states that observational notes contain the ***who, what, how*** and ***where*** of a situation, and as little interpretation as possible. The researcher made use of all her senses during the interviews.

### ***Methodological notes (MN)***

These are reflections about the strategies and methods used in the observations, or reminders about how subsequent observations will be made (Polit & Beck 2008:406).

### ***Theoretical notes (TN), or analytical notes***

These notes document the researcher's thoughts about how to make sense of what is happening. These notes are the researcher's efforts to attach meaning to observational notes, and they serve as a starting point for subsequent analysis (Polit & Beck 2008:406). The researcher interpreted, inferred, and connected her observations, in order to build her analytical scheme.

### ***Personal notes (PN)***

The researcher kept a record of personal notes. These are comments about the researcher's own relations, feelings, and experiences in the field (Polit & Beck 2008:406).

#### ***2.5.3.4 Data analysis***

In qualitative research, data analysis is an ongoing process, done throughout data collection activities. Data collection and data analysis are interdependent processes. As the researcher was collecting data, she was engaged in active analysis of the data.

The researcher was immersed in the data. This has also been referred to as dwelling with the data. This required a significant degree of dedication to reading, analysing, synthesising, and documenting what had been discovered. The researcher transcribed and analysed the audiotaped interviews to identify themes and categories.

A comprehensive description of each theme was obtained through concurrent data collection and analysis, since the analysed data gave direction as to what information was relevant.

Data was analysed manually by means of Microsoft Word word-processing software 2007 version, as the researcher wanted to have a feel for the participants' responses.

Data was analysed using Tesch's framework of data analysis as described in Creswell (2002:256-283). These steps are;

1. Carefully read transcripts to understand the whole;
2. Read through an interview, write down ideas that emerge while asking yourself questions like "what is the importance of the information gathered or what is it about?"

3. Read all transcripts, make a list of all topics, and then cluster similar topics together;
4. Try to identify major categories and write these on the margin;
5. Create codes for similar topics; rearrange these to see if they become categories; and
6. Recode the data if necessary for categories and sub-categories.

#### ***2.5.3.5 Discussion of the findings on QOL of PLWHA in Swaziland who are on ART, and a literature control***

The results of phase 3 of this research were discussed in the light of relevant literature and similar studies, to place them in the context of what is already known. The literature control also highlighted similarities and differences between the current study and other studies conducted in the past.

#### **2.5.4 Phase 4: Description of empowerment guidelines for PLWHA in Swaziland who are on ART**

In this phase of the study, the researcher was involved in the process of developing empowerment guidelines for PLWHA in Swaziland who are on ART. The guidelines were developed based on the study findings, the literature, and the three principles of QOL. These principles are the holistic principle, the human rights principle, and the greater involvement of PLWHA principle (GIPA). The guidelines are expounded in Chapter 6.

## **2.6 MEASURES FOR ENSURING TRUSTWORTHINESS**

Polit and Beck (2008:768) define trustworthiness as “the degree of confidence qualitative researchers have in their data”. It is described by Streubert Speziale and

Carpenter (2007:460) as establishing reliability and validity in qualitative research. Lincoln and Guba's (1985) model was applied to ensure the trustworthiness of the study, so as to convince the consumer that the results are worth paying attention to and worth taking account of (Lincoln & Guba 1985:290). Trustworthiness exists if the findings of a qualitative study represent reality. Hence the four criteria of credibility, transferability, dependability, and confirmability were used. The researcher finds it important to deal with each criterion separately, so as to explain how each is suitable for use in this research. Each criterion is therefore described as follows.

### **2.6.1 Credibility**

Credibility refers to confidence in the truth of the data and the interpretations of it (Polit & Beck 2008:539). For this study, credibility was achieved through prolonged engagement, reflexivity, triangulation, persistent observation, referential adequacy, peer debriefing, and member checks.

#### ***2.6.1.1 Prolonged engagement***

The researcher spent about 20-30 minutes with each participant (for both the individual interviews and the FGDs), explaining the purpose of the study and ethical issues involved. The researcher had sufficient time (45-60 minutes) with the participants to collect data, to have an in-depth understanding of QOL of PLWHA on ART, to ensure saturation of important categories.

In addition to understanding the culture and the environment which may influence the establishment of the truth value, prolonged engagement was also essential for building trust and rapport with participants, which made it easy for them to reveal accurate and rich information.

### **2.6.1.2 Reflexibility**

This is a process of reflecting critically on the self and of analysing and making note of personal values that could affect data collection and interpretation (Polit & Beck 2008:202).

This means that the researcher had to examine her own perspective of the phenomena under study. It entailed continuously examining her own experiences, values, background, and any prejudices or theoretical inclinations that could shape the analysis and interpretation of the study findings. For this reason, the researcher maintained a neutral position concerning HIV and AIDS, ART, and QOL, to avoid biases.

### **2.6.1.3 Triangulation**

This is defined as the use of multiple references to draw conclusions about what constitutes the truth (Cormack 2000:406; Gillis & Jackson 2002:416). Combining methods in the same study can overcome the deficiencies inherent in the use of one particular method.

The researcher embarked on the convergence of multiple perspectives to ensure that almost all important aspects, methods, and processes that should be undertaken in the collection of the data are not left out. For generating and refining the attributes of QOL during concept analysis, the researcher made use of multiple data resources. Furthermore, when defining the concepts, the researcher used a general-sources strategy, which includes the dictionary definition of the concept, the theoretical usage of the concept, as well as the general linguistic usage of the concept. In addition, the researcher utilised a qualitative, exploratory, descriptive, and contextual design for this research.

Purposive sampling was used to select the research participants. In-depth semi-structured individual interviews and FGDs were used to collect the data. Data was analysed using Tesch's framework of data analysis as outlined in Creswell (2002:256-283).

#### ***2.6.1.4 Member checking***

Researchers are encouraged to return to the participants for data and interpretation verification (Babbie & Mouton 2003:277). Credibility was ensured by conducting interviews with four of the participants who identified with the themes.

#### ***2.6.1.5 Peer examination***

A panel of experts in qualitative research, in the form of supervisors, ensured that the professional standard of this research project was not compromised by the researcher. The experts checked whether there were any biases, acute portrayal of the phenomenon, omissions, errors in interpretation, whether all the important themes were included, and whether all the interpretations knitted together into a cogent, useful, and creative conceptualisation of the phenomenon.

In addition, the researcher's consultation with different experts in the fields of HIV and AIDS, ART, QOL, and qualitative research facilitated the acquisition of expert knowledge, which helped the researcher to effectively instill research quality.

#### ***2.6.1.6 Structural coherence***

The focus throughout the research was QOL of PLWHA in Swaziland who are on ART.

### ***2.6.1.7 The authority of the researcher***

The researcher has been fully trained by professionally recognised and acknowledged experts in qualitative research. Therefore, the researcher was capable of undertaking this research project. In addition, two qualified researchers supervised the study. The researcher has also been involved in the supervision of students in an academic research project at the nursing college where she is working.

### ***2.6.1.8 Referential adequacy***

By referential adequacy, Babbie and Mouton (2003:277) refer to the materials used in documenting findings. The researcher used audiotape and notebooks to document all the interviews.

### ***2.6.1.9 Peer debriefing***

A colleague who is outside the context of this study, who has a general understanding of the nature of the phenomenon under study, reviewed the perceptions, insights, and analysis of the research.

## **2.6.2 Transferability/applicability**

This refers to the extent to which the findings from the data can be transferred to other settings or groups (Polit & Beck 2008:316). The obligation for demonstrating transferability rests on the reader and the user of the study. Transferability has been ensured through the following methods:

### **2.6.2.1 Thick description**

Lincoln and Guba (1985:290) contend that transferability is achieved through collecting sufficient detailed descriptions of data in a relevant context and setting and reporting them with precision.

There was a comprehensive description of the research methods used, and participants' direct responses are given. This provides sufficient information to permit judgement about the transferability of the research findings.

### **2.6.2.2 Purposive sampling**

A qualitative researcher uses purposive selection of participants and location to maximise the range of specific information required.

The researcher used purposive sampling to select 12 PLWHA on ART for the individual interviews and 12 PLWHA on ART for the FGDs.

### **2.6.3 Dependability/consistency**

This refers to data stability over time and over different conditions (Polit & Beck 2008:316). It means consistency when other researchers follow the same research methodology with participants in similar contexts, and that they may reach the same results. According to Babbie and Mouton (2003:278), credibility measures can be used to ensure dependability, because there can be no credibility without dependability.

Dependability has been ensured through the following methods:

### ***2.6.3.1 Dense description of the research methods***

The researcher has clearly and fully described the research methods.

### ***2.6.3.2 Dependability audit***

The researcher has a comprehensive collection of documents, which will allow an independent auditor to make conclusions about the data. These documents include field notes, interview transcripts, notes from member checks, and drafts of the final report.

## **2.6.4 Confirmability/neutrality**

Neutrality is defined as freedom from bias in the research procedure and results such that there would be agreement between two or more independent people about the data's relevance or meaning. In qualitative research, neutrality should not be viewed by the characteristics of the researcher, but by the neutrality of the data (Polit, Beck & Hungler 2001:315). Babbie and Mouton (2003:278) state that neutrality of data can be achieved through an audit trail. Neutrality was achieved through an audit trail, bracketing, and intuition.

### ***2.6.4.1 Audit trail***

The researcher has a comprehensive collection of documents that will allow an independent auditor to make conclusions, interpretations, and recommendations about the data, which can be traced back to their sources. Her documents include field notes, interview transcripts, tapes, and drafts of the final report.

**Table 2.2: Strategies for ensuring the trustworthiness of the study**

<b>Criteria</b>	<b>Strategy</b>	<b>Application</b>
<b>Credibility/ truth value</b>	Prolonged engagement	<ul style="list-style-type: none"> <li>The researcher spent a month at the VCT centre to understand the culture and the environment in which data was collected.</li> <li>The researcher spent 20-30 minutes with each participant and focus group, to build rapport and explain the purpose of the study and ethical issues involved.</li> <li>The researcher spent 45-60 minutes in conversation with participants and conducting in-depth individual interviews and FGDs, until data saturation was reached.</li> </ul>
	Reflexibility	<ul style="list-style-type: none"> <li>Examination of the researcher's perspectives about QOL, HIV and AIDS, and ART, to avoid biases.</li> <li>The keeping of field notes.</li> </ul>
	Triangulation	<ul style="list-style-type: none"> <li>Multiple data sources were used for generating and refining the attributes of QOL during concept analysis.</li> <li>Use of qualitative, explorative, descriptive and contextual design.</li> <li>Purposive sampling.</li> <li>A workshop, in-depth semi-structured individual interviews, FGDs, observations, field notes, and a literature control.</li> </ul>
	Referential adequacy	<ul style="list-style-type: none"> <li>Use of notebooks, videotapes, and audiotapes.</li> </ul>
	Peer debriefing	<ul style="list-style-type: none"> <li>An impartial colleague who is experienced in qualitative research reviewed and critiqued the study and made recommendations.</li> </ul>
	Member checking	<ul style="list-style-type: none"> <li>This was done through testing analytical categories and interpretations with participants.</li> </ul>
	Authority of the researcher	<ul style="list-style-type: none"> <li>Use of the research supervisors who are experts in qualitative research and hold doctoral degrees in nursing science.</li> </ul>
	Dense description of methodology	<ul style="list-style-type: none"> <li>Adequate description of the research methodology, a literature control, and verbatim quotations were taken from the narratives.</li> </ul>
	<b>Transferability/ applicability</b>	Thick description
Purposive sampling		<ul style="list-style-type: none"> <li>Purposive sampling of expert nurses involved in AIDS care for validation of the domains of QOL and purposive sampling of PLWHA on ART.</li> </ul>
Data collection		<ul style="list-style-type: none"> <li>Data was collected until data saturation was reached.</li> </ul>
<b>Dependability/ consistency</b>	Dependability audit	<ul style="list-style-type: none"> <li>The use of the research supervisor as a debriefer.</li> </ul>
	Dense description	<ul style="list-style-type: none"> <li>Dense description of research methods.</li> </ul>
<b>Confirmability/ neutrality</b>	Audit trail	<ul style="list-style-type: none"> <li>The keeping of field notes.</li> </ul>
	Bracketing and intuition	<ul style="list-style-type: none"> <li>The use of bracketing and intuition during data collection and analysis.</li> </ul>

## **2.7 ETHICAL AND LEGAL CONSIDERATIONS**

Research ethics committees are essential to protect individual patients and clients, as well as the public health (Van der Wal 2005:155). Ethical considerations are important in research and include ethical conduct towards participants' information, as well as honest reporting of the results. The research was approved by the UNISA Research Ethics Committee and the Swaziland Scientific and Ethics Committee.

According to Van der Wal (2005:151), when applying ethical principles to research, it is helpful to bear the following three considerations in mind. These are the participants, the institution, and the integrity of the researcher. The researcher has discussed how the above were ensured.

### **2.7.1 The participants**

The research participant is always the researcher's first concern (Van der Wal 2005:151). Adhering to strict ethical guidelines is even more important in this research, since the participants are highly vulnerable. PLWHA are vulnerable, firstly, because stigmatisation relegates them to this position, and, secondly, because they meet all the criteria set for vulnerable groups (Van der Wal 2005:149). These criteria are:

- limited economic development;
- inadequate protection of human rights;
- discrimination on the basis of health status;
- inadequate understanding of scientific research;
- limited availability of healthcare and treatment options; and
- impaired ability of individuals in the community to provide informed consent.

Because ethical issues in social research are important, most of the professional associations have created and published formal codes of conduct describing what is

acceptable and unacceptable professional behavior (Babbie & Mouton 2003:528). For this reason, the ethical and moral principles laid down by the Democratic Nursing Organisation of South Africa (DENOSA 1998), the Swaziland Scientific and Ethical Guidelines, and the ethical standards contained in Burns and Grove (2005:176-208) and Polit and Beck (2008:167-192) were adhered to in this study.

### **2.7.1.1 Informed consent**

According to the Nuremberg Code (1949), as cited in Burns and Grove (2005:193), informed consent means that “the person involved should have legal capacity to give consent/agreement, should be situated as to be able to exercise free power of choice without the intervention of any element of force, fraud, deceit, duress, overreaching or other ulterior form of constraint or coercion, and should have sufficient knowledge and comprehension of the elements of the subject matter involved to enable them to make understanding and enlightened decisions”.

Based on the above, it can be safely stated that the principle of free and informed consent is a core value in health. It is not just about permission giving, but is rather a decision-making process which is sensitive to context and consists of four elements, namely (1) disclosure, (2) comprehension, (3) competency, and (4) voluntarism (Burns & Grove 2005:193).

For participants to give consent, they received an explanation of the following:

- the research, the procedures that would be followed, and the aim of each procedure;
- the physical risks or discomfort, or any invasion of the patient’s privacy, or any threat to dignity;
- the methods that would be used to ensure anonymity and confidentiality;
- the tasks expected of them, so that they could make an informed choice to participate voluntarily in the research;
- the advantages of the research to the participants, or to society;

- the type of data that would be collected;
- how participants would be selected, and how many would be participating;
- the condition that participation was strictly voluntary, and that failure to volunteer would not result in any penalty or loss of benefits; and
- who to contact in case of further questions, comments, or complaints.

The above was explained in a full, non-technical, clear explanation that was “at the intellectual level of the client” (Van der Wal 2005:152). The principle of veracity was upheld, in that the whole truth, and nothing but the truth, about the research was told (Van der Wal 2005:152). Coercion, threats, and inducement were avoided, since they limit the voluntary or autonomous choices of participants. Consent was solicited on an ongoing basis.

### ***2.7.1.2 Autonomy***

Autonomy means the right to self-determination. Individuals have the right to conduct themselves as autonomous agents, without external control, coercion, or exploitation, especially when they are asked to participate in research. For this study, autonomy was ensured by informing participants that they had the right to the following:

- to withdraw from the study at any point in time; and
- to refuse to provide any information.

### ***2.7.1.3 Confidentiality and anonymity***

According to Burns and Grove (2005:188), confidentiality means “the researcher’s management of private information shared by a subject that must not be shared with others without authorisation of the subject”. Confidentiality of patient information is essential to maintaining a bond of trust between the patient and the health professional and protecting the human rights of the patients.

An important point to note is that maintaining confidentiality is often more difficult in qualitative research than it is in quantitative research (Burns & Grove 2005:189). The nature of qualitative research requires that “the investigator must be close enough to understand the depth of the question under study and must present enough direct quotes and detailed description to answer the research question” (Ramos 1989, as cited in Burns & Grove 2005:189). In addition, the small number of participants used in qualitative studies and the depth of details gathered on each participant make it difficult to disguise the participant’s identity (Burns & Grove 2005:189). In spite of the above assertions, the researcher was able to safeguard the confidentiality of the participants by using the following advice from Polit and Beck (2008:180):

- Obtain identifying information (for example, name, address, etc.) from participants only when it is essential;
- Assign an identification (ID) number to each participant, and attach the ID number rather than other identifiers to the actual data;
- Maintain any identifying information and lists of ID numbers with corresponding identifying information in a locked file;
- Restrict access to identifying information to a small number of people on a need-to-know basis;
- Enter no identifying information onto the computer files;
- Destroy identifying information as quickly as practically possible;
- Make research personnel sign confidentiality pledges if they have access to data or identifying information; and
- Report research information in the aggregate: if the information for a specific participant is reported, take steps to disguise the person’s identity, such as through the use of a fictitious name.

In addition to the above:

- Participants were informed on an ongoing basis that they had the right to withhold information;
- Participants were told how the data was to be recorded, stored, and released;
- The personal identity of participants was concealed, and only summarised group information or anonymous quotations were published.
- Raw data containing participants' personal details was kept in a secured place once data had been entered on a database or once it had been analysed.

A breach of confidentiality could harm the interests of the patient, as well as the relationship between the researcher and the participant. It may be viewed as a serious ethical offence, and disciplinary steps may ensue (Strauss 1992:15). In this research, a breach of confidentiality can put the patient at risk of being stigmatised, discriminated against, and isolated, as AIDS is still a stigmatised disease.

#### **2.7.1.4 Privacy**

Sieber (1982), as cited in De Vos et al. (2005:61), states that privacy is “that which normally is not intended for others to observe or analyze”. Privacy is the right an individual has to determine the time, extent, and general circumstances under which personal information will be shared with or withheld from others (Burns & Grove 2005:186). Failure to provide privacy might cause loss of dignity, friendship, or employment, or might create feelings of anxiety, guilt, embarrassment, or shame (Burns & Grove 2005:186).

In this study, the participants' privacy was protected by informed consent. The rights, interests, and wishes of participants were assured at all times, and the researcher collected only necessary information, that is, information on QOL and on ART.

### **2.7.2 The institutions**

According to Van der Wal (2005:154), it is imperative that the institutions be treated as a person by the researcher. The ethics that apply to individual participants also apply to the institution. The ethical principles discussed above with regard to the individual participant were also assured for the institution. To ensure anonymity, the institution was protected by ensuring that it was not possible to relate particular data to a particular person in an institution (Brink 2001:51). It was ensured that statements made by participants or the researcher represented these individuals' personal opinions and were not necessarily the opinions of the institution at which the research was conducted (Van der Wal 2005:155).

### **2.7.3 The integrity of the researcher**

Before undertaking research, researchers must ensure that they are competent and adequately skilled to undertake the proposed investigation (De Vos et al. 2005:63). Investigating HIV and AIDS is sensitive. Thus the researcher's competence is very important. The researcher in this study was guided by scientific principles. She aimed at being objective and refrained from making value judgements (Loewenberg & Dolgoff 1988, as cited in De Vos et al. 2005:63). According to Thomas (2002:10), when doing research on the lived experience of a person living with AIDS, researchers must possess at least basic skills in HIV and AIDS counselling. As HIV and AIDS is an emotive infection, the researcher used empathy, trustworthiness, warmth, unconditional acceptance of PLWHA, and genuineness to help the participants to disclose their experiences of being on ART.

### **2.7.4 The quality of the research**

To ensure that the research was of high quality, the researcher did the following:

- She adhered to standards of research planning, implementation, and reporting;

- The standards of conduct, including supporting and opposing views, and being aware of personal biases and values, were strictly observed;
- The research findings were reported fully, without purposely omitting significant data, and making explicit any methods and research designs which might influence interpretation;
- The research supervisors, who are people with great knowledge, skills, and experience in research, ensured that the research was conducted in a moral, just, and valid way;
- The research methodology and techniques of analysis were disclosed accurately and completely;
- Limitations, omissions, and failures of the study were acknowledged; and
- Fabrication of the results was avoided.

## **2.8 TERMINATION**

The researcher explained the participants' rights to withdraw from the study. Qualitative research methods do not permit the faking of data in order to get better or more desired results. There was no coercion of the participants. In this study, fabricating the results would help neither the researcher nor the Ministry of Health in Swaziland, which needs to improve health services rendered to the people in this era of HIV and AIDS and ART.

## **2.9 DISSEMINATION OF THE INFORMATION**

According to Polit and Beck (2008:691), no study is complete until the findings have been shared with others. Results have to be known, because they "contribute to the base of evidence for nursing practice", besides the fact that it is a researcher's professional responsibility to disclose the results of an investigation (Polit & Beck 2008:601). Furthermore, the value of a research study will never be fully appreciated unless it is shared (Streubert Speziale & Carpenter 2007:441).

A copy of the research report will be handed to the Ministry of Health and the RFMH VCT Centre, where the study was conducted. The information will be published in relevant journals. The participants will be informed of the research outcomes if they so desire.

## **2.10 CONCLUSION**

In this chapter, the researcher covered the various methodological steps involved in conducting this research. A qualitative, exploratory, descriptive, and contextual design was used for this study. This study was conducted in four phases. Phase 1 covers the literature review. Phase 2 carries the validation of the QOL domains by nurses involved in AIDS care. Phase 3 covers the assessment and description of QOL of PLWHA in Swaziland who are on ART. Data was analysed using Tesch's framework of data analysis as described in Creswell (2002:256-283). Data verification was applied through the use of Guba's (1985) model of trustworthiness, which includes the following four criteria for assessing trustworthiness:

- credibility;
- transferability;
- dependability; and
- confirmability.

Phase 4 covers the development of guidelines that will be used to empower PLWHA in Swaziland who are on ART. The guidelines were reviewed by external reviewers for their clarity, simplicity, generalisability, importance, and consistency (Chinn & Kramer 1999:111; Walker & Avant 2005:160-179).

The following chapter deals with a review of related literature.

## CHAPTER 3

### REVIEW OF RELATED LITERATURE

#### 3.1 INTRODUCTION

In the previous chapter, the research design and methods were comprehensively discussed. This chapter details a review of related literature. A review of relevant literature is conducted “to generate a picture of what is known about a particular situation and the knowledge gaps that exist in it, and this background enables the researcher to build on the works of others” (Burns & Grove 2005:37). Relevant literature refers to “those sources that are pertinent or highly important in providing the in-depth knowledge needed to study a selected problem” (ibid.). Nieswiadomy (2008:89) states that there are many purposes for reviewing the literature before conducting a research study, the most important one being to determine what is already known about the topic that you wish to study. According to Polit and Beck (2008:65), a review of related literature is a crucial part of a study, since “it lays the foundation of the whole study”.

Both primary and secondary literature sources were consulted, but the researcher relied mostly on primary sources. Primary sources are “a description of studies written by the researcher who conducted them”, and secondary sources are “descriptions of studies prepared by someone other than the original researcher” (Polit & Beck 2008:106).

For this study, a review of related literature was done mainly for the following reasons:

- To identify a research problem. Through the initial literature review, the researcher was able to identify and formulate the research problem for this particular study. It was identified through a literature review that QOL of PLWHA in Swaziland who are on ART was assessed based on CD4 cell count and the presence or absence of side effects caused by ARVs. Although the CD4 cell count gives important information, it does not

reveal the subjective QOL, which is the main concern that prompted the researcher to conduct the study. According to the researcher, QOL is more than blood tests and medication side effects.

- To refine the research objectives. The objectives of the study were to describe the concept of QOL, to identify the relevant domains that need to be considered when assessing QOL of PLWHA in Swaziland, to assess and describe the QOL of PLWHA in Swaziland who are on ART, and to develop guidelines that will be used to empower PLWHA in Swaziland who are on ART. These objectives were refined through the literature review.
- To identify what is known about the phenomenon under inquiry. The phenomenon under inquiry was QOL of PLWHA who are on ART. This helped to orient the researcher to what is known about QOL, in general, and QOL of PLWHA on ART, in particular, and it enabled her to develop guidelines that will be used to empower PLWHA who are on ART.
- To identify a relevant paradigmatic perspective for the study. Through the literature review, the researcher identified Betty Neuman's Systems Model as a suitable approach for the study. Betty Neuman's Systems Model was chosen for its philosophy of holism. For the development of the guidelines, the researcher adopted the framework of Dickoff et al. (1968). This framework was chosen because of its comprehensiveness in theory development. The framework addresses six aspects that are important in any nursing activity. These are purpose, agency, reciprocity, context, dynamics, and procedure. Section 6.2 provides a detailed description of this framework.
- To assist in the concept analysis of QOL. In order to conduct a valid QOL assessment, concept analysis of QOL had to be done. Various sources were consulted to give meaning to the concept of QOL and its associated domains. (See section 3.2 for a concept analysis of QOL.)

- To assist in the interpretation of the study findings and to develop implications and recommendations. The study findings were interpreted in the light of other relevant studies (see Chapter 5). The literature review assisted the researcher to make relevant recommendations for nursing practice, research and education. (See Chapter 7 for recommendations of the study.)
- To assist in the development of guidelines that will be used to empower PLWHA in Swaziland who are on ART. (See Chapter 6 for the empowerment guidelines.)

### **3.2 CONCEPT ANALYSIS OF QUALITY OF LIFE**

In this section, the researcher was engaged in analysis of the concept of QOL. There are many reasons why researchers conduct concept analysis. Concept analysis is a strategy that allows one to examine the attributes or characteristics of a concept (Walker & Avant 2005:63). According to Burns and Grove (2005:122), concept analysis is a strategy through which a set of characteristics essential to the connotative meaning of a concept is identified. The purpose of concept analysis is to distinguish between the defining and the non-defining relevant attributes of a concept, to arrive at precise operational definitions of a concept, and to accurately reflect the theoretical base of a study (Walker & Avant 2005:64).

For this study, the researcher did concept analysis to obtain a concise operational definition of the concepts of quality, life, and QOL. This conceptual analysis also formed the basis for the whole literature review. Furthermore, concept analysis focused the whole literature review.

In order for the researcher to assess QOL of PLWHA in Swaziland who are on ART, the concept of QOL had to be clearly defined. The researcher was of the opinion that QOL cannot be assessed without a clear definition of the concept. According to Walker and

Avant (2005:63) and Chinn and Kramer (1999:107-174), the defining of concepts during concept analysis is a formal linguistic exercise to determine the defining attributes of the concept. Through the process of concept analysis, the researcher was able to identify the defining attributes, or the essential domains, of QOL.

### **3.2.1 Definition of the central concepts**

Copi and Cohen (1994:173) state that concept definition helps to reduce vagueness and ambiguity in a given context when a concept has more than one distinct meaning, and the context does not make clear which meaning is intended. Therefore, for the purpose of reducing vagueness in the concepts identified, the researcher had to define the concepts. Concept definition of QOL was done by providing the dictionary meaning and the meaning in context.

The concept of QOL has been examined in many of the available dictionaries and thesauruses, but a limited number of dictionaries or thesaurus contained the term, because it is a phrase, and many dictionaries and thesauruses do not generally include phrases among their entries. However, when the phrase is broken down, there are many definitions of the words “quality” and “life”.

Dictionary definitions of “quality” and “life” are provided, after which the contextual (subject) definitions of QOL are analysed through a literature search and the creation of conceptual meaning in the context of this study, that is, PLWHA in Swaziland who are on ART. The analysis of the concept of QOL began with an intense examination of the word “life”.

### **3.2.1.1 Life**

The concept of life is simple to mention, but very difficult to define. Since life is such a difficult concept to define, definitions of it are numerous. People define it in different ways, for different reasons.

The Oxford Advanced Learner's Dictionary (2000:683) defines the word "life" as "the period between birth and death". This definition does not include life in the uterus, whereas the Hyper Dictionary (<http://www.hyperdictionary.com>) defines "life" as "the state of being which begins with generation, birth and ends with death". This definition includes life in the uterus.

In addition, the Hyper Dictionary states that "life" means "the union of the body and soul, and also the duration of their union". This dichotomist definition implies that human life is the integration of the body (flesh) and the soul. The body itself does not make up life, as it needs the soul. The word "soul" comes from the Greek word *psuchee*, meaning "breath".

The word "life" can be defined in many ways to suit one's purposes. Words are our servants, not our masters, so one can use any words to describe the concept of life for one's own convenience. A human being is like a diamond with its many facets. The facets are not separate entities; rather, they reflect various aspects of the whole. They may serve similar or overlapping functions, yet they are distinguishable. They are not parts; they are aspects, facets, or faces, of the whole.

For this study, the concept of life as applied to a human being means a physiological, psychosocial, spiritual, sociocultural, and an emotional being that has needs and is in constant interaction with the environment. He or she influences the environment and, in turn, is influenced by it. This human being is with dignity, which should not be obscured by any developmental or sickness-oriented labels, such as "HIV and AIDS". Subsequent

to defining the concept of life, the researcher searched for the meaning of the concept of quality in the context of this study.

### **3.2.1.2 Quality**

One of the important challenges that have been faced by healthcare professionals for decades is to define the term “quality”. Ask any healthcare professional what is meant by the term, and he or she may have difficulty explaining the concept clearly. Even experts have difficulty defining the term.

It is known that if something is better than other similar things, then it has quality. The difficulty with this definition comes from the misuse of the concept. So far there is no universal definition of the term “quality”. The result of the inability to define the term is that most definitions will bear a resemblance to others, but none of them will be *the* definition. Quality, like life, is a concept that has a multitude of meanings. It depends on the context or perspective in which it is being used. It is a much more complicated term than it appears, yet it is used every day. Quality cannot be defined, in principle because it is an abstract concept.

According to the Oxford Advanced Learner’s Dictionary (2005:1187), “quality” means “a high standard”. In addition to the meaning of “a high standard”, the Concise Oxford English Dictionary (2002:1170) expresses the idea that quality should be measured against a set standard. The Concise Oxford English Dictionary (2002:1170) defines “quality” as “the standard of something as measured against other things of similar kind”. The Concise Oxford English Dictionary (2002:1170) further defines quality as “general excellence, high social standing, a distinctive attribute or characteristic”. Blackwell’s Dictionary of Nursing (2003:561) defines “quality” as “a characteristic that denotes excellence, superiority and fineness”.

It can be concluded that quality can mean many things, ranging from a high standard,

superiority in its kind, having a high degree, or grade, of excellence, or worth, being exceptionally good, being world-class, having zero defects, and being of superior grade and fineness.

### **3.2.1.3 Subject definition of “quality of life”**

Once the two words “quality” and “life” had been examined separately, there was a need for the researcher to examine the words as part of the concept “quality of life”. In order to conduct a valid and reliable study of the QOL of PLWHA who are on ART, a clear definition of “QOL” was required. For centuries people have been concerned with seeking “a good life”, or “a quality life”. In that search, the prevailing question has been “What is the quality of any particular life?” Many individuals, healthcare professionals, and researchers have used the term “quality of life” without clearly defining the term. According to McKeivitt, Redfern, La-Placa and Wolfe (2003:865), QOL is an important but poorly defined outcome in health and healthcare research.

For many years there has been a lack of agreement on how to define “quality of life”. Because of this, there is no universally accepted definition of this concept. There is a lack of unanimity concerning the concept, with the construct reported to be multifaceted and complex, with a variety of meanings reflecting the context in which it is explored (Lukkarinen & Hentinen 2006:30; Anderson & Burchardt 1999; Haas 1999; and Rustoen, Moun, Wiklund & Hanestard 1999, as cited in Cleary & Drennan 2005:578).

As there is a lack of agreement on the definition of the concept, literature is replete with definitions of QOL. According to the Scottish Executive Publication of September 2006, there are over 100 subject definitions of quality of life (<http://www.scotland.gov.uk/publications.2006/01>). These definitions range from those with a holistic emphasis on the social, emotional, and physical wellbeing of patients after treatment, to those that describe the impact of a person’s health on his or her ability to lead a fulfilling life (Carr et al. 2001:1241).

Different authors define QOL from the perspective of their own research interests and objectives. Therefore, QOL definitions vary widely. Philosophers are concerned with the nature of human existence, and thus define quality of life as a good life (Holmes 1989 and Faden & LePlege 1992, in Anderson & Burckhardt 1999:301). Ethicists debate the shift in healthcare decision making according to the perspective of sanctity of life, to quality of life, and social utility (Edlund & Tancredi 1985, in Anderson & Burckhardt 1999:301). Economists are concerned with the allocation of resources to achieve alternative goals, and thus look at quality of life in terms of adequacy of resources (Grabowski & Hansen 1990, in Anderson & Burckhardt 1999:3001). Physicians focus on health and illness-related variables (Pealman & Uhlman 1988, in Anderson & Burckhardt 1999:3001). Nurses, in keeping with the discipline's holistic approach, take the broadest view in defining quality of life (Farquhar 1995:506).

Quality of life has been defined and measured in a number of different ways by researchers. Several researchers have defined quality of life in terms of life satisfaction (Ferrans 1985, in Farquhar 1995:504; Zhan 1992, in King & Hinds 1998:42; Browne, Boyle, Mcgee, Joyce, McDonald, Omarley & Hiltbrunner 1994, in Hellstron, Persson & Hallberg 2004:585). Other researchers incorporate symptoms of specific diseases into their conceptualisation and measurement of life quality (Lukkarinen & Hentinen 2006:30; Aaronson 1991 and Schipper 1991, in King & Hinds 1998:25; Clinch & Schipper 1993, in King & Hinds 1998:42; Oleson 1990, in King & Hinds 1998:42; Cummings 2000:56; and Hagerty 2001:74-75).

In her taxonomy, or classification, of definitions based on a systematic review of literature, Farquhar (1995:503) identified four major types of QOL definitions. These are:

- General or global definitions;
- Component definitions (definitions which break the concept into a series of component parts or dimensions);

- Focused definitions (definitions that focus on only one or two of the component parts); and
- Combination definitions.

Global definitions are the most common type of QOL definitions within the literature, according to Farquhar. Because of their generality, they offer little insight into the possible components of QOL, or how the concept could be operationalised. They incorporate ideas of satisfaction/dissatisfaction and happiness/unhappiness. For example, Abrams (1973), as cited in (Farquhar 1995:503), defined QOL as “the degree of satisfaction or dissatisfaction felt by people with various aspects of their lives”, and Andrews (1974), as cited in Farquhar (1995:503), relates the extent to which pleasure and satisfaction characterise human existence.

Component definitions are the ones that break QOL into a series of component parts or dimensions, or identify certain characteristics deemed essential for any evaluation of QOL. All these dimensions can contribute to global definitions. They are more useful for empirical work than global definitions, as they come closer to operationalising the concept.

Focused definitions are those definitions that refer to only one concept, or a small number of the concepts, of QOL. Focused definitions can be either implicit or explicit. Implicit definitions focus on one component, or a small number of the components, of QOL. Explicit definitions use terms such as “health-related QOL”, or micro-economic definitions of “quality”, rather than of the term “QOL” itself. Combination definitions combine global definitions and component definitions. Table 3.1 graphically represents a taxonomy of QOL definitions.

**Table 3.1: A taxonomy of quality of life definitions**

TYPE	NAME OF TYPE	DESCRIPTION
I	Global definitions	The most common, general type of definitions. They usually say little about the possible components of QOL. They usually incorporate ideas of satisfaction/dissatisfaction or happiness/unhappiness.
II	Component definitions	They break down QOL into a series of components, dimensions, or domains, or identify characteristics deemed essential to any evaluation of QOL.
IIa	Non-research-specific definitions	They identify a number of dimensions of general QOL, but may not necessarily claim to cover every possible dimension.
IIb	Research-specific definitions	They are explicitly tailored to meet the objectives of a particular piece of research. They may therefore overlook or exclude certain dimensions of QOL considered less relevant to the aims of the research.
III	Focused definitions	They refer only to one dimension, or a small number of the dimensions, of QOL.
IIIa	Explicit definitions	They focus on a small number of dimensions of QOL considered essential to QOL, and do so explicitly.
IIIb	Implicit definitions	They focus on one or two dimensions of the broader concept of QOL, but implicitly, without making the concept clear.
IV	Component definitions	These are global definitions (the same as Type I) that also specify dimensions (as in Type II).

(Farquhar 1995:503)

Other researchers define the concept of QOL in terms of objectivity and subjectivity. According to Ventegodt et al. (2003:1032), QOL can be divided into subjective QOL, existential QOL, and objective QOL. Subjective QOL is how good a life each individual feels he or she has, and the way each individual personally evaluates how he or she views things (Ventegodt et al. 2003:1032). Whether an individual is content with life and happy are aspects that reflect subjective QOL.

Existential QOL means how good one's life is at a deeper level. It is assumed that an individual has a deeper nature, that deserves to be respected, and that the individual can live in harmony with (Ventegodt et al. 2003:1032).

Objective QOL means how one's life is perceived by the outside world. This perception is influenced by the culture in which a person lives. Objective QOL reveals itself in a person's ability to adapt to the values of a culture, and tells us little about the person's life, for example, the person's social status (Ventegodt et al. 2003:1032). According to Ventegodt et al. (2003:1032), these three subtypes of QOL overlap and they can be placed in a spectrum, from the subjective QOL, through the existential QOL, to the subjective QOL.

There have been debates on the issue of measurement of QOL. The debates include whether QOL should be objectively or subjectively measured, whether it should be uni- or multidimensional, whether it should be relative or absolute, the role of values in QOL, the place of self-evaluation in QOL, and the role of culture in QOL.

Early efforts to define and measure QOL took either an economic or objective social-indicators approach. However, studies conducted in the 1970s showed that objective measures of life conditions accounted for only a modest proportion of an individual's subjectively reported QOL and/or wellbeing (Haas 1999:729).

Cummings (2000:56) reports a range of studies from as early as 1970 onwards demonstrating that individuals report levels of satisfaction with the environment in which they live, regardless of the objective poverty of their environment.

Studies by Andrews and Withey helped to re-orient QOL research towards subjective measures (Campbell, Converse & Rodgers 1976, in Rapley 2003:14). The prevalent use of economic indicators as measures of national QOL began to be challenged as studies focused on subjective responses to life conditions. Table 3.2 lists the objective and subjective indicators of QOL.

**Table 3.2: Objective and subjective indicators of QOL**

<b>OBJECTIVE INDICATORS</b>	<b>SUBJECTIVE INDICATORS</b>
Life expectancy	Sense of community
Crime rate	Material possessions
Unemployment rate	Sense of safety
Gross domestic product	Happiness
Poverty rate	Satisfaction with life as a whole
School attendance	Relationship with family
Working hours per week	Job satisfaction
Perinatal mortality rate	Sex life
Suicide rate	Perception of distributive justice, class identification, hobbies, and club membership.

(Rapley 2003:11)

Today, there is consensus around the need to combine objective and subjective aspects of QOL, based on an acknowledgement of the strengths and weaknesses of each approach, as many models now incorporate both objective and subjective domains of QOL (Keith 2001:51; Cummings 2000:56; and Hagerty 2001:7).

Concerning the debate about whether QOL is unidimensional or multidimensional, the majority of QOL definitions stress the multidimensional nature of the concept typically manifested in the specification of a number of QOL domains (Falce 1997:127). Table 3.3 represents the domains of QOL by different authors.

Unidimensional definitions include those where QOL is regarded as synonymous with health alone (Michalos 2004:59). In most instances, QOL has also been unidimensionally defined in terms of life satisfaction. However, Cella and Tusky (1991), in King and Hinds (1998:24), recommend avoiding the term “QOL” when discussing or measuring only a single dimension of the concept. Their idea is that a single dimension does not add up to QOL, as this concept has many domains, or attributes.

Looking at the importance of personal values, a number of researchers have emphasised the importance of personal values and aspirations of individuals in

determining their QOL (Keith 2001:52). Personal values reflect cultural and social influences and develop and change over time. Values cannot be separated from culture.

The impact of culture on QOL has been considered very important. Culture is defined as a patterned behavioural response that develops over time as a result of patterning the mind through social and religious structures and intellectual and artistic works (Potter & Perry 2003:410). It is shaped by values, beliefs, norms, and practices that are shared by members of the same group. Culture guides our thinking, doing, and being and becomes patterned expressions of who we are (Potter & Perry 2003:410). Culture shapes how we explain and value our world. It is a lens through which we give our world meaning. Research has shown that the perception of the causes and the treatment of illness and disease vary with culture. Culture influences how, where, and when people seek health care.

Some experts agree that perceptions of quality of life are embedded in cultural beliefs on what constitutes what is normal, even when it comes to physical appearance and body functions. They argue that what is considered a good life varies between individuals in different societies and cultures, and that the attribute of QOL may vary from one culture to another, hence the dimension of culture being incorporated in the definition of quality of life by the WHO (1991), Clinch and Schipper (1993), in King and Hinds (1998:42), and Haas (1999:733).

Self-evaluation is an important form of evaluation of QOL. Self-evaluation becomes a problem in cases of individuals that lack communication skills, such as young children, elderly people with dementia, people with cognitive impairments or severe distress, and people with learning difficulties. Keith (2001:51) describes this as a potentially serious problem with efforts to assess subjective QOL. It is precisely the above types of individuals for whom information on QOL is most needed for decision making (Addington-Hall & Kalra 2001:1420). A study by Slevin, Plant, Lynch, Drinkwater and Gregory (1988:109) found wide discrepancies between doctors' and patients'

assessments of patients' QOL and concluded that doctors could not adequately measure QOL. This is because of the subjective nature of QOL.

#### **3.2.1.4 Quality of life definitions**

As was mentioned earlier, there has been a lack of agreement on how to define QOL, and, as such, the concept has many definitions. Ferrans and Powers (1985), in ChingSuet (2001:219), define quality of life as the extent to which an individual's sense of wellbeing stems from satisfaction or dissatisfaction with the aspects of life that are important to that individual. This definition only looks at satisfaction with life, thus gives individual parts of the components of QOL. It is an example of a unidimensional definition of QOL. Similarly, Dalkey and Rouke (1973), in Farquhar 1995:504, describe QOL as "a person's sense of wellbeing, his satisfaction or dissatisfaction with life, or his happiness or unhappiness". However, Hagerty (2001:7) defines QOL as "a term that implies the quality of a person's whole life, not just some component part of it, and it therefore follows that if QOL is to be segmented into its component domains, those domains in aggregate must represent the total construct". This implies that one component of wellbeing does not constitute QOL. Consequently, health alone does not constitute QOL.

The above is in agreement with Cummins (2000:56), who defines QOL as "both objective and subjective, each axis being the aggregate of seven domains, and those are material wellbeing, health, productivity, intimacy, safety, community, and emotional wellbeing". Objective domains comprise culturally relevant measures of objective wellbeing. Subjective domains comprise domain satisfaction weighted by its importance to the individual. This definition implies that QOL is a multidimensional construct encompassing domains that reflect the person's subjective and objective wellbeing.

In addition to subjective and objective factors, Falce and Perry (1996:67) argue that personal values, together with subjective and objective factors, give an overall QOL

appraisal. Falce and Perry define a personal value as “the relative importance to an individual of objective life conditions and subjective wellbeing with regard to a given aspect of life”.

Cella (1994), in King and Hinds (1998:42), defines quality of life as a patient’s **appraisal** of and satisfaction with his or her current level of functioning, compared to what he or she perceives to be possible, or ideal. In this definition, Cella has identified physical wellbeing, functional wellbeing, emotional wellbeing, and social wellbeing as important domains of quality of life. Cella defines QOL as a person’s evaluation of what is, instead of what is supposed to be.

A shorter definition of QOL is given by Calman (1984), in Carr et al. (2001:1243), who views it in terms of experiences. He defines the concept as “the **discrepancy** between our expectations and our experiences”. According to Calman, what one experiences should match one’s expectations, in order to maintain a good QOL. Any mismatch can decrease individuals’ QOL. This definition is different from Cella’s (1994) definition, in that the individual is comparing expectations with experiences.

Oleson (1990), in King and Hinds (1998:42), asserts that QOL is a cognitive **experience** manifested by satisfaction with life domains that are of importance to the individual, and an affective experience manifested by happiness. She identifies the consequences of a positively perceived QOL as the development of personal potential and self-actualisation. Domains identified by Oleson are health and functioning, socio-economic status, the psychological/spiritual domain, and the family. Oleson’s definition is similar to Falce and Perry’s definition, in that in her definition, personal values are deemed important to QOL.

Expanding on the issue of experiences, Zhan (1992), in King and Hinds (1998:42), defines quality of life as “the **degree** to which a person’s life experiences are satisfying”. QOL, according to this author, is a multidimensional concept that cannot be measured

by either the subjective or the objective approach. Zhan identified life satisfaction, self-concept, health functioning, and socio-economic factors as the main domains of QOL.

Cella and Tulsy (1990), in Carr and Higginson (2001:1359), define QOL in different terms, but the meaning is the same as in the above definitions. They define the concept as “the **appraisal** of one’s current state against some ideal”. Kleinpel (1991:223) found that the concept of QOL was associated with vague and abstract meanings, including life association and perceptions of wellbeing.

The University of Toronto Quality of Life Research Unit (1994) defines quality of life as “the **degree** to which a person enjoys the important possibilities of her life”. Possibilities result from the opportunities and limitations each person has in his or her life, and reflect the interaction of personal and environmental factors. Enjoyment, according to this definition, has two components, namely the experience of satisfaction, and the possession or achieving of some characteristics. The conceptual framework for this definition has three life domains, each of which has three subdomains. Table 3.3 shows the domains of QOL by the Quality of Life Research Unit (1994).

**Table 3.3: Domains of quality of life by the University of Toronto Quality of Life Research Unit (1994)**

<b>The being domain</b>	<b>The belonging domain</b>	<b>The becoming domain</b>
<p>It includes the basic aspects of who one is, and it has three subdomains, namely:</p> <p><b>The physical being</b>, which includes aspects of physical health, personal hygiene, nutrition, exercise, grooming, clothing, and physical appearance;</p> <p><b>The psychological being</b>, which includes the person’s psychological health and adjustment, cognitions,</p>	<p>It includes the person’s fit with his or her environment, and it also has three subdomains, namely:</p> <p><b>Physical belonging</b>, which is defined as the connections the person has with his or her physical environment, such as home and the workplace, the neighbourhood, school, and community;</p> <p><b>Social belonging</b> includes links with social environments</p>	<p>This refers to purposeful activities carried out to achieve personal goals, hopes, and wishes.</p> <p><b>Practical becoming</b> describes day-to-day actions, such as domestic activities, paid work, school or volunteer work, and seeing to health or social needs.</p> <p><b>Leisure becoming</b> includes activities that promote relaxation and stress</p>

<p>feelings and evaluations concerning the self, and self-control; and</p> <p><b>The spiritual being</b>, which reflects personal values, and personal standards of conduct and spiritual beliefs, which may or may not be associated with organised religions.</p>	<p>and includes the sense of acceptance by intimate others, family friends, co-workers, and the neighbourhood and community; and</p> <p><b>Community belonging</b>, which represents access to resources normally available to community members, such as adequate income, health and social services, employment, educational and recreational programmes, and community activities.</p>	<p>reduction. These include card games, neighbourhood walks, and family visits, or activities of longer duration, such as vacations or holidays.</p> <p><b>Growth becoming</b> activities promote the improvement or maintenance of knowledge and/or skills.</p>
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(<http://www.utoronto.ca/qol/concepts.html>)

Fainsinger (2000:38) defines QOL as maximising the comfort of patients and families across four broad domains, namely the physical domain, the psychological domain, the spiritual domain, and the existential domain. A similar approach is taken by Bertolino (2000), in Kaasa (2000) (<http://www.edc.org.lactact>). She identifies physical symptoms, psychological distress, and social and financial issues, all of which are related to spiritual or existential problems, as core elements of the concept of quality of life.

Some authors have taken a broad approach in defining QOL. Gill and Feinstein (2000), Orley and Herrman (1998), McKenna and Whalley (1998), and Saunders, Egger, Douvan, Tallon and Frankel (1998) are all in agreement that quality of life is a much broader concept, that encompasses both medical and non-medical aspects, including physical functioning (the ability to perform daily activities), psychological functioning (emotional and mental wellbeing), social functioning (relationships with others, and participation in social activities), the perception of one's health status, pain, and overall satisfaction with life (Berlin & Fleck 2003:2). This definition incorporates the health of an individual, an approach taken in Lukkarinen and Hentinen's (1998) definition of QOL, in ChingSuet (2001:219), who state that it is "a concept representing individual responses to the physical, mental and social effects of illness on daily living that influence the extent to which personal satisfaction with life circumstances can be achieved".

Osoba (1994), in King and Hinds (1998:42), concurs with the above authors, by stating that QOL is “a multidimensional construct encompassing perceptions of both positive and negative aspects of physical, emotional, social and cognitive functions, as well as the negative aspects of somatic discomfort and other symptoms produced by a disease or its treatment”.

In addition to the domains of wellbeing, Schalock (2000:118), in his conceptual model, has deemed the concept of individual rights as being important in QOL appraisal. He defines QOL as “a concept that reflects a person’s desired conditions of living related to eight core dimensions of one’s life: emotional wellbeing, interpersonal relationships, material wellbeing, personal development, physical wellbeing, self-determination, social inclusion, and rights”. The above definition is further supported by Felce (1997:126) and Clark and Bowling (1989), in Farquhar (1995:503), who have defined the concept in terms of individual rights.

Some definitions have recognised the importance of culture in the definition of QOL. The WHO (1991) defines QOL as “the individual’s **perception** of his or her position in life, within the cultural context and value system, his/her goals, expectations, parameters and social relations, and is a broad-ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment” (WHOQOL group 1991, in Berlin & Fleck 2003:3). The emphasis within this definition is the cultural context and the subjective nature of QOL, which is conceived as an internal experience. In addition, the WHO’s definition of QOL is the first definition that has directly and formally incorporated cultural components as integral parts of its theoretical basis, rather than acknowledging cultural influences as extraneous variables (Skevington 2002:135).

Clinch and Schipper (1993), in King and Hinds (1998:42), have suggested that the

cultural setting is a major determinant of the definition of QOL. They define QOL as “the **perception** of the impact of the disease” and maintain that it is “both subjective and culturally bound”. Short as the definition may be, it carries weight, since it talks about the impact of disease, subjectivity, and culture. The shortfall of this definition is that it looks at QOL only in terms of disease impact, so it implies that a person’s QOL is affected only by disease. The definition is thus sickness-oriented.

Naess (1999:115) took only the subjective approach when defining QOL. He defines it as “the individual’s **experience** or **perception** of how well he or she lives”. Naess is of the opinion that QOL is all about subjective wellbeing rather than objective wellbeing. Haas (1999:733) is in disagreement with the above, based on the fact that Naess is only concerned with wellbeing, not QOL. In addition, Haas (1999:733) has incorporated the concept of culture in his definition. According to Haas (1999:733), “QOL is a multidimensional evaluation of an individual’s current life circumstances in the context of the culture in which they live and the values they hold. QOL is primarily a subjective sense of wellbeing encompassing physical, psychological, social and spiritual dimensions”.

In some circumstances, according to Haas, objective indicators may supplement or in the case of individuals unable to subjectively perceive, serve as proxy assessment of QOL. Haas recognizes the importance of the context of culture, an important variable of QOL which was first identified by WHO as it influences QOL. Haas also identifies the importance of personal values in QOL.

In review of literature on QOL, Ferrans (1985) identified five broad domains into which QOL can be grouped. These categories focus on the patient’s (1) ability to live a normal life, (2) happiness, or satisfaction, (3) achievement of personal goals, (4) ability to lead a socially useful life, and (5) physical and mental capabilities (actual or potential) (Farquhar 1995:504).

Aaronson (1991) and Schipper (1991), in King and Hinds (1998:25), are in agreement that there are four to five generally accepted domains of QOL. These are the physical domain, the psychological domain, the social domain, somatic-/disease- and treatment-related symptoms, and the spiritual domain.

Flanagan (1978) conducted a study into developing and applying a research approach to improve QOL. He identified seven domains of QOL. These are the physical domain, material wellbeing, social relationships, community relationships, civic activities, personal development and fulfilment, and recreation (Flanagan 1978:138).

Burchardt, Woods, Schultz and Ziabarth (1989), in Anderson and Burchardt (1999:300), interviewed 204 adults with a variety of chronic illnesses about what QOL meant to them. Responses verified the domain structures identified by Flanagan (1978:138), with one addition, namely a concern with the maintenance of independence. This additional domain was also identified by the WHO as a domain that influences QOL. When Ferrel, Wisdom and Winzl (1989), in King and Hinds (1998:38), asked cancer patients and bone marrow transplant survivors what QOL meant to them, similar domains were identified.

Drummond (1995), in Anderson and Burchardt (1999:300), interviewed a sample of 22 Scottish people with asthma about the meaning of QOL, and he found that interpersonal relationships were the most important determinant of QOL. Factors related to work, social life, leisure time, and self-determination were also considered important by members of this sample, while physical factors, including asthma, were considered unimportant to them. This corresponds with Snoek's (2000:25) assertion that physical health is not a strong predictor of people's subjective wellbeing. Snoek (2000:25) states that "it takes more than improving people's physical circumstances to enhance their subjective QOL". Table 3.4 represents a summary of the various different domains of QOL by various authors.

**Table 3.4: Quality of life domains by various authors**

<b>QOL domains</b>	<b>Author(s)</b>
<b>5 domains:</b> physical, psychological, social, somatic, spiritual.	Aaronson (1991) and Schipper (1991), in King and Hinds (1998:25).
<b>2 domains:</b> satisfaction, dissatisfaction.	Abrams (1973), in Farquhar (1995:503).
<b>2 domains:</b> pleasure, satisfaction.	Andrews (1974), in Farquhar (1995:503).
<b>4 domains:</b> symptoms, psychological distress, social domain, financial issues.	Bertolino (2000), in Kaasa 2000 ( <a href="http://www.edc.org.lactact">http://www.edc.org.lactact</a> ).
<b>3 domains:</b> life satisfaction, psychological wellbeing, subjective wellbeing.	Browne, Boyle, McGee, Joyce, McDonald, Omarley, and Hiltbrunner (1994), in Hellstron, Persson, and Hallberg (2004:585).
<b>7 domains:</b> physical domain, material wellbeing, social relationships, community relationships, civic activities, personal development-fulfilment, recreation.	Burchardt et al. (1999:300).
<b>2 domains:</b> expectations, experiences.	Calman (1984), in Carr, Gibson, and Robinson (2001:1243).
<b>8 domains:</b> overall health, pain, physiological function, role functioning, social functioning, mental health, energy/fatigue, cognitive functioning.	Campsmith, Nakashima, and Davidson (2003) ( <a href="http://www.hqlo.com/content">http://www.hqlo.com/content</a> ).
<b>10 domains:</b> physical domain, functional-family wellbeing, emotional wellbeing, spirituality, treatment satisfaction, future orientation, sexuality/intimacy, social functioning, occupational functioning.	Cella and Tulsy (1990), in Carr and Higginson (2001:1359).
<b>4 domains:</b> physical wellbeing, functional wellbeing, emotional wellbeing, social wellbeing.	Cella (1994), in Kinghorn and Gamlin (2001:247).
<b>6 domains:</b> symptom distress, cognitive adaptation, socio-economic level, aggressiveness of treatment, severity of disease, functional alterations.	Cowan, Graham, and Cochrane (1992), in King and Hinds (1998:43).
<b>4 domains:</b> physical functioning; emotional or psychological functioning; social functioning; symptoms of disease, or its treatment.	Clinch and Schipper (1993), in King and Hinds (1998:42).
<b>7 domains:</b> health; material wellbeing; community wellbeing; work, or productive activity; emotional wellbeing; social/family connections; safety.	Cummins (2000:56).
<b>10 domains:</b> functional ability, level of activity, mental state, privacy, freedom, respect, freedom of choice, emotional wellbeing, maintenance of dignity, longevity.	Clark and Bowling (1989), in Farquhar (1995:504).
<b>2 domains:</b> satisfaction, or happiness; dissatisfaction, or unhappiness.	Dalkey and Rourke (1973), in Farquhar (1995:503).
<b>3 domains:</b> life satisfaction, pleasant affect, unpleasant affect.	Diener and Suh (1997:200).
<b>5 domains:</b> interpersonal relationships, work, social life, leisure, self-determination.	Drummond (1995), in Anderson and Burchardt (1999:3000).
<b>3 domains:</b> values, goals, needs.	Emerson (1985), in Felce and Perry (1996:67).

<b>4 domains:</b> physical, psychological, spiritual, existential.	Fainsinger (2000:38).
<b>6 domains:</b> physical wellbeing; material wellbeing; social wellbeing; productive wellbeing; emotional wellbeing; rights, or civic wellbeing.	Felce (1997:126).
<b>3 domains:</b> personal values, subjective factors, objective factors.	Felce and Perry (1996:67).
<b>6 domains:</b> a normal life, happiness, achievement of personal goals, a socially useful life, physical capabilities, mental capabilities.	Ferrans (1985), in Farquhar (1995:504).
<b>1 domain:</b> satisfaction, or dissatisfaction.	Ferrans and Powers (1985), in ChingSuet (2001:219).
<b>4 domains:</b> physical wellbeing, psychological wellbeing, social wellbeing, spiritual wellbeing.	Ferrel, Wisdom, and Winzl (1989), in King and Hinds (1998:42).
<b>6 domains:</b> material wellbeing, social relationships, community relationships, civic activities, personal development and fulfilment, recreation.	Flanagan (1978:138).
<b>4 domains:</b> physical functioning, psychological functioning, social functioning, health status.	Gill (2000), in Berlin and Fleck (2003:2).
<b>4 domains:</b> physical wellbeing, psychological wellbeing, social wellbeing, spiritual wellbeing.	Haas (1999:733).
<b>7 domains:</b> health, material wellbeing, feeling part of one's local community, work and productive activities, emotional wellbeing, relationship with family and friends, personal safety.	Hagerty (2001:74-75).
<b>5 domains:</b> functional status, psychological domain, social wellbeing, health perception, disease and treatment-related symptoms.	Holzemer and Wilson (1995:5).
<b>3 domains:</b> human experience, fulfilment, personal happiness.	Hornquist (1982:57).
<b>5 domains:</b> physical, emotional, mental, social, behavioural.	Janse, Gemke, Uiterwaal, Tweel, Kimpen, and Sinnema (2004:653).
<b>2 domains:</b> life association, perception of wellbeing.	Kleinpel (1991:223).
<b>2 domains:</b> wellbeing, personal development.	Lane (1996), in Christoph and Noll (2003:197).
<b>4 domains:</b> objective environment, behavioural competence, perceived QOL, psychological wellbeing.	Lawton (1991), in Hellstrom, Persson, and Hallberg (2004:585).
<b>2 domains:</b> subjective wellbeing, global wellbeing.	Lehman (1983), in Oliver (1995:1191).
<b>3 domains:</b> physical domain, mental domain, social effects of illness.	Lukkarinen and Hentinen (2006:30).
<b>4 domains:</b> physical functioning, psychological functioning, social functioning, health status.	McKenna and Whalley (1998), in Berlin and Fleck (2003:2).
<b>4 domains:</b> physical, mental, social, emotional.	Meeberg (1993:37).
<b>1 domain:</b> experiences, or perceptions.	Naess (1999:115).
<b>5 domains:</b> health and functioning, socio-economic status, psychological domain, spiritual domain, family.	Oleson (1990), in King and Hinds (1998:42).
<b>4 domains:</b> physical functioning, psychological functioning, social functioning, health status.	Orley and Herman (1998), in Berlin and Fleck (2003:2).
<b>5 domains:</b> physical domain, emotional domain, social domain, cognitive domain, somatic discomfort.	Osoba (1994), in King and Hinds (1998:42).
<b>1 domain:</b> satisfaction with life.	Rejeski, Mihalko, and Shannon (2001:23).

<b>4 domains:</b> physical functioning, psychological functioning, social functioning, health status.	Saunders et al. (1998), in Berlin and Fleck (2003:2).
<b>8 domains:</b> physical wellbeing, material wellbeing, social inclusion, emotional wellbeing, rights, interpersonal relationships, personal development, self-determination.	Schalock (2004:206).
<b>4 domains:</b> behavioural domain, cognitive domain, emotional domain, social activities.	Tartar (1988), in Meeberg (1993:33).
<b>3 domains:</b> physical, psychological, social.	Testa (1996:835).
<b>3 domains:</b> the being domain (physical, psychological, spiritual), the belonging domain (physical, social, community), the becoming domain (practical, leisure, growth).	University of Toronto QOL Research Unit (1994, <a href="http://www.utoronto.ca/qol/concepts.html">http://www.utoronto.ca/qol/concepts.html</a> ).
<b>3 domains:</b> subjective wellbeing, objective wellbeing, existential being.	Ventegodt, Merrick, and Anderson (2003:1032).
<b>4 domains:</b> physical domain, psychological domain, limitations, satisfaction.	Walker and Roser (1987), in Snoek (2000:25).
<b>6 domains:</b> physical domain, environmental domain, social relationships, psychological domain, level of independence, spiritual domain.	WHOQOL (1995), in Berlin and Fleck (2003:3).
<b>4 domains:</b> life satisfaction, psychological wellbeing, physical wellbeing, socio-economic factors.	Zhan (1992), in King and Hinds (1998:42).

From the definitions of QOL examined above, it can be concluded that there are challenges inherent in defining the concept of QOL. Although there are challenges, there are also areas of consensus. Table 3.5 illustrates the most common domains, the number of definitions incorporating these domains, and the common indicators for each of the domains.

**Table 3.5: Common domains and the indicators for each of the domains**

Domain	Number of definitions	Indicators
<b>Physical</b>	30	Activities of daily living, leisure, overall physical health, personal hygiene, nutrition, exercise, general physical appearance, and personal safety.
<b>Social</b>	30	Relationships, social support, community roles, community integration and participation, cultural roles, role function, employment, acceptance, personal relationships, and sexual activities.

<b>Psychological</b>	24	Psychological health, adjustment, cognitions, feelings, self esteem, self image, self-worth, coping, life satisfaction, perception of wellbeing, and perception of illness.
<b>Spiritual</b>	10	Personal values, personal standards, spiritual beliefs, spiritual support, meaning and purpose of life, hope, certainty and uncertainty about the future, and transcendence.
<b>Emotional</b>	10	Contentment, self-concept, lack of stress, positive affect, status, respect, fulfilment, sexuality, and self-esteem.

Table 3.6 illustrates the least-mentioned domains and the number of definitions that include these domains.

**Table 3.6: The least common domains of QOL**

<b>Domain</b>	<b>Number of definitions</b>	<b>Indicators</b>
<b>Satisfaction or dissatisfaction</b>	6	Contentment, joy, pleasure, happiness with values, goals, and needs.
<b>Somatic discomfort</b>	4	Effects of illness, pain, coping, anger, anxiety, denial, and fear.
<b>Functional wellbeing</b>	4	Activities of daily living, productive contribution, choice control, leisure, hobbies, education, independence, and competence.
<b>Health status</b>	4	Overall health status.
<b>Financial wellbeing</b>	3	Financial status, ability to meet daily needs, financial independence.
<b>Material wellbeing</b>	2	Financial status, employment, housing, and ability to meet daily needs and standards of living.
<b>Expectations and experiences</b>	2	One's hopes, one's dreams, one's ambitions, and one's present lifestyle.
<b>Rights</b>	2	Respect, dignity, equality, citizenship, autonomy, goals, personal values, choices, and level of independence.
<b>Work</b>	2	Type of employment, financial status, and work security.

Other domains mentioned are level of independence, personal development, safety,

self-concept, future orientation, achievement of personal goals, privacy, dignity, and longevity.

### ***3.2.1.5 Definition of QOL based on the review of the different QOL definitions***

The researcher therefore concludes that the concept is multidimensional, subjective, culture bound and dynamic. It is multidimensional, as can be seen from the various dimensions identified by different authors (see Table 3.4). These domains are many, and they overlap. Based on the list and distribution of the domains, QOL can be defined as a concept that has physical, social, psychological, spiritual, and emotional domains. There is a consensual view that, taken together, the core QOL dimensions, or domains, should sum up the concept of QOL, as a whole (Keith 2001:52). The number and range of individual domains specified within QOL definitions is large, although some writers note the considerable overlap that exists between these domains (Keith 2001:53).

A number of reviews of QOL domains have been conducted in an attempt to produce a definitive list of domains (Hagerty 2001:74). The above shows that QOL is influenced by or composed of many domains. The issue here is the importance of each domain to an individual. It is important to note that the weight that people attach to each particular domain will differ between different individuals and different cultures. Moreover, the importance of each particular domain is unlikely to remain static over time. People have values, and these values change over time.

The above shows that the notion of incorporating a definitive standardised set of domains into QOL definitions is subject to criticism. For example, Keith (2001:52) argues that, since the core dimensions of QOL may vary from one culture to another, cross-cultural generalisation about QOL domains is invalid (Keith 2001:52). Values and priorities change in response to life circumstances. Viewed this way, both the determinants and the evaluations of QOL are highly specific.

All the definitions of QOL that have been examined reveal that QOL is subjective. Three of the definitions state that it is both subjective and objective (Cummings 2000:56; Zhan 1992, in King & Hinds 1998:42; and Felce & Perry 1996:67). This proves that the concept is indeed subjective, and it does not mean the same thing for everyone under the same circumstances. This confirms Carr et al.'s (2001:1241) view that people with different expectations will report having a different QOL, even when they have the same clinical condition. Cella (1994), in Kinghorn and Gamlin (2001:247), states that QOL is similar to the assessment of pain, as they are both subjective phenomena. Although Ferrans (1985), in Farquhar (1995:504), agrees that QOL is subjective, she also states that objective indicators must not be completely disregarded. She suggests that subjective measurement of QOL is more direct, but that objective indicators can verify subjective indicators.

The researcher is of the opinion that QOL is subjective, in that an individual's experiences or perceptions remain the most valid criteria for assessing QOL. This view is based on the fact that there is no objective reality beyond our subjective experience of the world, and that QOL reflects the subjective values held by individuals. It is clear that each individual constructs a pattern of assumptions about self and the environment that creates conceptions of what is important to that individual. These subjective standards about what is important guide behaviour and define satisfaction or dissatisfaction with life. The challenge is to know what these patterns of assumptions are, and not to judge them by any standards.

The concept is also culture-bound (WHOQOL 1995, in Berlin & Fleck 2003:3; Haas 1999:733; Clinch & Schipper 1993, in King & Hinds 1998:42; and Felce & Perry 1996:67). What is considered a good life varies between different individuals and different societies and cultures, and it may be misleading to take a conception of QOL that has been developed in one cultural context and apply it to other cultures, or even to different ethnic communities living within the same geographical area. Keith (2001:52) argues that the core dimensions, or attributes, of QOL may vary from one culture to

another, in which case the search for a general, cross-cultural definition of QOL may be misguided.

Keith and Schalock investigated what they considered to be the etic and emic properties of the concept of QOL and found a high level of agreement about the core concepts of QOL across countries with quite different cultures (Keith 2001:51). Schalock (2004:210) examined over 100 definitions of QOL and concluded that the concept was “by its very nature, subjective”. The importance of cultural consideration was also a key in the development of the WHO’s international QOL assessment tool (WHOQOL).

Cultural consideration is very important for this study. HIV is an infection that is not only shaped by its biological qualities, but also by the cultural background of the people infected. In Swazi culture, HIV and AIDS is usually defined in relation to beliefs, sexual mores, and magical approaches. Since culture also influences a person’s view of health and illness, it is an important determinant of QOL.

The concept of QOL is dynamic, because the relative importance of each aspect of QOL changes as the individual moves through life. QOL is based on the values and aspirations of individuals. Values and priorities change in response to life circumstances. For example, material wellbeing can be of prime importance in adulthood, but can be overtaken by religious or spiritual wellbeing in older age.

Based on the cultural aspects of QOL, it can be concluded that in order to understand QOL of PLWHA in Swaziland who are on ART, it needs to be assessed using relevant context-specific domains, rather than automatically using the domains of QOL already explored. This is because individuals will report a different QOL, based on their experiences. The experience of being on ART in Swaziland may be different from the experience in other countries, because of differences in cultural background. This is the reason why the researcher had to contextualise the domains obtained through a literature review (see Chapter 4).

### 3.3 QUALITY OF LIFE AND ANTIRETROVIRAL THERAPY (ART)

Issues pertaining to the use of ARVs have been the subject of debate ever since ARVs were first approved by the US Food and Drug Administration in 1987. Much research on ARVs has been done since then. According to Naveet, Raja, Hemraj, Vivek, Chandermohan, and Sunilkumar (2006:5), “since 1989, more than ten health-related quality of life (HRQOL) instruments have been used in research with HIV-infected individuals”. The research has documented the relationship between HRQOL and HIV status, symptoms, the use of ARVs, and the use of drugs for the prophylaxis of opportunistic infections. Many people claim that ARVs have created another divide, in addition to the social divides that already exist. One is either on ARVs, or one is not, and one is either for ARVs, or one is against them.

For the purpose of ensuring clarity in this discussion, arguments for and against ARVs were examined. The issue is to ascertain whether ARVs improve or lower the QOL of PLWHA on ART. Proponents of ARVs are of the view that ARVs have changed AIDS from a terminal, unmanageable infection to a chronic and manageable infection. This is consistent with the view of the Center for Disease Control (CDC), which defines AIDS as a chronic and manageable disease. By definition, a chronic illness persists usually longer than six months and can also affect functioning in any dimension (Potter & Perry 2005:101). Describing HIV and AIDS as a chronic illness implies that it can be a severe condition, but that it is manageable, although not curable.

According to the proponents of ARVs, people who before would have died now live a longer life because of ARVs. The drugs have brought numerous individuals back from the brink of death, which is why they have been labelled “Lazarus drugs” (<http://www.Irinmers.or/webspecials/arv>). Highly active antiretroviral therapy (HAART) has also been shown to improve the health of many seriously ill people (Nieukerk, Gisolf, Reijers, Lange, Danner & Sprangers 2001:1985; and Cohen, Revicki, Nabulsi, Sarocco & Jiang 1998:1495).

The literature contains many testimonials of people who have been rescued from death by HAART. HAART involves a treatment regimen consisting of a combination of three or more ARVs. It is the standard treatment for HIV infection. Proponents of ARVs claim that ARVs improve QOL of PLWHA, based on the fact that these drugs:

- Increase the CD4 cell count and slow down HIV replication, to such an extent that the viral load in the blood is reduced to very low, or even undetectable, levels in 65% to 81% of HIV-infected patients within six months of treatment (Calles & Schwardwald 2001:111);
- Reconstitute the immune competence, since depressed cell-mediated immunity accounts for most of the morbidity and mortality of HIV-infected individuals;
- Reduce the chances of being attacked by opportunistic infections and cancers;
- Slow the progression from HIV to full-blown AIDS; and
- Suppress the mutation of HIV. Reduced viral replication reduces both the number of virions (halts clinical progression) and the number of mutations (prevents resistance) (Global AIDS Learning and Evaluation Network (GALEN) (2002:17).

As a result of the above:

- The mortality rate of HIV-infected individuals is reduced (Burgoyne & Tan 2008:469);
- Stigma and discrimination caused by HIV and AIDS can be reduced or eliminated;
- The number of AIDS orphans will be reduced;
- The risk of HIV transmission will be decreased; and
- Life will be prolonged (Burgoyne & Tan 2008:469).

According to GALEN (2002:16), evidence of these benefits has been established by many studies. Proponents of ARVs argue that HIV-infected patients should be given the drugs to assist them in recovery, as they claim that it is unethical to deny an HIV-infected patient the only available treatment, namely ARVs.

Opponents of ARVs base their arguments on drug toxicity of ARVs, as well as scientific references that question the merit of prescribing these drugs. Although ART has been seen by proponents as a saviour for many HIV-positive people, some researchers have revealed that these drugs have severe side effects. These drugs can be toxic and can be detrimental to a natural immune response to HIV.

Side effects of ARVs that have been identified by Burgoyne and Tan (2008:469), Sulkowski, Thomas, Mahta, and Chaisson (2003:115), Puoti, Garcia, Rockstroh, Benhamou, Barreiro, and McGovern (2008:1), Montessori, Press, Harries, Akagi, and Montaner (2004:1082), Carr and Cooper (2000:1423), Sulkowski, Thomas, Chaisson, and Moore (2000:74), Rudolf and Krikorian (2005:258), and Volberding (2002:110) include:

- Gastrointestinal effects: abdominal cramps, nausea, vomiting, diarrhoea, constipation, and intestinal gas;
  - Skin problems: rashes, exfoliation, ulceration, necrosis, prurities, and dry skin;
- Liver, pancreas, and kidney problems: jaundice, liver toxicity, and liver damage;
- Pancreatitis, kidney stones, and hematuria;
- Neurological and mental problems: peripheral neuropathy, pain numbness, and weakness;
- Headache, dizziness, confusion, anxiety, paranoia, and depression;
- Bone marrow suppression: anaemia, leucopenia, neutropenia, and thrombocytopenia;
- Other problems: fever, chills, fatigue, insomnia, malaise, anorexia, myopathy, and myalgia; and
- arthralgia, heart palpitations, and loss of normal heart rhythm.

Opponents of ARVs are also concerned with the issue of ethics. Whereas proponents see it as ethically right to give HIV-infected people the drugs, opponents are of the idea that such drugs should not be given, because they have not been properly tested

through a controlled study. To take these drugs is, in effect, to participate in what has been called the largest uncontrolled clinical trial in the history of medical science, because no one can say for sure what long-term effects the drugs can have on a patient (Shernoff 2002:25). This argument is based on the fact that no studies show that AZT and other ARVs have been tested on animals, and have shown any benefits or, at least, side effects.

Opponents of ART also argue that there is a solid body of published research that would suggest that these drugs are indeed harmful. Furthermore, according to the opponents, it is unethical to administer drugs whose clinical actions in relation to dosage and time application are poorly known, or not known at all. According to Cullinan and Reid, in *Health e-news* (2005), "What the ARVs are unable to do is to address the many social challenges patients experience". Although ARVs are assumed to improve QOL, they do not address the social circumstances of the individuals infected with HIV.

According to Kirton et al. (2001:175), it is further understood that, although new treatments for HIV and AIDS hold promise, QOL for these individuals may still be compromised. One Swazi paediatric doctor once remarked that "when we put a child on ARVs, we are not only promoting respiration, but we want the child to go to school and engage in sports like any other child". Based on the above assertion, one is forced to question the effect of these drugs on QOL, as per the main aim of this study. One is forced to ask oneself whether these drugs improve or lower the patient's quality of life. One way to find out the answer to this question is to ask PLWHA who are on ART. Based on the fact that there are equal arguments for and against the use of ARVs, it is evident that the answer to this question does not lie in a literature review, but rather with PLWHA who have experienced being on ART.

There are two fundamental components of QOL, according to Cella (1992), in Kinghorn and Gamlin (2002:245). These are subjectivity and multidimensionality. Subjective assessment of components, according to Cella (1992), refers to the fact that quality of

life can only be determined by asking the patient questions about his or her quality of life.

Whether ART improves QOL is unknown. Dudgeon (1992), in Kinghorn and Gamlin (2002:245), states that the ultimate goal of medicine is to improve patients' QOL. Fallowfield (1990), in Kinghorn and Gamlin (2002:245), suggests that the current advancements in medical science appear to have led to a decline in the art of medical science, and that medical intervention for a few may result in states of life that are, in her opinion, worse than death. Can this be true with ART?

Although the literature on QOL is expansive, little work has been done that focuses on defining and measuring the meaning and dimensions of QOL of PLWHA who are on ART. Currently the response to this treatment is measured in terms of clinical tests, such as the test that measures the CD4 cell count. While this test offers valuable information, it has limitations, in that it does not take into consideration the patient's feelings, and mental, social, and psychosocial needs, yet all these factors have an important bearing on the patient's quality of life, as per the definition of QOL by the WHO.

The concept of QOL of PLWHA on ART has also been looked at in terms of side effects. It has been assumed that, because ARVs decrease viral load, improve CD4 cell count, and reduce opportunistic infections, quality of life will be improved. According to the above statement, quality of life is determined by the viral load and CD4 cell count. Mathematically, this statement can be expressed as follows:

$\uparrow$ Viral load +  $\downarrow$ CD4 cell count =  $\downarrow$ quality of life

$\downarrow$ Viral load +  $\uparrow$ CD4 cell count =  $\uparrow$ quality of life

In this case, it implies that quality of life can only be assessed based on laboratory tests,

yet there are many factors involved in QOL besides these tests, as has already been mentioned.

As indicated by the HIV AND AIDS update of 2006, AIDS is now considered a chronic illness. This requires a shift of focus in nursing. When cure is not possible, caring is the primary objective. Nurses have now to focus on improving QOL of PLWHA who are on ART. Quality of life is to be taken as an important indicator of the efficiency of ART, compared to other indicators, such as laboratory tests.

### **3.4 CONCLUSION**

This chapter dealt with a review of related literature. Its main focus was on concept analysis of the concepts of life, quality, and QOL. Several definitions of QOL were discussed. It was necessary to accurately define QOL, because the way QOL of HIV-infected people on ART is measured and evaluated is related to the clarity with which QOL is defined. Through an analysis of the definitions of the concept of QOL, the researcher reached the conclusion that the concept is culture-bound, dynamic, and subjective, or self-perceived, in nature.

In addition, it was identified that the concept of QOL is multidimensional, and that the domains that account for an individual's QOL are the physiological, psychological, social, and spiritual domain. This is consistent with the holistic nature of nursing. In nursing, holism encompasses consideration of the domains listed above. These domains are essential in an individual's QOL. They may appear to be different from one another, but they interact and they are interrelated. They overlap to some extent, and factors in one component directly affect factors in another component.

An important concern to note is the authenticity and exhaustive nature of these domains when contextualising them to PLWHA in Swaziland who are on ART. It is important, therefore, that the researcher refines and validates these domains, through a workshop

strategy involving expert nurses working with PLWHA in Swaziland who are on ART. The refined domains of QOL will facilitate the process of exploration of the experience of being on ART by PLWHA in Swaziland, which constitutes phase 3 of this research. The next chapter encompasses a discussion of the validation of the domains of QOL, in preparation for an exploration of the experiences of PLWHA in Swaziland who are on ART.

## CHAPTER 4

### VALIDATION OF THE DOMAINS OF QUALITY OF LIFE

#### 4.1 INTRODUCTION

The previous chapter dealt with a review of the literature. Several definitions of QOL were analysed. From the analysis, four domains of QOL were identified by the researcher as relevant in the exploration of QOL of PLWHA in Swaziland who are on ART. These domains were the physiological, psychological, spiritual, and social domains. This chapter presents the findings of the process of validation of the above domains.

#### 4.2 THEMES THAT EMERGED DURING THE DATA ANALYSIS

Collected data was transcribed verbatim and analysed as soon as possible. Data was analysed using Tesch's framework of data analysis as described in Creswell (2002:256-283). Since the group discussions yielded a lot of rich data, the researcher used a coding system to transform the raw data into a standardised form for data processing and analysis (Polit & Beck 2008:749). Coding is a means of categorising, and a code is a symbol or abbreviation used to classify words or phrases in the data (Burns & Grove 2005:548). The researcher attached codes to corresponding data that defines different domains of QOL. The last two categories were not identified by the researcher during the literature review, but were revealed through the workshop and were coded. The following codes were used to identify the different domains:

- *Ph* for the physiological domain;
- *Ps* for the psychological domain;
- *Sp* for the spiritual domain;

- *Se* for the socio-economic domain;
- *Co* for the cognitive domain; and
- *En* for the environmental domain.

#### **4.2.1 The physiological domain**

According to Henderson, Fall-dickson, Schlenk, Kim, Matthews, and Erlen (2008:369), “the domain of physical wellbeing pertains to individuals’ perception of their own bodily functions, including disease symptomatology, side effects of medication or general physical wellbeing”. Attributes of the physiological domain include age, genetic structure, gender, race, biological rhythms, basic needs, growth, acid-base balance, circulation, digestion, electrolyte balance, immune response, mobility, reproduction, respiration, temperature regulation, physical health, and past illnesses.

Of all the basic needs of an individual, the participants emphasised the importance of two particular needs, namely nutrition, and intimacy. Nutrition was cited as being important for adherence, immunological development, and treatment success. Participants expressed that most Swazis are very poor, and that this directly affects the QOL of PLWHA. They felt that there is a strong correlation between HIV and AIDS and poverty. HIV and AIDS increases poverty and poor people are particularly vulnerable to HIV and AIDS. Poverty predisposes people to engage in high-risk sexual behaviour, which leads to faster progression of AIDS and a decline in the efficacy of ARVs. Participants also mentioned that it is not only the HI virus that suppresses the immune system and makes PLWHA susceptible to a host of opportunistic infections, but also hunger. Opportunistic infections are caused by organisms that would not produce significant disease in a person with a well-functioning immune system (Schwarzwald 2001:85). The participants felt that after being attacked by opportunistic infections, an HIV-infected individual may have a poor QOL. QOL has been discussed in Chapter 3. These opportunistic infections may interfere with the activities of daily living.

One participant stated that:

*In Swaziland, I feel we [nurses] are going nowhere in the fight against the epidemic, because of poverty. Poverty has promoted prostitution, and prostitution has increased the prevalence of HIV and other sexually transmitted infections, and, as such, provision of ARVs will do little to improve the lives of the people. We should see how we deal with the problem of hunger first, before giving ARVs.*

Participants stated that the rampant poverty in Swaziland made it impossible for clients on ART to meet the proper dietary requirements for ART success, and that there was therefore poor adherence. There was, however, a feeling among participants that nurses cannot just deny those who need the drugs, because of poverty, while PLWHA wait for food relief. One concerned participant stated that:

*It is a pity, because we educate people about a balanced diet, yet some families cannot afford even a plate of porridge. How do we expect them to afford the luxury of a balanced meal three times a day? Maybe government can do something, like offering some incentives in the form of food or money, to alleviate the problem of hunger.*

There was, however, disagreement among participants concerning the matter of incentives. While some felt that government should provide incentives, others felt that these could have a negative impact on the epidemic. One participant mentioned that:

*In some countries where there are financial incentives for PLWHA with a low CD4 cell count, of 200 and less, PLWHA deliberately don't take the ARVs, to drop the CD4 cell count, so that they can get the incentives. The mere fact that government is providing incentives means that it is rewarding them [PLWHA] for being HIV-positive, and people will deliberately infect themselves. If government provides incentives, it has to provide them for all other chronic illnesses.*

Participants finally reached consensus that, as a strategy for dealing with poverty and poor adherence, government should provide food and financial assistance for PLWHA in Swaziland who are on ART.

Although appreciative of the fact that government is offering ARVs free of charge, as per the “Free-For-All Initiative”, participants stated that these services were still centralised and that people from rural areas had to travel long distances to access the drugs. One participant was concerned that:

*ARVs are available only in referral hospitals, which are far away for some of the people. There is a need to train nurses, so that they have the capacity to give these drugs at the clinic level and have mobile clinics to take care of those far away.*

Concerning the issue of intimacy, participants stated that PLWHA feel that they are deprived of love, intimacy, and sexual satisfaction, due to the stigma that is associated with the illness, yet love is important for a relationship and for survival. In addition, participants stressed the fact that all human beings are intimate beings, and that having HIV or AIDS does not change this fact.

#### **4.2.2 The psychological domain**

Neuman (1995), as cited in George (2002:343), defines the psychological variable of a person as “the mental processes and relationships”. Participants stated that the psychological variables of clients are aspects that are very important to consider when providing holistic care to PLWHA. Psychological problems that were noted by participants that are of concern are: AIDS-related stigma and discrimination, fear, anger, denial, anxiety, confusion, depression, distress, loss of dignity, uncertainty, hopelessness, and helplessness. AIDS-related stigma refers to the prejudice and

discrimination directed at people living with HIV or AIDS and the groups and communities that they are associated with (<http://www.avert.org/aidsstigma.htm>).

Participants felt that PLWHA in Swaziland still suffer self-stigmatisation, and are stigmatised by their families, and by communities and health workers. Consequences of stigma identified by participants include rejection by family due to the stigma associated with this illness. The client may lose family, social, and cultural roles, depending on how his or her family and society define the illness. At community level, stigma can manifest itself in the client being ostracised, rejected, or verbally or physically abused. The client may lose his or her employment due to the chronicity of the infection. This can cause a lot of confusion and distress within the family. One participant commented that:

*One problem that is common in all PLWHA is stigma. It is a pity, because we [nurses] are the perpetrators of stigmatisation. We stigmatise them [PLWHA] by testing them without their consent, and refusing to admit them. We may talk of measures to combat stigma, but it is still within us. We still stigmatise them one way or the other.*

The participants also stated that stigma makes it difficult to deal with the epidemic. Stigma directed at PLWHA not only makes it more difficult for people trying to come to terms with and manage their illness on a personal level, but it also interferes with attempts to fight the AIDS pandemic as a whole. Participants mentioned that the stigma experienced by PLWHA had a negative impact on ART adherence. This stigmatisation often results in secretive behaviour among those infected, and failure to take protective measures, which perpetuates the spread of the epidemic in Swaziland. One participant shared her experience of counselling an HIV-positive woman who was on ART and was scared of being rejected by her family:

*She [the woman on ART] has to hide her ARVs at a neighbour's house for fear of being rejected by her husband and family. She goes there in the morning and*

*evening to take the drugs. And then it is obvious that no protective measures are taken, and one wonders if she takes her ARVs on time. Who can blame her though? Nobody wants to be rejected.*

To minimise the possibility of HIV-infected individuals being rejected by their families or society, or both, participants felt that stigma should be dealt with at individual, family, and community level. Participants felt that, as nurses, they should be role models in reducing the stigma associated with HIV and AIDS.

The following are some other effects of stigma that an HIV-positive client on ART may experience that were identified by the participants:

- Stigma may lead to social isolation, loss of hope, loss of reputation, and feelings of worthlessness;
- It may discourage individuals from contacting health and social services, thereby increasing the risk of transmission of HIV;
- It may discourage an individual from engaging in risk-reduction practices;
- It exacerbates problems faced by AIDS orphans; and
- It may cause non-adherence to ART by PLWHA.

Measures to combat stigma that were identified by participants include education, avoidance of judgemental attitudes towards PLWHA, and maintenance of confidentiality. There was, however, disagreement among the participants concerning the issue of confidentiality. While some felt that confidentiality had to be maintained, others felt that maintaining confidentiality would cause the infection to spread. One participant was of the view that:

*Although we [nurses] are now and again reminded of the importance of maintaining confidentiality regarding all client information, it appears that we are losing sight of its importance, and this unfortunately results in stigmatisation of*

*PLWHA. Sometimes we want to normalise the situation, yet PLWHA will feel stigmatised.*

The participants further stated that the HIV-infected patient may have difficulty accepting his or her HIV-positive status and coping, because of his or her perception of the illness. HIV and AIDS is an infection with many associated perceptions and meanings. Whether one accepts the illness depends on one's perceptions of the illness. Perception of the illness as an infection of prostitutes, gays, and lesbians will mean that the patient will not accept the illness if he or she does not belong to one of the above groups. The meaning that the individual ascribes to HIV and AIDS may also influence the way he or she accepts and copes with the illness. Different individuals may see HIV and AIDS in different ways. Individuals may see it as a punishment, or an enemy, or a conspiracy, or an irreparable loss, or a challenge, or a shameful illness, and so forth. One participant stated that:

*We all know how AIDS originated. It was known as a disease for gays and prostitutes. We dissociated ourselves from it, because we are not prostitutes, and we are not gays and lesbians. It is now very difficult to change the mindset of people, but maybe with time they will change, seeing that a pastor's wife has died, a neighbour, a nurse, and everybody is getting sick.*

In addition to the above, it was mentioned that the labels we give to HIV make it difficult for PLWHA to accept their status, because these labels stigmatise. Common labels, according to some participants, are *umbulalave* (nation killer), *mashayabhuce* (destroyer), *silwane* (animal), *ligciwane* (a germ), and *ingculaza* (sexually transmitted infection).

Concerning the labels given to PLWHA, one participant mentioned that:

*The intention of these unpleasant labels was not to stigmatise them [PLWHA] per se, but to label the epidemic so badly that people would do all in their power to take preventive measures.*

The following are factors contributing to the stigma associated with HIV and AIDS, according to the participants:

- There is a lot of inaccurate information about how HIV is transmitted;
- HIV infection is often thought to be the result of personal irresponsibility;
- Religious or moral beliefs lead some people to believe that being infected with HIV is the result of a moral transgression that deserves to be punished;
- AIDS is a life-threatening disease;
- HIV is associated with behaviours such as homosexuality, drug addiction, and prostitution.
- HIV is a sexually transmitted infection (STI). STIs are always highly stigmatised in Swaziland.

According to participants, psychological variables also include the patient's perception of wellbeing and life satisfaction. PLWHA may experience fear, anger, anxiety, denial, confusion, depression, and distress. All these emotions stem from uncertainty. The individual may be uncertain about the future, about opportunistic infections, and about the occurrence of side effects caused by the drugs.

Participants revealed that HIV and AIDS was known for its ability to rob PLWHA of their dignity, and that this may have serious implications on the self-concept of the individual. PLWHA may have a low self-image, or low self-esteem or self-worth. The individual may also experience feelings of hopelessness and helplessness. Helplessness can occur when a person is forced into the position of temporary or permanent dependence on others. One participant mentioned that feelings of hopelessness were caused by the fact that HIV and AIDS is incurable and that being on ART is permanent and lifelong. One participant commented that:

*The hospital situation makes it possible to degrade PLWHA to the point of nothingness. It is impossible to maintain confidentiality there in our situation. It is known that if you [the client] are there, it is because you have HIV. You are stigmatised solely because you happen to be in a place where PLWHA are cared for.*

Participants also mentioned that psychological problems caused by HIV and AIDS and ART affect the grieving process. As a result of the continual stigma surrounding HIV and AIDS, PLWHA may experience a prolonged grieving process. PLWHA may be angry, they may suffer denial, they may have feelings of guilt, they may become depressed, suffer loneliness, fail to accept, lose hope, and may even commit suicide.

#### **4.2.3 The spiritual domain**

The spiritual domain of an individual's life encompasses his or her beliefs and values and what gives his or her life meaning and a sense of wholeness (Puchalski 2008:79). The spiritual domain "represents the totality of one's being and serves as an overriding perspective that unifies the various aspects of an individual" (Potter & Perry 2005:546).

The participants stated that the spiritual dimension of an HIV-infected individual encompasses the need to find satisfactory answers to the questions concerning the meaning of life, the illness, and death. It is an integral component of one's being. The individual may seek to find meaning and purpose in life after having been diagnosed as having HIV. The meaning that the HIV-infected individual ascribes to his or her experience of being seropositive and the experience of being on ART may influence the ways in which he or she copes with the illness and with being on ART.

According to participants, failure to cope with the illness or with being on ART may be the result of:

- the invasive nature of the disease;
- society's reaction to the disease (stigma and discrimination);
- the disease being synonymous with uncontrollable destruction;
- the incurability of the infection; and
- the side effects of ART.

Participants stated that the belief system of PLWHA may be weakened. The individual may experience spiritual doubt. The individual's faith in whatever religion he or she believes in may now be weakened. For example, these are some questions an individual may ask himself or herself concerning spirituality, as identified by one participant:

*If he or she [the person with HIV] is a Christian, the individual may ask himself or herself what kind of God could allow such an infection to befall him or her, how He (God) could allow such suffering to take over his or her life, and how the God that he or she loves so much could allow him or her to suffer so much.*

One participant who was concerned that the spiritual dimension of clients was often ignored stated that:

*We do have church services in the mornings, but maybe it is just a general church service, and what we need are spiritual support groups for spiritual guidance, that will specifically be focused on HIV and AIDS, to bring back hope and trust.*

According to participants, PLWHA may also experience uncertainty about the present and the future. The individual may ask himself or herself what the future holds for him or her:

*Is there hope for the future if this illness has no cure, and the present treatment has severe side effects? Can I still continue having a life after this? If I have a life, what quality will this life have?*

All participants stressed that human beings need reasons for living and a set of beliefs that will help to explain the meaning of life, suffering, health and illness. If there are no reasons, the individual begins to die. One participant was of the opinion that some PLWHA resort to suicide because of HIV:

*If I am okay, my life is meaningful. If I am sick, what is the meaning of this life? Rather than living a meaningless life, I had better die peacefully. This is why some [PLWHA] deliberately stop taking ARVs, because rather than suffering because of side effects, they would rather die and rest in peace.*

#### **4.2.4 The socio-economic domain**

This domain was identified through the literature review and was incorporated in the environmental domain by the researcher, but through analysis of the participants' presentations, it became clear that it was a very important domain, so the researcher decided that it needed to be discussed separately.

Participants stated that socio-economic status was related to health. Lack of money affects the quantity and quality of resources that can be bought, and therefore affects health. Participants stated that poverty in Swaziland was a common phenomenon, which resulted in people being greatly affected by the HIV and AIDS epidemic. One participant stated that:

*Poverty leads to poor nutrition, poor living conditions, and poor access to health care, which are all breeding grounds for HIV.*

#### 4.2.5 The cognitive domain

The cognitive domain concerns how individuals think, their intellectual capabilities, their level of development, and their preferred thinking styles (<http://www.nald.ca/adultlearningcourse/glossary.htm>). An individual's cognitive abilities affect his or her view of health and illness. This domain is also linked to the psychological domain, as it involves cognitive abilities, educational achievements, and life experiences. Cognitive abilities determine the individual's ability to reason, conceptualise, use knowledge, and make decisions. An individual's definition and understanding of health and illness, and his or her capacity to seek appropriate resources or health care, depend on his or her cognitive abilities.

Both participant groups identified that there was a knowledge deficit about ART and HIV among PLWHA and the nurses. The nurses stated that despite having worked with PLWHA for more than a year, they still lacked knowledge on ART and lacked confidence at times.

*We [the nurses] have put all our efforts into educating the public about HIV, but some individuals do not understand the effects of the disease on the individual, the family, and the community. This lack of understanding of this epidemic is disturbing, especially when Swaziland is leading as far as the rate of HIV infection is concerned, and we have had this epidemic for two decades already.*

*We are expected to educate people about HIV and AIDS and ART, yet even we as nurses are not currently updated. We lack knowledge and competence.*

Participants indicated that lack of understanding of ARVs is the major cause of non-adherence, yet ART is an empowering tool for people to live longer and have life with quality. Participants stated that PLWHA are always preoccupied with thoughts related to the following:

- A world of nothingness filled with stigma and being neglected by everyone;
- Being sentenced to death, as HIV is incurable;
- A predetermined life; and
- Being deprived of certain things, for example, being able to get married and have children.

The main challenge identified by the participants is that nurses have not addressed the thinking aspect of patients. One participant commented that:

*What is currently happening is that nurses only concentrate on the physical aspect of the person. As long as he or she is gaining weight and has no opportunistic infections, it is assumed that all is well. We have totally forgotten to nurse the person holistically, including the psychological aspect. Once in a while we should just ask the client about their family and their community.*

#### **4.2.6 The environmental domain**

The participants acknowledged that the environment was very important in caring for PLWHA on ART. They emphasised that if the patient's environment is not conducive, nurses' efforts to improve the QOL of PLWHA on ART will be useless. The environment deals with the sociocultural system, the health care system, and the political system.

The sociocultural system deals with the patient's expected social roles, such as family and community roles, and cultural aspects such as values, beliefs, and customs. It also refers to the ability to interact successfully with people and within the environment of which each person is a part. It includes culture, family, group membership, language, lifestyle, relationship with others and roles. According to participants, PLWHA may lose family and community roles due to the stigma attached to HIV, as already discussed in section 4.4.2 on the psychological domain.

The health care system of Swaziland consists of the formal and the informal health care sectors. The formal health care sector is based on Western medicine and consists of public and private health services, including Rural Health Motivators (RHMs). The informal health care sector consists of traditional health practitioners, community and family caregivers, PLWHA, and other unregulated service providers. There are many problems inherent in the health system in Swaziland, according to participants. These include acceptance of traditional health practitioners and other unregulated service providers, and health sector funding.

Participants stated that in Swaziland, the traditional health system and other unregulated health services have a wider acceptance among PLWHA, because:

- They believe that the products produced by these services are more effective than those produced in the Western health care system;
- They lack knowledge on the efficacy of ARVs;
- The products produced by these services are marketed more often than those produced by the modern health care system; and
- The products produced by these services are readily available and are unregulated.

One participant said:

*The idea that the disease is caused by organisms that are not visible to the naked eye may be simple for us and many educated people to understand, but the idea may not be well understood and accepted by some cultures, including Swazis. In Swaziland, AIDS is never accepted by everybody as a natural occurrence. It is attributed to supernatural spirits, sorcerers, and witchcraft.*

Although appreciative of the fact that ART services are offered free of charge, participants stated that these services were still centralised, inefficient, and

unresponsive to new needs, contrary to the Swaziland National Health Policy (2007) mission statement, which states that services should be available, affordable, accessible, and socially acceptable. The participants stated that the services are not available in outreach clinics, but are only available in private clinics and referral hospitals, which are very far from most of the clients, and that PLWHA cannot afford the travelling expenses.

The political system deals with power. Power itself may be defined in different ways. Power includes not only material or physical resources, but also psychological and cultural aspects. Participants felt that PLWHA are powerless most of the time when it comes to decision making. Their rights are often violated, yet protection of human rights and democratic governance are vital in all efforts to provide care and to prevent and mitigate the effects of the epidemic. The rights of PLWHA, as identified by the participants, include the rights to the following:

- privacy and confidentiality;
- sexual and reproductive health;
- the right to marry and start a family;
- non-discrimination, equal protection, and equality before the law;
- freedom of opinion and expression;
- an adequate standard of living;
- the highest attainable standard of health;
- education;
- work;
- public and private life; and
- freedom of association

Participants also noted that not all institutions use the same ART guidelines when rendering care to PLWHA, and that this has sometimes resulted in problems of client referrals.

### 4.3 DISCUSSION OF THE WORKSHOP FINDINGS

As much as the four domains of QOL obtained through the literature review were not directly revealed to the participants, it is worth noting that through the participants' discussions and the data analysis, these domains were revealed with additional information. Two extra domains of QOL were also identified as important in rendering holistic care to PLWHA who are on ART. The domains of QOL identified through the workshop include (1) the physiological domain, (2) the psychological domain, (3) the spiritual domain, (4) the socio-economic domain, (5) the cognitive domain, and (6) the environmental domain.

The workshop confirmed that the concept of QOL of PLWHA is multidimensional and culture-bound. This is consistent with the holistic nature of nursing. In nursing, holism encompasses consideration of the domains listed above. According to Bishop (2005:229), chronic illness imposes heavy physical, social, emotional, and economic burdens on patients, families, and society, thus the above domains are considered relevant in the QOL of PLWHA, as HIV infection and AIDS are chronic illnesses.

The findings also suggest that though the domains may appear to be different from one another, they interact and are interrelated. They overlap to some extent, as factors in one component directly affect factors in another component.

Concerning the physiological domain, participants stressed the importance of nutrition and intimacy. They felt that most PLWHA in Swaziland are poor and unable to meet their need for adequate nutrition, which is vital for adherence, immunological development, and treatment success. Much research has been done on the role of nutrition in HIV infection, and it has been concluded that nutrition is critical for PLWHA, since it prevents muscle wasting, strengthens the immune system, reduces viral mutations, decreases the incidence and severity of opportunistic infections, and lessens the debilitating symptoms of HIV (McMeans 2001:97). In addition, the Foundation for

Professional Development (2007:229) asserts that it is not only poverty that predisposes PLWHA to nutritional deficit, but also psychological problems, such as depression, anxiety, withdrawal, and physical problems, such as malabsorption, and metabolic disturbance, for example, diarrhoea and vomiting.

Most of the clinics distributing ARVs in Swaziland give patients food supplements in the form of corn soya provided by the World Food Programme, but Okello (2008) noted that hungry family members quickly consume the monthly rations intended for HIV-positive patients (<http://www.aegis.com/news/IRIN/208/IRO80925.html>).

The problem of poverty and malnutrition was also identified during the Abuja Summit of 2001 (<http://www.dawodu.com/hiv1.htm>). The Abuja Declaration No. 4 states that “we recognize the role played by poverty, poor nutritional conditions and underdevelopment in increasing vulnerability”. In response to the above declaration, Swaziland adopted the eight Millennium Development Goals (MDGs) (<http://www.indexmundi.com/swaziland/millennium-development-goals.html>). Although Millennium Goal No.1 is aimed at eradicating poverty and hunger, these are problems that still prevail in Swaziland. A massive effort is needed to cushion the impact of the HIV and AIDS epidemic, and nutritional care and support should be integral elements of any action taken (<http://www.who.int/nutrition/topics/hiv aids/en>).

The prevalence of poverty in Swaziland was also confirmed by Dlamini (2009), who states that poverty is the biggest barrier, and that people can't take pills everyday when they don't have food (<http://www.irinnews.org/report.aspx?ReportID=83872>). Gwebu (2009), an adherence officer who followed up patients who failed to come to hospital for drug refills, concluded that the people in Swaziland are poor (<http://www.irinnews.org/report.aspx?ReportID=83872>).

Participants felt that intimacy was important to PLWHA, yet it is often assumed that HIV has killed intimacy. According to Kasiram, Dano and Partab (2006:55), intimacy and

sexuality are integral to the human experience. However, intimacy is elusive when accompanied by hopelessness and negativity. In addition, the above authors have noted that both HIV and intimacy are topics that are shrouded in secrecy and silence, and that health professionals should provide an environment that helps nurses move beyond seeing only illness and stigma to being able to render compassionate care.

The psychological aspect of PLWHA was mentioned by participants as being very important, as it is linked to PLWHA' QOL. Research studies suggest that stigma and discrimination are a problem that is still faced by PLWHA, and which is undermining health workers' efforts to improve PLWHA' QOL. A lot of research has been done on stigma, and it has been concluded that stigma is linked to the QOL of PLWHA (Piot & Seck 2001:1109; Emler 2007:740; Chan, Han & Holzemer 2004; Khakha 2003; Surlis & Hyde 2001, in Chirwa, Greeff, Kohi, Naidoo, Makoe, Dlamini, Kaszubski, Cuca, Uys & Holzemer 2009:15; Holzemer, Human, Arudo, Rosa, Hamilton, Corless, Robinson, Nicholas, Wantland, Moezzi, Willard, Kirksey, Portillo, Sefcik, Rivero-Manded & Maryland 2009:161; and Monico 2009) (<http://www.irinnews.org/report.aspx?ReportID=83872>).

There is substantial evidence in support of participants' idea that stigma exacerbates the problems faced by PLWHA. Hughes, Davis, and Gudmundsdottir (2008:342) state that despite overwhelming evidence of the success of antiretroviral therapies in reducing HIV-associated morbidity and mortality, stigma and discrimination persist, undoubtedly in part because of cultural taboos of sex and drug use, and their links to viral transmission. In addition, Li, Wang, Williams, and He (2009:23) assert that stigma associated with HIV may severely affect both physical and mental health and can cause depression, anxiety, sadness, feelings of guilt, and psychiatric disorders.

Furthermore, stigma has been identified as a major barrier to adherence to ART (Robertson, White & Fogel 2009:51; and Piot & Seck 2001:1109) and may affect social interaction (Li et al. 2009:28). Stigma may affect health-seeking behaviour (White, White

& Cormier 2008:430). It can adversely affect both people's willingness to be tested for HIV and their adherence to ART (Swaziland Demographic and Health Survey (SDHS) 2006-2007:190). Stigma also undermines prevention, care, and support and increases the impact of the HIV and AIDS epidemic on individuals, families, communities, and nations (UNAIDS 2002). It further hinders voluntary counselling and testing, as well as access to treatment, and ultimately increases morbidity and mortality, and results in verbal abuse, negative self-perception, health care neglect, social isolation, and fear of contagion (Newman 2002, in Holzemer, Uys, Chirwa, Greeff, Makoae, Kohi, Dlamini, Stewart, Mullan, Phetlu, Wantland & Durrheim 2007:1002).

In their study of the provider role in client engagement in HIV care, Mallinson, Rajabiun, and Coleman (2007:83) concluded that after 25 years of the HIV pandemic, PLWHA accessing HIV services continue to perceive stigma, discrimination, marginalisation, and paternalism from health care providers. These problems continue to be barriers to timely access to and appropriate use of contemporary therapies, which contributes to unnecessary morbidity and mortality. Piot and Seck (2001:1107) agrees with the above, by maintaining that HIV-related stigma may well be the greatest obstacle to action against the epidemic, for individuals and communities, as well as for political, business, and religious leaders. The above authors further argue that an all-out effort against stigma will not only improve the QOL of people living with HIV and those who are most vulnerable to infection, but will also meet one of the necessary conditions of a full-scale response to the epidemic.

In addition to the above, UN secretary general Ban Ki Moon states that:

Stigma remains the single most important barrier to public action. It is the main reason why too many people are afraid to see a doctor to determine whether they have the disease or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world. On national level, the stigma

associated with HIV can deter governments from taking fast, effective action against the epidemic, whilst on a personal level it can make individuals reluctant to access HIV testing, treatment and care. (<http://www.avert.org/aidsstigma.htm>)

The problem of stigma and discrimination was also identified at the Abuja Declaration of 2001. The Abuja Declaration No.12 states that “we are aware that stigma, silence, denial and discrimination against PLWHA increase the impact of the epidemic and constitute a major barrier to an effective response to it”.

According to the SDHS (2006-2007:190), “reduction of stigma and discrimination in a population is thus an important indicator of the success of programmes targeting HIV and AIDS prevention and control”.

Uys (2000), in Holzemer et al. (2007:10002), asserts that many health care providers have come to believe that unless HIV and AIDS programmes begin to address stigma, as well as prevention, treatment, and care, the disease will never be overcome. Holzemer et al. go on to state that in order to develop anti-stigma strategies, researchers and programme managers need a better understanding of the phenomenon of stigma. This includes understanding stigma in the context of the sociocultural beliefs of a community, developing strategies needed to measure stigma, documenting the impact of stigma, and tracking that impact over time.

The participants’ suggestions for reducing HIV-related stigma are consistent with the views of Piot and Seck (2001:1110), who state that VCT services are central to tackling stigma, because they constitute the entry point for care and treatment. In addition, Li et al. (2009:29) recognise the importance of education as a means of reducing stigma. According to the above authors, “when communicating with PLWHA, nurses should avoid judgmental attitudes regarding transmission routes and should use neutral words, because most PLWHA are highly sensitive to the responses of others, especially health care providers”. They also assert that nurses should ensure confidentiality.

According to UNAIDS (2002), people working on the frontlines of HIV and AIDS care and prevention have both the responsibility and a unique opportunity to overcome stigma within their professions and workplaces. Their professional codes of ethics and conduct, social and professional authority, and their ability to act as educators and role models for their communities, all place them under the obligation to be change agents for reducing stigma. The Code of Professional Nursing Conduct (1978) for Swaziland states that nurses are to maintain confidentiality, except where disclosure is required by law or order of a court, or is necessary in the public interest. In addition, UNAIDS (2002) states that leadership at all levels has a clear responsibility to create a more open society that is free from stigma, silence, or denial about the epidemic of HIV and AIDS. Furthermore, the active involvement of PLWHA is central in the fight against stigma, and the mass media can serve as powerful tools to help reduce stigma (UNAIDS 2002). In addition to reducing stigma, Mitchell (2002:252), state that preservation of human dignity is and should be a central issue in everyday nursing.

The findings of the nurses' workshop concerning the relationship between spirituality and health are consistent with other studies linking spirituality and health. Spirituality may have a positive impact on physical health and health-related QOL (Dalmida 2007) (<http://www.stti.confex.com/stti/congrs07/technogram/paper>). Religiosity and faith significantly influence adherence (Holstad, Dilorio & Magowe 2006) (<http://www.nursingworld.org/mainmenucategories>). Spirituality is an inner resource for overcoming difficulties in the everyday lives of human beings, and as spiritual activities increase, emotional distress decreases (Sowel et al. 2000:73-74). Spiritual practices act as a buffer when individuals are faced with negative life events (Scarinci, Griffin, Grogoriu & Fitzpatrick 2009:69). The use of spiritual coping or spiritual practices may enhance self-empowerment, leading individuals to find meaning and purpose in their lives (Baldacchino & Draper 2001:838). A strong sense of coherence and strong spirituality are associated with higher ratings of QOL (Delgado 2007:233). There is a

significant positive correlation between spirituality and wellbeing (Reed 1986, in Sowel et al. 2000:74).

The spiritual domain is interrelated with the physiological, psychological, cognitive and social domains. All physiological, psychological, sociocultural and developmental variables make up the spiritual state. Factors that affect spirituality include health status, cultural context, family, and developmental stage.

The characteristics of spirituality which were identified by the participants are consistent with those identified by Kozier, Erb, Berman and Burke (2000:220), namely:

- A relationship with self, that is, knowledge of who one is, and one's capabilities;
- A relationship with nature, that is, knowledge of plants and animals, preserving nature, and communication with nature;
- A relationship with others, that is, caring for others when they need help, and sharing self.
- A relationship with deity, that is, prayer and meditation, religious articles, being in nature, and church participation.

In view of the above characteristics of spirituality, it can be concluded that spirituality is an important dimension of life that needs to be considered in the care of PLWHA. In addition, Scarinci et al. (2009:75) state that it is important for nurses to recognise the power of the spiritual dimension of their patients and themselves, so that they can enhance this dimension in their care. Spiritual beliefs result in several positive outcomes, including a framework for understanding life, a source of support, and coping mechanisms.

The findings of the nurses' workshop recognise the importance of considering the socio-economic dimension of an individual's life when assessing his or her QOL. Participants stated that socio-economic status is related to health. This is consistent with the views

of Stanhope and Lancaster (2004:123), who state that socio-economic status is inversely correlated with mortality and morbidity for almost every disease. As is the case with other diseases, HIV and AIDS also contribute to the undermining of poor peoples' opportunities, security, and power. The possibilities of poor people to prevent HIV, to access care, and to mitigate the effects of HIV and AIDS need to be specifically addressed in poverty alleviation strategies.

Concerning the socio-economic status of PLWHA in Swaziland, participants stated that poverty in Swaziland is a common phenomenon. This is confirmed by the Second National Multisectoral HIV and AIDS Strategic Plan (2006-2008), which states that the majority of people in the country (69%) are classified as poor (that is, living below the poverty line of €128.60 (US\$22) per month), possibly due to poor distribution of available resources and rising unemployment, which is estimated to be at 29%. Although Swaziland has enacted Millennium Development Goal No.1, which is aimed at eradicating poverty and hunger, and health sector funding has improved from 7.9% of the national budget in 2007-2008, to 10.6% in 2008-2009, and 17% in 2009-2010 (which is above the 15% minimum stipulated by the Abuja Declaration), the problems of poverty and hunger still exist. Okello (2008) pointed out that there is a vicious cycle of poverty and HIV in Swaziland (<http://www.aegis.com/news/IRIN/208/IRO80925.html>). First an individual gets sick, then he or she gets laid off from work, then the individual will lack money to buy food, and he or she will become a beggar, will stop taking medication, and will get sicker.

The nurses' workshop also revealed that the cognitive domain is important in assessment of the QOL of PLWHA who are on ART. Concerning the cognitive domain, participants stated that the majority of Swazis lack knowledge about HIV and AIDS and ARVs. Lack of knowledge has a negative impact on the epidemic. Drivers of the epidemic, as identified by the Second National Multisectoral HIV and AIDS Strategic Plan (2006-2008), include inadequate public awareness of the epidemic. The Plan states that although several studies indicate that a high proportion of the population is

aware of the AIDS epidemic and understands its dangers, misconceptions about the disease are still very common. Currently in the media there are many reports that contradict established facts about HIV and AIDS, such as claims of cures by some faith healers and traditional healers, the promotion of unproven drugs and treatments, and practices such as sexual intercourse with virgins.

SDHS (2006-07:xxvi) revealed that only half the population have what can be considered comprehensive knowledge about the modes of transmission of HIV and HIV prevention strategies. In addition, lack of knowledge about HIV and AIDS was also identified by Nyamathi, Vatsa, Khakha, MacNeese, Leake, and Fahey (2008:447) and Barnett (2005) (<http://www.lse.ac.uk/collections/DESTIN/whoswho/barnett.html>). The Abuja Declaration No. 10 states that:

We recognize the essential place that education, in its widest sense, has played, and will continue to play, in the fight against HIV and AIDS in Africa. Education constitutes the most powerful, cost-effective tool for reaching the largest number of people with information and personal development strategies that promote long-term behaviour change. We commit ourselves to scaling up the role of education and information in the fight against HIV and AIDS.

Participants' inputs about the importance of the environmental domain are confirmed by Kirk (2002:60), who states that "the environment has long been accepted as a legitimate domain of nursing, and its significance is acknowledged through nursing models such as those of Roy and Rogers". Roy (1991) states that the environment is all the conditions, circumstances, and influences surrounding and affecting the development and behaviour of persons or groups, the input into the person as an adaptive system involving both internal and external factors (Korzier et al. 2000:39). In addition, Parse (1998), in George (2002:438), states that human beings and the environment are inseparable, interchanging energy, unfolding together for greater complexity and diversity, and influencing one another's rhythmic patterns of relating. Human beings and

the environment interchange energy to create what is in the world, and each person chooses the meaning given to the situation he or she chooses.

Neuman (1995), in George (2002:344), defines the environment as all the internal and external factors or influences that surround the client. Leininger (1993), in George (2002:590), takes a broader view of the environment, by saying that the environment is the totality of an event, situation, or particular experience that gives meaning to human expressions, including physical, ecological, and social interactions, and emotional and cultural dimensions. A sociocultural system refers to system functions that relate to social and cultural expectations and activities (Neuman 1995, in George 2002:343).

Concerning the health system, the workshop revealed that the existence and utilisation of both the formal and the informal health care sectors poses many problems for the health care system. Although the existence and utilisation of both the formal and the informal health care sectors was recognised nine years ago at the Abuja Declaration as a source of conflict, little has been done to ensure that the two health care sectors work together in harmony in Swaziland. The Declaration states that:

We recognize the need to intensify our efforts in all areas of research such as traditional medicines and vaccine development. We commit ourselves to explore and further develop the potential of traditional medicine and traditional health practitioners in the care and management of HIV and AIDS.

Monico (2009) claims that most patients start ART late or they default on their treatment, because of persistent beliefs in the power of traditional medicine and faith healing. She also claims that Swaziland has no programme for providing HIV and AIDS education to traditional healers and faith healers, many of whom discourage people from taking ARVs (<http://www.irinnews.org/report.aspx?ReportID=83872>).

Research by Nyika (2007) of the Centre for the AIDS Programme of Research in South Africa warns that there are loopholes in the practice of African traditional medicine that have the potential to expose participants to harm, due to the fact that these traditional medicines have not been subjected to the same rigorous assessment of their effectiveness and safety as licensed medicine has. Hence, the issue of African traditional medicine is treated with laxity, especially where ethical and regulatory issues are concerned (<http://www.medicalnewstoday.com/articles/65460.php>).

A country's political system has an effect on the health status of its citizens. In support of the above, Putzel (2003), in his research of HIV and AIDS in Uganda and Senegal, concluded that politics is the primary framework for examining a country's success in dealing with HIV and AIDS, and argues that a country's success or failure in the fight against HIV and AIDS is significantly determined by the country's politics (Dickinson 2006:2). He added that HIV and AIDS and human rights are closely linked. On the one hand, abuse of human rights can lead to vulnerability to HIV and AIDS, as when those at risk are denied the right to appropriate health information and care. On the other hand, being HIV-positive can lead to non-exercise or non-enjoyment of human rights, as when those who are living with the virus suffer one or more acts of being discriminated against (<http://www.avert.org/stigma.htm>). In addition to the above, Leininger (1993), in Kozier et al. (2000:205), states that the political system is a major determinant of what health programmes will be available, and which health practitioners may provide health services and which may not.

Participants asserted that the decentralisation of health services is a must if the HIV and AIDS epidemic is to be tackled with any success. Dickson (2006:3) confirms this by stating that decentralised political environments can provide greater political space for acting on HIV and AIDS and are an important factor in enabling responses. In addition, Whiteside (1999), in Dickson (2006:3), asserts that democracy and good governance may help slow the epidemic and minimise its impact. He argues that a fair legal system, respect for human rights, a credible and competitive electoral process that makes HIV

and AIDS an election issue, a vibrant and active civil society, and increased transparency may have an impact on combating the spread of the epidemic.

The United Nations General Assembly 2006 High Level Meeting on AIDS, held from 31 May to 2 June 2006, declared that:

We must overcome any legal, regulatory, trade and other barriers that block access to prevention, treatment, care and support, commit adequate resources, promote and protect all human rights and fundamental freedoms for all, promote gender equality and empowerment of women, promote and protect the rights of the girl child in order to reduce the vulnerability of the girl child to HIV and AIDS, strengthen the health systems and support health workers, support greater involvement of PLWHA, scale up the use of known effective and comprehensive prevention interventions, [and] do everything necessary to ensure access to life-saving drugs and prevention tools.

#### **4.4 CONCLUSION**

This chapter dealt with a validation of the domains of QOL obtained through a literature review. The process of validation was undertaken using a workshop of nurses working with PLWHA. The main aim of validation was to contextualise the domains of QOL to PLWHA in Swaziland. The domains that were contextualised were the physiological, psychological, spiritual, socio-economic, cognitive, and environmental domains.

It is important to realise that, as much as the important domains of QOL were identified and validated, a central statement that will lead to a central question should be developed. The central statement recognises that the needs of PLWHA who are on ART revolve around the six interrelated domains of QOL. These are the physiological, psychological, spiritual, socio-economic, cognitive, and environmental domains. It is

therefore logical to state that the central question shall include issues that relate to the six domains that sum up the QOL of PLWHA in Swaziland who are on ART. Hence the central question was:

***How is your life since you started ART?***

The above central question was broken down into the sub questions listed below, based on the six domains of QOL related to HIV and AIDS and ART.

**The physiological domain:**

- Since you started ART, how has your life changed?
- How has your sexual life changed since you started ART?
- How have the drugs interfered with your nutritional needs?
- How can your physiological life be improved?

**The psychological domain:**

- How are you coping with the treatment?
- How has the treatment interfered with your self-concept (the way you see yourself)?
- How is your family and society reacting to you and the drugs you are taking?

**The spiritual domain:**

- How has the condition and treatment interfered with your spiritual life?
- How can your spiritual life be strengthened?

**The socio-economic domain:**

- How has your condition and your treatment interfered with your relationships?
- How has your condition and your treatment interfered with your economic life or financial independence?
- How can your socio-economic life be improved?

**The cognitive domain:**

- How much knowledge do you have about HIV and antiretroviral drugs?
- What is constantly in your mind concerning HIV and the drugs?

**The environmental domain:**

- How do you feel about the health care you are receiving?
- How has your condition interfered with your personal freedom or independence?

With the above questions, the researcher was able to assess the QOL of PLWHA in Swaziland who are on ART, which constitutes Phase 3 of this research.

## **CHAPTER 5**

### **FINDINGS OF THE QOL OF PLWHA IN SWAZILAND WHO ARE ON ART AND LITERATURE CONTROL**

#### **5.1 INTRODUCTION**

The previous chapter dealt with a validation of the domains of QOL by a sample of nurses involved in the care of PLWHA in Swaziland who are on ART. The process of validation was undertaken through a workshop strategy. The validated domains were used to structure the interview guide that was used to collect data during in-depth semi-structured individual interviews and FGDs with PLWHA who are on ART.

This chapter presents the findings based on both the individual semi-structured interviews and the FGDs with PLWHA in Swaziland who are on ART. In this chapter, the researcher describes the process of gaining access to the field of study, and her findings on how is the QOL of people living with HIV and AIDS in Swaziland who are on ART. This chapter serves as a basis for the development of guidelines that can be used to improve their QOL.

#### **5.2 GAINING ACCESS TO THE FIELD OF STUDY**

In order to gain access to the field of study, the researcher had to seek permission from the Swaziland Ministry of Health Scientific and Ethics Committee (MOHSEC), the hospital administration, and the sister in charge of the VCT study site. These parties were considered to be the gatekeepers of the study site.

In order to gain permission from MOHSEC, the researcher submitted the research proposal for their review and approval. The researcher had some problems gaining

approval from this committee. She was kept waiting for six months before permission was granted. The reason for the delay was that the committee met twice a year, and the researcher had to wait until it met. Another problem that was encountered by the researcher was the issue of sample size. The committee wanted the researcher to increase the sample size to 80 participants per region, and to cover all the four regions of Swaziland. The committee was mainly comprised of statisticians who were concerned with numbers, and their interests lay more in quantitative research and the generalisability of findings. In order to clear this hurdle, the researcher had to justify her sample size and research approach. The researcher had to educate the committee about qualitative research. The committee had to be made aware of the fact that in qualitative research, data saturation was more important than figures. This means that the study was context-specific. After this explanation, permission was granted.

In order to gain permission from the administrator, the researcher had to explain in writing the purpose of the research, her reason for choosing that particular site, what the research entailed, ethical guidelines and reporting procedures that would be followed, the amount of time to be spent in the field, and any disruptions that were anticipated. The administrator stated that they had experienced problems of certain researchers not reporting their findings. The site administrator was assured that the findings would be reported, and permission was then granted.

The researcher had fewer problems in obtaining consent from the sister in charge of the VCT clinic, since the researcher is well known at the institution. The sister in charge was more concerned about the issue of confidentiality. She was assured that confidentiality would be maintained. The sister in charge gave permission for the research after reviewing the clearance certificate issued by UNISA's Health Studies Research and Ethics Committee (HSREC), and permission letters from MOHSEC and the hospital administrator.

After approval from UNISA's HSREC, MOHSEC, the hospital administration, and the sister in charge of the study site, the researcher spent the first month of data collection at the centre where data was collected, familiarising herself with the setting, staffing, and general interactions with personnel, with the aim of understanding the phenomenon under investigation, that is, QOL of PLWHA within the concrete natural context in which ART services are offered to them. According to Babbie and Mouton (2003:272), one understands events against the background of the whole context and how such a context confers meaning to the events concerned, so that one can truly claim to understand events. The RFMH VCT clinic was purposely selected, as it offers ART services and is attached to the work setting of the researcher.

The clinic is attached to a large referral hospital in the hub of Swaziland. It offers VCT services to both patients admitted to the hospital and outpatients. Services that are offered at the clinic include pre-ART and ART services. Services include HIV testing and counselling, education, ARV refills, consultations, follow-up, treatment of opportunistic infections, and management of the side effects of ARVs.

The nurses expressed interest in the study, as they had a problem of some PLWHA defaulting on their antiretroviral treatment for unknown reasons. The sister in charge mentioned that sometimes they are very busy, and that the researcher should not interpret it as neglect. The researcher was assigned one nurse who had been working at this VCT centre for more than six years to assist her with the logistics of data collection.

### **5.3 DISCUSSION OF THE FINDINGS OF THE QOL OF PLWHA IN SWAZILAND WHO ARE ON ART**

This section discusses the findings on how is the QOL of PLWHA who are on ART in Swaziland. The research findings are reflected within the six domains of QOL that were

identified through the literature review and were validated by a sample of expert nurses involved in the care of PLWHA who are on ART. These are the physiological, psychological, spiritual, socio-economic, cognitive, and environmental domains.

### 5.3.1 Physiological benefits and challenges of ART

The domain of physical wellbeing pertains to individuals' perception of their own bodily functions, including disease symptomatology, side effects of medication, or general physical wellbeing (Henderson et al. 2008:369). From the analysis of the data, five categories emerged related to the physiological domain. These are clinical improvement of PLWHA due to ART, inability to meet nutritional needs for ART adherence and success, non-adherence to ART, occurrence of side effects of ARVs, and inconsistent condom use by PLWHA. Table 5.2 represents a summary of the themes, categories, and subcategories of the physiological domain.

**Table 5.1: Themes, categories, and subcategories of the physiological domain**

Theme	Category	Subcategories
<b>5.4.1 Physiological benefits and challenges of ART</b>	5.4.1.1 Clinical improvement of PLWHA associated with the use of ART	<ul style="list-style-type: none"> <li>Increased CD4 cell count resulting to reduction of opportunistic infections and improvement of activities of daily living</li> </ul>
	5.4.1.2 Inability to meet nutritional needs for ART adherence and success	<ul style="list-style-type: none"> <li>Lack of funds, associated with poverty and unemployment</li> <li>ARVs perceived to be causing increased appetite and hunger pangs</li> <li>Lack of nutritional support for PLWHA</li> </ul>
	5.4.1.3 Non-adherence to ART by PLWHA	<ul style="list-style-type: none"> <li>Failure to adhere to ART due to non-disclosure of HIV status</li> <li>Lack of reminders from family, friends, and significant others</li> <li>Lack of food for PLWHA and their families, associated with poverty</li> <li>Tiring lifelong ART routine of PLWHA</li> <li>Busy life schedule of PLWHA</li> </ul>
	5.4.1.4 Occurrence of side effects of ARVs	<ul style="list-style-type: none"> <li>Disfiguring effects of ARVs</li> </ul>
	5.4.1.5 Inconsistent condom use by PLWHA	<ul style="list-style-type: none"> <li>Condoms perceived as reducing the pleasure of sex</li> </ul>

		<ul style="list-style-type: none"> <li>• Misconceptions held by PLWHA and society about condoms</li> <li>• The expressed desire to have or bear children by PLWHA</li> <li>• ARVs perceived to be increasing the sexual desire of PLWHA</li> </ul>
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### **5.3.1.1 Category 1: Clinical improvement of PLWHA, associated with the use of ART**

The findings of the study revealed that ART improves the physiological aspect of PLWHA. One main subcategory emerged from this category. This is the increased CD4 cell count, resulting in a reduction in the number of opportunistic infections and an improvement in the activities of daily living. This subcategory is discussed below.

- **Increased CD4 cell count, resulting in a reduction in the number of opportunistic infections and an improvement in the activities of daily living**

The majority of the participants (n=22) stated that their CD4 cell count had increased as a result of ART. These are some of their responses:

*Before I started the drugs [ARVs], my CD4 cell count was checked, and it was 40, and now it is 513 after three years on treatment.*

*I started the drugs with a very low CD4 cell count of 8, but it has improved to 400 after three years, but I must mention that there was a problem before I started the drugs. I was told to wait for my blood tests for two weeks, yet I was already sick, and that is why my CD4 cell count dropped so low before I started the drugs. I think people should be started on the drugs without their CD4 counts being looked at.*

Concerning a reduction in the number of opportunistic infections and an improvement in the activities of daily living, all the participants stated that they started ART when they were sick with many opportunistic infections, but that they had since improved physically. They stated that due to the fact that they had improved physically, they were able to engage in the activities of daily living. One of the participants responded as follows:

*I was sick, very sick, when I was started on treatment [ART]. I could not do anything for myself, as I was very weak, and could not stand up alone without assistance. Now here I am feeling very strong and able to care for myself, and I have even gone back to work.*

Sharing the same sentiments, another participant mentioned that:

*When I started the drugs, I was terrible, very weak, and had TB. I had no hope of survival, although the doctor and nurses assured me that I would survive. But I did not have any hope of surviving, because I was vomiting the pills, because they were many, but now I have regained my strength, though sometimes I feel a bit weak.*

The findings of this study support the fact that ART increases the CD4 cell count and reduces the number of opportunistic infections. Much research has been done on the influence of HAART on clinical improvement and CD4 cell count, and all of the investigations have concluded that ART improves the clinical state of PLWHA and increases their CD4 cell count (Gazzola, Tincati, Bellistri, Monforte & Marchetti 2009:328; Ghanekar, Stranford, Ong, Walker, Maino & Levy 2001:1885; Kumarasamy, Solomon, Anitha, Chaguturu, Yepthomi, Flanigan, Balakrishnan, Kalamalini & Mayer 2004:11; Beard, Feeley & Rosen 2009:1343; Fox, McCoy, Larson, Rosen, Bii, Sigei, Shaffer, Sawe, Wasunna & Simon 2009:137; Beretta, Lazzarin, Hasson, Fumagalli,

Clerici, Ferrante, Saniabadi & Adachi 2000)  
(<http://www.gateway.nlm.nih.gov/meetingabstracts/ma>).

Although this study indicates that ART improves the physical wellbeing of PLWHA in Swaziland, this however, does not mean improvement in QOL of PLWHA in Swaziland due to ART as it is only a unidimensional improvement, yet according to the researcher QOL is a multidimensional concept. This means that improvement has to be attained in all the relevant domains of QOL.

Most studies done on the effects of ARVs on PLWHA have noted that physical improvement is short-term (on average, two years). This research has revealed that there is continued physical improvement beyond two years on ART, based on the fact that all nine of the participants that had been on ART for more than two years had continued to improve physically. What remains unclear, therefore, are the consequences of the use of these ARVs beyond nine years, as none of the participants had been on ART for a period of more than nine years.

#### ***5.3.1.2 Category 2: Inability to meet nutritional needs for ART adherence and success***

Although ART improves some aspects of PLWHA in Swaziland, 20 participants revealed that they were poor and could not provide for their nutritional needs and the nutritional needs of their families. Subcategories that emerged from this category included: (1) lack of funds, associated with poverty and unemployment, (2) ARVs perceived to be causing increased appetite and hunger pangs, and (3) lack of nutritional support for PLWHA. These subcategories are discussed below.

- **Lack of funds, associated with poverty and unemployment**

This study revealed that 11 participants were not employed and, as such, were very poor and were not able to provide food for themselves and their families. One of the participants responded as follows:

*As I am unemployed, I depend on the food rations from the clinic [corn soya] and handouts from the community. We consume the food from the clinic [corn soya] within two weeks of receiving it, since everyone at home depends on it for survival and after that, survival is difficult.*

Emphasising the need for food, one participant commented that:

*I am unemployed and very poor. I don't have any means to support my family. The major problem is food. I know I am supposed to take these drugs with food. Sometimes we go for days without food, which is wrong. I am a beggar most of the time. I am tired of this life.*

One participant, who lives on handouts, stated that:

*I am ashamed to ask for handouts anymore. Who would expect a grown-up man like me to live on handouts? Why can't the government do something for us? Because we will be killed by hunger before we are killed by the [HI] virus.*

This study's findings are consistent with the findings of other studies, which revealed that unemployment in Swaziland is high, and increasing at an alarming rate. The 2007/2008 Swaziland Integrated Labour Force Survey estimated the rate of unemployment in Swaziland to be 28.2% in the working-age population, which numbered 599,528 people. This means that for every 100 economically active persons, there were about 28 persons who are unemployed. In terms of regions, unemployment

in Lubombo was 31.8%, in Hhohho it was 27.2%, in Manzini it was 27.1%, and in Shiselweni it was 43.1%. The Ministry of Enterprise and Employment in 2008 estimated that the total number of unemployed persons stood at 135,702 in 2007.

The problem of unemployment was also highlighted during the budget speech of 2009/2010, as the Minister of Finance stated that “Swaziland faces a serious problem of unemployment, whereby about a third of the labour force is unemployed, particularly the youth”. Although new jobs have been created in the textile industry, under the African Growth and Opportunity Act (AGOA), and in the sugar and transport industries, this growth is still too minimal to tackle the existing problem.

The unemployment situation directly affects food availability at household level. Lack of money means lack of food. Lack of food negatively influences QOL. The shortage of food, which was identified by the participants, is confirmed by the Swaziland Amnesty International Annual Report of 2007, which states that over 40% of Swaziland's population requires food aid. This report also revealed that poverty and lack of food continue to impede the ability of PLWHA to access health services, adhere to treatment, and have a good QOL.

Although ARVs are offered and CD4 cell count tests are administered free of charge in Swaziland, there are some medical requirements that are still expensive, such as the viral load test, other medical tests, the cost of hospitalisation, regular visits to the clinic, and the cost of other necessary medication to treat opportunistic infections and side effects of ART, that can consume all the financial resources that the patient has, until poverty sets in and he or she is unable to meet his or her nutritional needs.

- **ARVs perceived to be causing increased appetite and hunger pangs**

Three participants mentioned that ARVs increased their appetite and caused hunger pangs. Here are the responses of two of the participants:

*Since I started with the drugs, my appetite has increased, but the problem is that I do not have the necessary food, and I end up taking the drugs on an empty stomach, and this causes nausea and dizziness.*

*I have an increased appetite now. I feel hungry most of the time, but I don't have enough food to satisfy the hunger. I am also tired of the clinic food, because I have it for breakfast, lunch, and supper.*

The participants' responses about ARVs causing increased appetite are confirmed by UNAIDS (2008), who identified that ARVs may increase appetite and that it is possible to reduce some side effects and promote adherence if some of the medicines are taken with food. Due to the increased appetite caused by ARVs, ART is associated with sustained weight gain and an increase in body mass index (BMI) and energy requirements, which are raised by 10 to 30 percent following HIV infection in adults (Silva, Skolnik & Gorach 1998, and Schwenk, Beisenherz, Kremer, Diehl, Salzberger & Fatkenheuer 1999, in Gillespie & Kadiyala 2005:56). If there is insufficient food, as was the case with the study participants, a high rate of defaulting from the treatment may be expected. Nurses at the study site reported a default rate of 30%. Defaulting on treatment results to lowered QOL.

- **Lack of nutritional support for PLWHA**

In addition to the 11 participants who were not employed, four employed participants raised the concern of lack of nutritional support from government. These are the comments of three participants:

*If only government can provide us with money, say, at least €200 [US\$26] per month, so that we can buy other things, like meat and fruit, because the clinic food is just porridge.*

*Government has to give us the drugs [ARVs], together with enough food, otherwise people will die of hunger.*

*I am not asking to be paid as a lazy person. All I need is to be employed, so that I can take care of myself and my family. Government has to make sure that once you are put on these drugs [ARVs] and are okay, you are employed.*

Based on the participants' responses, it is evident that the government of Swaziland has to provide PLWHA with nutritional assistance, in addition to the corn soya of the clinic. Given the need for adherence in delaying resistance to these drugs, nutritional support is critical to sustaining antiretroviral treatment. A study done by Marston and DeCock in 2004 in Nairobi listed lack of food as the most likely cause of non-adherence to ARV drug therapy (Gillespie & Kadiyala 2005:55). A study conducted in Kenya in 2006 of PLWHA enrolled in the nutrition supplement programme "HAART and Harvest Initiative" reported that while PLWHA were on ART, greater adherence to the medication was observed, as well as fewer side effects and a greater ability to satisfy increased appetite. The majority of patients experienced weight gains, recovered physically, gained strength, and were able to resume labour activities (UNAIDS 2008).

The growing impact of the epidemic has shown that promotion of simple but important food security, nutrition, and public health interventions, alongside and as part of HIV and AIDS treatment initiatives, is critical to an effective HIV and AIDS response (Gillespie & Kadiyala 2005:58). These authors further state that HIV and AIDS responses which include prevention, care, treatment, and mitigation must also take into account the integral role of food and nutrition. Stillwagon (2002:985), in her pioneering work, found falling calorie and protein consumption to be strongly correlated with HIV prevalence in 44 sub-Saharan African countries, including Swaziland.

Food scarcity is one factor that was also identified by the World Food Programme as a cause of patients abandoning ART in Swaziland (Swaziland Amnesty International Report 2007) (<http://www.thereport.amnesty.org/en/regions/africa/swaziland>). Supporting the participants' response that lack of food is a problem, Weiser, Leiter,

Bangsberg, Butler, Percy-de Korte, Hlanze, Phaladze, Lacopino and Heisler (2007:1589) are of the view that both food insufficiency and HIV infection are major public health problems in sub-Saharan Africa, and that food insufficiency is a major risk factor for increased sexual risk-taking behaviour among women in Botswana and Swaziland.

There is substantial evidence that adequate nutrition is important for achieving the full benefits of ART and an improvement in QOL. Nutrition can have a significant influence on the success of ART, by affecting drug efficacy and adherence to drug regimens, resulting in an improvement of the QOL of PLWHA. Based on the relationship between nutrition, ART success, and QOL, it can be safely concluded that because PLWHA who are on ART in Swaziland have a challenge in meeting their nutritional need, their QOL is negatively affected. Figure 5.1 illustrates the relationship between nutrition, adherence, and QOL. The first, vital, biggest gear (nutrition), when adequately provided, sets the second medium gear in motion (adherence, and increased drug efficacy), resulting in an improvement in the QOL of PLWHA (the third gear).



**Figure 5.1: Nutrition and ARV adherence gear for PLWHA in Swaziland who are on ART**

### **5.3.1.3 Category 3: Non-adherence to ART by PLWHA**

Adherence is defined as “the ability to follow the instructions on how to take medication, and this means taking the drugs at the same time, the correct dosage and consistency, without missing a dose” (National Guidelines for Antiretroviral Treatment and Post-Exposure Prophylaxis for Adults and Adolescents 2006:33). Adherence is generally defined by the WHO (2003) as “the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds with agreed recommendations from a health care provider”.

The study revealed that 16 of the participants were not conversant with the term “adherence”. To them it meant just taking medication any time, as long as the medication is taken daily. The term “adherence” was explained to them. When they were asked if they were adhering to their medication schedule, they expressed that they faced many challenges, which caused them not to adhere. The challenges mentioned by the participants were: (1) failure to adhere due to non-disclosure of HIV status; (2) lack of reminders from family, friends, and significant others; (3) lack of food for PLWHA and their families, associated with poverty( discussed in section 5.4.1.2); (4) the tiring, lifelong routine of ART; and (5) a busy life schedule.

- **Failure to adhere to ART due to non-disclosure of HIV status**

Four participants mentioned that they did not disclose their HIV-positive status to any member of their family or friends, because of fear of stigmatisation. Two of the participants mentioned that:

*I have to hide my tablets from my wife, because I am scared that I might be discovered that I have the virus and she may reject me.*

*I did not disclose my status to anyone because of the stigma, and I am ashamed of the disease, so it has to be kept a secret.*

One participant, who had not disclosed her status to her daughter, said that she had difficulty taking the medication at the right time:

*When she [the daughter] is not around, I don't have any problems, but problems occur when she is around, because I can't take them [the ARVs] in front of her. They [teenagers] are inquisitive, if you know them, so I can't say that I take them [the ARVs] properly. I am not sure of her reaction if she discovers that I am taking ARVs.*

This study clearly indicated that HIV and AIDS is still a stigmatised condition and, as such, ARVs are also stigmatised. The findings of this study confirm the findings of other studies, namely that serostatus disclosure is positively related to adherence. A study conducted by Stirratt, Remien, Smith, Copeland, Dolezal, and Krieger (2006:483) on the role of HIV serostatus disclosure in antiretroviral medication adherence found that 19% of the sample reported missing medication doses due to concerns about serostatus disclosure. These authors further state that participants who reported greater serostatus disclosure to others demonstrated higher rates of adherence.

- **Lack of reminders from family, friends, and significant others**

All of those participants that did not disclose their status to anyone did so for the reason that they had nobody to remind them to take their tablets. One participant mentioned that:

*My husband does not care much about the drugs [the ARVs]. Most of the time he is away with friends, and I even forget that clinic booklet. I forget to tick. I only tick when I come to the clinic for refills, because I know the nurses will be very angry with me.*

The above confirms the direct relationship between disclosure and adherence. The participants that had disclosed their seropositive status had people to remind them to take their ARV doses, and they consequently adhered to the therapy. In support of the above, a study conducted on the relationship between adherence to antiretroviral treatment and three different sources of social support (a partner, friends, and family) found that support from friends and family was significantly related to adherence (Power, Koopman, Volk, Israelski, Stone, Chesney & Spiegel 2004:245).

- **Tiring lifelong ART routine**

Sixteen participants who were not adhering to their treatment raised the concern that the routine of ART was tiring. These are some of their comments:

*You know how tiring it is to take the same medications in the morning and in the evening, at the same time every day. I try, but sometimes I don't remember whether I've taken them, or whether it was yesterday or the day before yesterday [when I took them], because you do this every day, and sometimes it's confusing.*

*Most of the time I simply forget. You know this routine of taking the same medicine at the same time for the rest of your life is tiring. You just lose interest and motivation.*

This study clearly indicates that the adherence rate of 95% is not yet being achieved by many people on ART in Swaziland yet adherence to treatment is critical to obtain the full benefits of ART (Steel, Nwokike & Joshi 2007:4). Even when the clinic is staffed by eight expert clients, (clients who have been on ART for a long time and are willing to share their experiences of being on ART with other clients), the current average adherence rate at is estimated to be as low as 75%. This shows that adherence is still a problem in Swaziland. Adherence concerns have been one of the reasons cited in arguments opposing the administration of ARVs in developing countries and resource-poor settings (Stevens, Kaye & Corrah 2004:280; and Gill, Hamer, Simon, Thoe & Sabian 2005:1243).

Unlike other chronic diseases, the rapid replication and mutation rate of HIV means that very high levels of adherence, of 95% and more, are required to achieve durable suppression of viral load. Adherence rates of more than 95% are necessary in order to maximise the benefits of ART. This means that patients should not miss more than three ARV doses in one month (Swaziland National Guidelines for Antiretroviral Treatment and Post-Exposure Prophylaxis for Adults and Adolescents 2006:33).

Adherence levels of below 95% are associated with poor virological and immunological response. The individual adherence rate is calculated by the following formula (Steel et al. 2007:5):

$$\text{Number of pills taken/number of pills prescribed} \times 100$$

For example, if 60 pills are prescribed per month, and the individual takes 57 pills in that month (missing three pills), the adherence rate will be  $57/60 \times 100 = 95\%$ .

For assessing adherence, the pill count, reminder booklet, return date, and pharmacy records were used at the study clinic. However, indirect adherence assessment methods such as these may be deceiving, according to Steel et al. (2007:4). These authors base their assertion on the fact that pill count has the limitation of giving wrong results, due to pill dumping, fabrication, and manipulation, and pharmacy records are based on the assumption that patients that collect their medication regularly are adhering to treatment, which may not be the case.

- **Busy life schedule of PLWHA**

One participant mentioned that because of his busy schedule, he did not always take the medication, or he did not always take it on time:

*Most of the time I don't remember when it is time to take the drugs [the ARVs]. I am moving around, and I don't always carry them around, because of the stigma that is attached to the disease.*

This was also identified by Ware, Wyatt, and Tugenberg (2006:904), who did a study on social relationships, stigma, and adherence to antiretroviral therapy for HIV and AIDS. They discovered that persons with HIV and AIDS will not subordinate other interests to prioritise adherence. This is the reason why the nurses at the study clinic insist that PLWHA should try to fit the ART medication regimen into their lifestyle, because many

PLWHA are not prepared to rearrange the daily schedule of their lives to fit in the taking of the required regular doses of their ARV medication. In one of the health talks presented at the clinic, a nurse insisted that if one is a partygoer, one should take the drugs with one in one's bag when one goes to the party, because most partygoers will not miss a party just because it coincides with the time of one of their scheduled ARV doses.

#### **5.3.1.4 Category 4: Occurrence of side effects of ARVs**

Concerning the issue of side effects of ARVs, one subcategory emerged from this category. This was the perceived disfiguring effects associated with the use of ARVs. This subcategory is discussed below.

- **The perceived disfiguring effects associated with the use of ARVs**

The study revealed that three participants were concerned about disfiguring side effects of ARVs. These participants mentioned that they had had disfiguring side effects that were lowering their self-esteem, interfering with their adherence to ART, and subsequently lowering their QOL. These are their responses:

*I don't know which is better, to continue with the drugs and not feel happy as I am, because of this enlarged abdomen that I have because of the drugs [or to stop taking the drugs]. I explained it to the doctor, but he said that I should be patient, because they cannot change the drugs just because of the abdominal enlargement. You can easily tell if someone is on the drugs – thin legs and broad shoulders. I am ashamed, because I know I am noticed by everyone.*

*I cannot quite understand what is really happening with my body. It means I am unlucky, because I see people doing well on the drugs, but I am being disfigured*

*here. I have noticed that my legs are hardening and I am developing a big tummy. First I thought I was gaining weight, but now I have realised that I am out of shape because of the drugs. I have voiced this concern, but the nurses said I should exercise. Sometimes I am tempted to stop them [the drugs].*

According to the literature, the above condition is called lipodystrophy. According to Kinlaw and Marsh (2004:484), the prevalence of lipodystrophy in patients on HAART is approximately 40% and has been attributed to the use of protease inhibitors and a nucleoside analogue called stavudine. This condition includes both the loss of facial and limb fat, and central obesity. The participants' responses indicate that lipodystrophy is a major concern for PLWHA. The research clearly shows that although ART prolongs life, PLWHA are also very concerned about their appearance. They are more concerned about self-image than they are about a prolonged life. According to Cichocki (2007), lipodystrophy is one side effect that is a marker for AIDS, and it can cause emotional symptoms such as altered self-image (<http://www.aids.about.com/cs/conditions/a/lipodystrophy>). So far there is no treatment for lipodystrophy in Swaziland.

Several published reports show that there is an association between side effects, non-adherence to ART and poor QOL (Ammassari, Murri, Trotta, Ravisio & Delonis 2001:445; Chesney 2000:S171; Chesney, Ickovics, Chambers, Gifford, Neidig & Zwickl 2000:255; Chesney, Neilands, Chambers, Taylor & Folkman 2006:421; Fogarty, Roter, Larson, Burke, Gillespie & Levy 2002:93; Johnson, Charlebois, Morin, Catz, Goldstein & Remein 2005:193; Johnson, Elliot, Neilands, Morin & Chesney 2006:355; Johnson & Folkman 2004:139). These findings were also noted in studies conducted by Weiser, Wolfe, Bangsberg, Thior, Gilbert, Makhema, Kabaabetswe, Dickenson, Mompoti, Essex, and Marlink (2003:281), and Chesney, Morin, and Sherr (2000:1599), who concluded that side effects pose a major barrier to adherence. In addition, Johnson and Neilands (2007:575) did a study on coping with HIV treatment side effects and

concluded that side effects from HIV treatments impact QOL and adherence to care. These authors further state that the high demands associated with ART pose a challenge to treatment success.

### **5.3.1.5 Category 5: Inconsistent condom use**

The study revealed that most of the participants (22 of them) are still engaged in sexual relationships. According to Kasiram et al. (2006:55), intimacy and sexuality are integral to human existence. Eighteen participants mentioned that although they used condoms every time they had sex, they faced certain challenges. Four participants openly stated that they did not use condoms every time they had sex. Subcategories identified within this category are as follows: (1) condoms perceived as reducing the pleasure of sex, (2) misconceptions held by PLWHA and society about condoms, (3) the expressed desire to have children, and (4) ARVs perceived to be increasing sexual desire.

- **Condoms perceived as reducing the pleasure of sex**

Although 18 of the participants stated that they used condoms consistently, they mentioned that they did not like using condoms. One of the reasons cited for this dislike of using condoms during sex was that it was like eating something that was coated. Another reason cited was that it was an unnatural act to use condoms during sex, and yet another reason cited was that using condoms reduced sexual pleasure. These are some of their comments:

*I no longer enjoy sex. I just do it for my wife who is also HIV-positive. Every time I think about sex, I think about the virus and the condom, and I lose [sexual] desire.*

*The oil that is used in the condom [the lubricant] does not smell good, and it makes me lose [sexual] appetite. You have sex, and all that you can smell is the condom, not us [the couple].*

Although most of the participants (18 of them) revealed that they used condoms consistently during sexual intercourse, this does not reflect the reality, when one looks at the prevalence of HIV and AIDS in Swaziland. At 26.1%, Swaziland has the highest HIV and AIDS prevalence rate in the world, with 44 new infections happening every day. This is consistent with the findings of a study conducted in Swaziland on condom use, which revealed that condom use in Swaziland was as low as 33.9% (National Multisectoral Strategic Framework for HIV and AIDS 2009-2014:21).

Furthermore, Swaziland's first Demographic and Health Survey (2006-2007) revealed that 99% of the survey participants knew about HIV and AIDS, and nearly half of the participants admitted to having multiple sex partners and to having sex without a condom. An attitude survey carried out in a random sample of commuters at a bus rank in Manzini, Swaziland's central commercial town and densest population centre, found that most of the participants used condoms only occasionally. This is the town where the VCT centre where the research was done is located.

In addition, according to UNAIDS (2007), condom use in Swaziland has proved to be a failure for the government and health NGOs, a failure whose consequence is apparent in new statistics on the epidemic released by the Joint UN Programme on HIV and AIDS. It is asserted that health care workers should have emphasised education, abstinence, and faithfulness to their partners from the start of the relationship (<http://www.unaids.org/en/knowledgecentre/resources/featurestories/archive/2007/2>).

The above findings suggest that condoms are used in principle, but not used in practice, in Swaziland. This is of particular concern when one looks at the prevalence of HIV and AIDS in Swaziland. One limitation in getting the true picture of condom use is that it is difficult to assess whether condoms are actually used. Estimates on the rate of condom use are calculated from self-reports and figures of the number of condoms distributed. People know what they should be doing and they know what is expected of them, that

is, to use condoms during sexual intercourse. They will tell the researcher and health workers exactly what the health workers want to hear, as they know exactly what is expected of them.

The researcher is of the opinion that condom use cannot be assessed based on condom distribution figures, because these figures are deceiving, in the sense that condoms are adequately distributed, but in many cases they are not used. The national strategic plan objectives aimed to increase the number of male condoms available from 6,286,800 in 2004 to 10,000,000 by 2008, and to consistently have increased the number of sexually active persons that use condoms by 25% every year by the year 2008. In spite of this good distribution of condoms, the use of condoms remains controversial and unpopular, as judged by statistics on condom use, which have been as low as 33.9%. Condoms are not unpopular in Swaziland only, but in Africa as a whole (Van Dyk 2003:121).

- **Misconceptions held by PLWHA and society about condoms**

The study revealed that misconceptions about condoms still exist in Swaziland. One participant mentioned that:

*Condoms are unSwazi and are packed with the [HI] virus, so that we can all get infected and die.*

Another participant stated that he needed to penetrate the vagina at least once before he put on a condom. His reasoning was that:

*Condoms can't reduce AIDS; they are okay in boosting lust and sexual immorality, and to control childbirth. I cannot imagine myself living on that thing [a condom] for the rest of my life.*

After being probed about his assertion, he stated that:

*If you use condoms, you are free to sleep with anyone without worrying about HIV and AIDS. People should be educated to abstain or stick to one partner, instead of the condom, because people will continue to sleep around. You can't say to a person, "Don't sleep around, but if you do sleep around, we have condoms to protect you." We have to stick to one thing and not give options. You know how people are – once you give an option, they will relax.*

One participant, who does not use condoms consistently, and who is of the idea that once one is on treatment there is no need to use protection, stated that:

*Every time I insist on using a condom, he [the husband] refuses, saying that he does not feel anything [when he has sex with a condom]. What can I do? I need sex, like everyone, so I eventually give in.*

When asked if she was aware of the consequences of not using a condom every time she had sexual intercourse, she stated that:

*He [the husband] is the one who will end up being infected. I already have it [HIV], and I am on treatment, so I don't have any problems. Every time I insist that he use a condom, he says that it is not him who is sick, but me, so why should I try to make him worried?*

After being probed on the issue of re-infection, this participant stated that she was a human being and that she needed sex, and that if she had to die to satisfy her need for sex, she could not avoid it. One participant stated that she had lost her partner because of refusal to use condoms. She stated that:

*I wanted us to use condoms, but my husband refused, so we did not use them. He died last year. I feel I am responsible for his death. I am not sexually active now and am concentrating on raising my kids.*

Much has been said and written about the myths and misconceptions that hinder condom use in Swaziland, but little has been done to reflect these realities in existing HIV and AIDS awareness and prevention campaigns (<http://www.themountainmovement.blogspot.com/2008/05>). Although nurses in Swaziland encourage condom use, some influential community leaders have undermined the message of using condoms. Religious and traditional leaders have also described condoms as unSwazi, giving them negative labels such as *umkhumbi* (boat), *lijazi* (coat), etc. Some influential people have ridiculed condom use as being inconsistent with Swazi manhood. Many people believe that the flow of fluids involved in sexual intercourse and reproduction represents an exchange of gifts of self, which they regard as being of the utmost importance in a relationship, and for that reason they do not use condoms (Van Dyk 2003).

Malima (2009), a gender specialist at the United Nations Population Fund (UNFPA), commented that condom use awareness campaigns and condom distribution were of limited use in the context of high levels of poverty, which drove many women into sexual relationships for economic reasons (<http://www.irinnews.org/report.aspx?reportid=83872>). However, a social welfare official of the Women's Resource Centre in Mbabane feels that efforts to promote condoms must persist, in the light of the questionable alternative of promoting total sexual abstinence (<http://www.aegis.com/news/IRIN/2003/IR031218.html>).

- **Expressed desire to bear children**

Apart from the misconceptions regarding condom use by the participants in this study, the researcher also identified that PLWHA, like HIV-negative individuals, were inclined to conceive, which is not possible if one uses a condom. In this study some three participants showed a great desire to have kids. This is what one of the participants said:

*The problem I have is that I did not tell my in-laws about my [HIV] status and [ART] treatment. They want [me to have] kids, as I don't [yet] have any. I was told by nurses that, with the correct guidance, I can have HIV-negative babies, but how can I if I am [HIV-] positive? If you bake bread with a pan that is marked "Swaziland United Bakeries" (SUB), the bread that will come out will have that "SUB" label [meaning that if one is HIV-positive, the baby will also be HIV-positive].*

One participant who did not use condoms consistently stated that:

*Sometimes we use condoms; sometimes we don't, just to feel it [the sensation of having sex]. We never used it [a condom] last year, because I wanted his child, as we did not have any [children]. My problem at that time was a low CD4 count of 140, and the nurses were very angry with me, but I wanted a child. Fortunately I did not have any problems, and my baby is fine for now.*

The same concern was raised by the nurses at the workshop, namely that the majority of young PLWHA want to get married and have children.

- **ARVs perceived to be increasing sexual desire**

In this study, two participants stated that they could not do without sex because ARVs have increased sexual desire. When they were asked if they were having sexual intercourse more than before, their responses were as follows:

*I was normally [sexually] active before HIV, then HIV killed my [sexual] desire and took away my strength. The ARVs have increased my desire beyond when I was HIV-negative.*

*When I started the drugs, I told myself that I would never engage in sex anymore, but I found myself having this strong desire for sex that I could not resist.*

This issue of increased sexual desire was also brought up by the nurses during the validation workshop. Unfortunately, no study has been carried out to assess whether ARVs increase sexual desire among PLWHA in Swaziland. A possible explanation of increased sexual appetite, suggested by the nurses during the workshop, was that with the commencement of ART, the individual would gain strength, and all the systems of the body, including the reproductive system, would start to function normally. The researcher is of the opinion that baseline data should be collected before commencement of ART, so as to establish whether ARVs do indeed increase sexual desire.

### **5.3.2 Psychological challenges faced by PLWHA on ART**

The previous theme dealt with the physiological domain of PLWHA. This theme focuses on the psychological domain. Neuman (1995), in George (2002:343), defines the psychological variables of a person as “the mental processes and relationships”. Four categories emerged from the data analysis pertaining to the psychological domain, namely (1) the constant experience of stigma and discrimination due to HIV and AIDS and ART, (2) the experience of depression due to HIV and AIDS, (3) difficulty coping with the illness and its treatment, and (4) lowered self-esteem and self-image due to ART. Table 5.3 summarises the themes, categories, and subcategories of the psychological domain.

**Table 5.2: Themes, categories, and subcategories of the psychological domain**

Theme	Category	Subcategories
<b>5.4.2 Psychological challenges faced by PLWHA on ART</b>	5.4.2.1 The constant experience of stigma and discrimination due to HIV and AIDS and ART	<ul style="list-style-type: none"> <li>• AIDS is perceived as a stigmatising condition</li> <li>• ARVs exacerbate the stigma of HIV and AIDS</li> </ul>
	5.4.2.2 The experience of depression due to HIV and AIDS	<ul style="list-style-type: none"> <li>• The perception of HIV as a disease of prostitutes, gays, and lesbians, with ARVs being a constant reminder of one's HIV status</li> <li>• Lack of proper counselling from health care workers</li> </ul>
	5.4.2.3 Difficult coping with the illness and the treatment	<ul style="list-style-type: none"> <li>• The incurability of the HIV infection, such that ART becomes a lifelong treatment</li> </ul>
	5.4.2.4 Lowered self-esteem and self-image due to ART	<ul style="list-style-type: none"> <li>• The stigma attached to HIV and AIDS and ART</li> <li>• A negative perception of the illness and treatment</li> </ul>

### **5.3.2.1 Category1: The constant experience of stigma and discrimination due to HIV and AIDS and ART**

HIV and AIDS-related stigma refers to the prejudice and discrimination directed at people living with HIV and AIDS and the groups and communities that they are associated with (<http://www.avert.org/aidsstigma.htm>). In this category, the researcher identified two subcategories, namely: (1) HIV and AIDS being perceived as a stigmatising condition, and (2) ARVs exacerbate the stigma of HIV and AIDS.

- **The perception of HIV and AIDS as a stigmatising condition**

Regarding the perception of HIV and AIDS as a stigmatising condition, the majority of the participants (17 of them) revealed that when they were diagnosed with HIV, they were stigmatised in some way by their family members, friends, and community

members. This is what these participants had to say about the perception of HIV and AIDS as a stigmatising condition:

*You know, when this disease came, a long time ago, we were told that AIDS was for those who were behaving badly [prostitutes]. We accepted that. It [that perception] is now very hard to change, despite the fact that it [the disease] is now affecting everyone. When you have the disease, it is like you have been behaving badly, and it is even worse if you are a woman. It is one disease that you cannot tell anyone about, because people will shy away from you.*

*This is a misery disease. You don't have anyone to blame for it but yourself, for not taking the proper protective measures. You cannot tell anyone, because no one will feel sorry for you. They will say it is your mistake and that you have no one to blame. So what you do is to deal with it quietly without even involving your family.*

It is clear from the above responses that HIV and AIDS stigma still exists in Swaziland. As evidence that AIDS stigma is still pervasive in Swaziland, a study carried out by Holzemer et al (2007:1002) on stigma and the validation of the HIV and AIDS stigma instrument in five countries, Swaziland included, noted that AIDS stigma and discrimination were continuing to affect those living with and affected by HIV disease and their health care providers, particularly in southern Africa. In addition, the above researchers state that many health care workers in Swaziland have come to the conclusion that unless stigma is conquered, the HIV and AIDS epidemic will not be eradicated. The research has identified that stigma is a major barrier to adherence and negatively influences QOL.

- **The perception of ARVs as exacerbating the stigma of HIV and AIDS**

In addition to the perception of HIV and AIDS as a stigmatising condition, the study participants revealed that ARVs exacerbated the stigma of HIV and AIDS. As a result, all the participants who were stigmatised because of HIV felt that the ARVs had increased the stigma associated with their HIV-positive status. The participants had this to say about their perception of the influence of ARVs on their lives:

*Even if I never disclosed my [HIV-positive] status, I cannot hide the drugs [the ARVs]. Eventually people will find out that I have the virus [HIV]. You cannot hide the tablets. I wish there was a monthly injection. At least no one would know that you have the virus.*

*The going in and out of the clinic to collect the drugs revealed my status. I met some neighbours and could not hide what I had come for. You know, the minute they see you in the ART clinic, they know that you have AIDS.*

Research has been done on stigma and ART worldwide, and it has been concluded that the introduction of ART has lessened stigma. However, in this study, the researcher has concluded that ART has increased stigma. As evidence that ARVs have increased stigma, the researcher noted that at the clinic that most PLWHA, when given their pills, will discard the pill boxes. Some even emptied all the pills into new containers. It is evident that they are afraid of being seen with ARVs, which are used by stigmatised people. This therefore means that HIV and AIDS and ARV stigma is not yet gone.

A study conducted by Uys, Chirwa, Kohi, Greeff, Naidoo, Makoe, Dlamini, Durrheim, Cuca, and Holzemer (2009:1059) supports the above findings by concluding that stigma is greater for people that are on antiretroviral drugs than for those that are not on ARVs. According to Gerretsen (2008:4), these life-prolonging antiretroviral drugs have been identified for contributing to HIV-positive people being stigmatised in their communities. This researcher also found that the taking of antiretroviral drugs identifies people as

being HIV-positive. In addition, nurses treating HIV-positive patients were often treated as if they too were HIV-positive, with their neighbours sometimes not allowing their children to play with the nurses (Gerretsen 2008:4).

Corresponding with the above, one participant mentioned that taking medication was a marker for HIV infection, and that it could therefore be awkward taking medication outside the home, and that carrying the treatment as luggage may lead to involuntary disclosure of HIV status, resulting in stigmatisation.

A study done in Tanzania on universal access to ART revealed that the roll-out of ART has not eradicated HIV-related stigma, but has paradoxically increased it, and it has reduced counselling and testing and increased sexual risk taking. The researchers also found that some community leaders equated antiretroviral roll-out with increased HIV prevalence. They base their argument on the fact that PLWHA looked attractive and difficult to identify physically, because they get healthier as a result of treatment, and that they were engaging in unprotected sexual relationships, thus spreading the disease (Roura, Urassa, Busza, Mbata, Wringe & Zaba 2009:308). The researchers are of the view that scaling up ART means scaling up stigma and discrimination.

From this study, it is clear that HIV and AIDS stigma still exist in Swaziland and ARVs have increased stigma. According to literature, stigma negatively influences QOL. Oleson (1990), in King and Hinds (1998:42), state that QOL results from the development of personal potential and self-actualisation. The findings of the study reveal that PLWHA who are on ART cannot attain their highest potential and are not self-actualised and as such have a poor QOL.

### ***5.3.2.2 Category 2: The experience of depression due to HIV and AIDS***

Due to the constant experience of stigma and discrimination associated with HIV and AIDS and ART, PLWHA may be prone to depression. In this study, 18 participants

reported that they suffered depression, and two of them ended up in a psychiatric hospital because of severe depression, and they were still depressed and undergoing counselling. The researcher identified two main subcategories in this category, namely: (1) the perception of HIV and AIDS as a disease of prostitutes, gays, and lesbians, with ARVs being a constant reminder of one's HIV status; and (2) lack of proper counselling by health workers.

- **The perception of AIDS as a disease of prostitutes, gays and lesbians, with ARVs being a constant reminder of HIV one's status**

In this study, the researcher discovered that some PLWHA on ART do suffer depression due to their disease and the treatment they are receiving. Since the main aim of this study was to describe QOL, the researcher did not conduct any proper screening for depression in PLWHA. Participants reported to the researcher their experience of depression, and such reports were not verified. This is what one of the participants who was severely affected by depression had to say to the researcher:

*I thought this disease was for those who run around having sex with everyone. I was not like that [promiscuous], and that is why I got disturbed and ended up in hospital. Now I am stressed by the tablets each time I look at them, and I feel sick at heart. The tablets are sort of a reminder that I am HIV-positive. I cannot remove this out of my mind. Everywhere you go it is HIV and AIDS. What is most depressing is that these drugs are not yet a cure, and I have to take them for the rest of my life.*

Another participant that suffered from severe depression stated that:

*They say HIV and AIDS is an issue for all of us. It is not true. Every time you go to bed or you are alone, it haunts you, and you are alone and it [HIV and AIDS] is no longer a general thing. It's a personal thing. You alone suffer the effects of*

*ARVs, and you alone have to take ARVs every day. You ask yourself questions such as Why me? Who brought this thing, and why? How much time do I have left in this world? Who will take care of me when I am sick? Who will take care of my kids?*

Several studies that have been conducted on the relationship between HIV and AIDS and depression have concluded that depression may accompany an HIV-positive diagnosis. According to Thom (2009:8),

The prevalence of depression and anxiety in PLWHA is similar to that of people suffering from other serious chronic and life-threatening medical illnesses. A major factor is the psychological reaction to having such an illness. The individual is faced with the reality of serious illness and possible death at an early stage. In many cases there are additional stressors related to the stigma associated with HIV and AIDS and lack of social support for the infected individual.

Rabkin, Ferrando, Lin, Sewel, and McElhiney (2000:4130) conducted a study on the psychological effects of HAART and concluded that depression declined after two years of ART. The researcher's study revealed that depression continues even after two years of HAART, because the ARVs themselves contribute to depression. Participants mentioned that the thought of lifelong treatment depresses them and that ARVs were constantly reminding them of their HIV infection.

Several studies have indicated that there is a relationship between depression, non adherence, and QOL. Depression lowers an individual's QOL so it can be concluded that because PLWHA in Swaziland suffer depression due to ART, their QOL is lowered.

- **Lack of proper counselling from health care workers**

In spite of the fact that PLWHA are constantly discriminated against, and consequently suffer from depression, the researcher found that the lack of proper counselling from

health professionals contributed to PLWHA' depression. One participant, who had been on ART for a year, blamed the HIV testing campaigns for the fact that there was no time for proper counselling and claimed that the campaigns were being done just to satisfy the campaigners that many people were testing for HIV, and that they were not particularly concerned if the testing was being done without the people receiving proper counselling by professional counsellors. He stated that:

*I was occasionally sick but not critical before I went for testing. I did not get proper counselling before testing. I did it because it was advertised everywhere that one must test. So I tested and found out that I had the virus. I was not prepared for the results, and while I was shocked at the results, I was told that I had to have my CD4 count checked, which was found to be very low, and I had to start treatment before I got sicker. You see, now I had to deal with being HIV-positive and taking the drugs for the rest of my life.*

Still on the issue of testing campaigns, another participant stated that:

*People are offered incentives for testing. They test without knowing what will happen, and they end up being depressed and killing themselves, because they were not prepared for the results.*

One participant, commenting on the practice of public testing campaigns, stated that:

*Some influential people will claim to be taking the public test and will declare the results publicly. Those people are deceiving the public, since they first test privately and will appear to be confidently taking the public test, yet they already knew the outcome of the test.*

There is no study that has been done in Swaziland to assess the psychological effects of HIV public testing campaigns. It has just been assumed that such campaigns are effective in making people test for HIV.

### **5.3.2.3 Category 3: Difficulty coping with the illness and its treatment**

When the participants were asked whether they were coping well with the illness and the treatment, almost all of them (20) mentioned that they were trying to cope with the illness and the treatment. The main challenge to coping that was identified by the researcher was the incurability of HIV and AIDS, such that ART becomes a lifelong treatment. In this category, the researcher identified only one subcategory, namely the incurability of HIV and AIDS.

- **The incurability of HIV, such that ART becomes a lifelong treatment**

All the participants mentioned that they were trying to cope with the condition but were concerned about the fact that the disease is incurable and that they have to take ARVs for the rest of their lives. These are some of their comments:

*The drugs are an added burden. I have to deal with the disease and take the drugs for life. I wish a cure could be found soon, because it is tiring to take the drugs for a long time.*

*To make it better for people to take the medication correctly, maybe we can be given one tablet a month or one tablet a day, at least, so that we are not always thinking about the times to take the medication, or at least get an injection that will last for some months, like the pregnancy prevention injection.*

*Coping is difficult, although I am trying. What makes it difficult is that I have to take these drugs for life. You know how difficult it is to finish a week's prescription. I sometimes ask myself what kind of human being lives by the bottle*

*[ARVs]. There is no life here. If you don't take the drugs, you die. If you take them, they make you sick.*

This study revealed that PLWHA are facing challenges to coping with taking their antiretroviral treatment. These findings are supported by Mugavero, Ostermann, Whetten, Leserman, Swartz, Stangl and Thielman (2006:418), who carried out a study on coping with ARVs and concluded that there are many challenges faced by PLWHA that negatively affect their coping with the taking of their treatment. This negative coping is associated with poor ARV adherence and poor QOL.

#### **5.3.2.4 Category 4: Lowered self-esteem and self-image due to ART**

Self-esteem is characterised by feelings of confidence, achievement, independence, reputation, and feeling recognised, appreciated, and valued. The study revealed that ART has lowered participants' self-esteem. A lowered self esteem parallels a low QOL. Supporting these findings, Power, Tate, McGill and Taylor (2003:62) are of the opinion that HAART may have a negative impact on self-esteem and QOL, especially for those that are young and newly diagnosed. Ferrier and Lavis (2004:427) assert that if one is on ART, "you don't have a life, you have a medication schedule".

Nurses at the workshop expressed the view that meeting the need for a high self-esteem can be a difficult task for PLWHA. Sometimes it depends on the individual's acceptance of his or her condition. Acceptance of the condition depends on how he or she perceives the illness and its treatment. HIV and AIDS comes with many perceptions. Some see HIV and AIDS as a punishment from a higher spiritual being. Some see it as a curse, or a sickness of prostitutes, gays, and lesbians.

Concerning the effect of ARVs on self-esteem and self-image, 16 of the participants reported suffering from lowered self-esteem. In this category, two subcategories

emerged from the data. These are: (1) lowered self-esteem due to the stigma attached to the HIV infection and ART; and (2) negative perception of the illness and its treatment. The stigma and discrimination associated with HIV infection have already been discussed. The following discussion is on the subcategory of the negative perception of the illness and its treatment.

- **Negative perception of the illness and its treatment**

With regard to the perception of the illness and its treatment, some 10 participants perceived AIDS as an illness that is different from other illnesses. They mentioned that society does not perceive HIV and AIDS in the same way as it perceives other infections:

*If you have diabetes or any other illness, it is better, but if you have HIV, it is like you deserve it as a punishment.*

*To me HIV is different from any other illness. You are stigmatised because of it. There is no treatment, and it is a disease that is associated with shameful behaviour and a disease that you are not proud to reveal.*

On a lighter note, one participant was concerned about the shape of the ARV tablets:

*Why do they make ARVs in the shape of a coffin, whereas most tablets are round? Does it mean we are getting ready for our coffins?*

### **5.3.3 The influence of ART on the spiritual domain**

Having assessed the negative psychological effects of ART on PLWHA, the researcher identified that being on ART also affected the spiritual domain of PLWHA. The researcher noted that the word “spirituality” was used synonymously with the word

“religion” by all of the participants, but it was made explicit by the researcher that religion refers to an organised system of beliefs concerning the cause, nature, and purpose of the universe, especially beliefs in or the worship of God or gods, whereas spirituality refers to something that is born out of each person’s unique life experiences and his or her personal effort to find purpose and meaning in life (Andrews & Boyle 2003:436). From the participants’ responses, two categories were identified relating to the spirituality of PLWHA. It was identified that spirituality can serve as a source of support for PLWHA and can also be a source of conflict with ART. Table 5.4 outlines the themes, categories, and subcategories of the spiritual domain.

**Table 5.3: Themes, categories, and subcategories of the spiritual domain**

Theme	Category	Subcategories
5.4.3 The influence of ART on the spiritual domain	5.4.3.1 Spirituality as a source of support for the taking of ART	<ul style="list-style-type: none"> <li>• Increased spiritual beliefs and material support for PLWHA, enabling them to cope with HIV and AIDS and the demands of ART</li> <li>• Increased emotional support, resulting in decreased depression</li> </ul>
	5.4.3.2 Spirituality as a source of conflict for the taking of ART	<ul style="list-style-type: none"> <li>• Spirituality conflicts with the taking of ART, resulting in a change of religion</li> <li>• Spirituality conflicts with the taking of ART, resulting in the abandoning of ARVs</li> </ul>

### **5.3.3.1 Category 1: Spirituality as a source of support for the taking of ART**

The majority of the participants (21 of them) emphasised the importance of religion in coping with HIV and adherence to ART. Two subcategories were identified from this category, namely: (1) increased spiritual beliefs and material support, enabling PLWHA to cope with HIV and AIDS and ART; and (2) increased emotional support, thus reducing depression.

- **Increased spiritual beliefs and material support, enabling PLWHA to cope with HIV and AIDS and ART**

One participant, who derives spiritual support from attending church services, stated that:

*I was a believer even before I had HIV, but now I realise that I have to be strong in my beliefs, since this disease is not curable, and, who knows, maybe a cure will never be found, and I will eventually die. I have to know where my life will end [spiritually].*

Another participant stated that the members of the church that she attended helped her by donating food and money:

*Church members donate money and food for those who are sick every month, and I was encouraged to attend prayers, and I don't think I would have survived without their support. They don't have a problem with the HIV-positive status. Actually, they are encouraging people to come out and disclose their status, so that they can be helped.*

Clearly, the study indicates that spirituality serves as a source of strength for PLWHA to continue with life. Several studies have examined the role that spirituality plays in helping patients to cope with life-threatening illnesses. The findings of these studies are consistent with the participants' views that religious beliefs and practices are powerful sources of comfort, hope and meaning to their lives, they enable one to adhere to treatment, and they empower one (Andrews & Boyle 2003:436; Dalmida 2007 (<http://stti.confex.com/stti/congrs07/technogram/paper>); Holstad et al 2006 (<http://www.nursingworld.org/mainmenucategories>); Sowell, Moneyham, Hennessy, Guillory, Demi & Seals 2000:73; Scarinci, Griffin, Grogoriu & Fitzpatrick 2009:69; Baldacchino & Draper 2001:838; Delgado 2007:233; Reed 1986, in Sowel et al.

2000:74; Koenig 2004:1195; the Center for Interdisciplinary Research on AIDS (CIRA) (<http://www.cira.med.yale.ed/about-us/people-asp>; Meraviglia 2004 (<http://www.findarticles.com/p/articles/mi-mo825>; Pargament, Koenig & Tarakeshwar 2000:519; Pargament, Tarakeshwar, Ellison & Wulff 2001:497; McCullough, Hoyt, Larson, Koenig & Thoresen 2000:211).

In addition to the above, the goal of spiritual nursing care is to assist clients to integrate their own religious beliefs about God, to give meaning to their lives, as they face the illness of HIV and AIDS, which requires nursing care. Spiritual nursing care promotes clients' physical and emotional health, as well as their spiritual health. Furthermore, spiritual intervention is as appropriate as any other form of nursing intervention, and a balance of physical, psychosocial and spiritual health is essential to overall good health (Andrews & Boyle 2003:436).

While clients need the necessary information and knowledge to be able to cope with the disease (cognitive information), they also need to be equipped to cope emotionally and spiritually with the ravages of the disease (Van Dyk 2003:290). Research conducted in Ghana on the influence of religion on adherence to ART found that religion played a significant role in the successful treatment of HIV. At the study centre, health workers start daily clinical sessions for HIV treatment with prayers and religious songs. This influences adherence to ART (Dapaah 2009). Tsevat (2006:S1) did a study of PLWHA who are on ART. The results of his study showed that most PLWHA believed that through spirituality, life improved, and participants found the will to live.

- **Increased emotional support, resulting in decreased depression**

Concerning religion and depression, six participants stated that they were no longer depressed, as a result of going to church.

Two participants said:

*In church we are made to feel normal. No one is stigmatised. We just sing and pray and we are not isolated from the crowd. We are encouraged to take the drugs [the ARVs] and combine them with prayer, so that they can be effective.*

*In church, I forget about the virus. We are prayed for and encouraged that if we have faith, God will remove all our problems. This to me removes all the worries I have about the virus.*

The above participants' responses show that religion serves as an antidepressant for PLWHA. This corresponds to the findings of Yi, Mrus, Wade, Ho, Hornung, Cotton, Peterman, Puchalski, and Tsevat (2006:21), who did a study on religion, spirituality, and depressive symptoms in patients with HIV and AIDS and concluded that helping to address the spiritual needs of patients in the medical or community setting may serve to decrease depressive symptoms in patients with HIV. The participants' responses were also supported by Szaflarski, Ritchey, Leonard, Mrus, Peterman, Ellison, McCullough, and Tsevat (2006:28), who used path analysis to examine the conceptual model of the relationship between spirituality and QOL. The results showed that spirituality has both direct and indirect effects on patients' perceptions of living with HIV and AIDS. The authors also found that one third of a sample of patients with HIV and AIDS believed that their life was better than it was before diagnosis with HIV, as a result of spirituality.

A growing body of scientific knowledge suggests connections between religion, spirituality, and both mental and physical health (Koenig 2004:1194). Findings are strong in patients with severe or chronic illnesses who are having stressful psychological and social changes, as well as existential struggles related to meaning and purpose. Koenig (2004:1194) also states that many PLWHA who were not religious before may turn to religion for comfort, and that religion becomes increasingly important as patients face the goliath of HIV and AIDS.

Furthermore, Pargament et al. (2000:519) states that personal faith may benefit patients' physical health through its positive effects on their mental health. In addition, religious activities have been associated with better immune function, healthier behaviours, and better sleep. As a result, individuals with personal faith live significantly longer.

A study conducted in Tanzania that explored the world views, spirituality, and health beliefs of health care professionals and community health workers showed that there was a strong belief that spiritual and physical healing are equally essential in combating disease. Furthermore, the study concluded that churches and religious organisations play an important role in forming people's views on disease and health-seeking behaviours. Traditional healers and witchdoctors have a stronger presence in treatment in isolated areas where modern health facilities are limited, and that spirituality is the most important belief among participants, and that it influences their daily actions and perspectives (Harding 2009).

In addition, the researcher's investigation showed that because of a multitude of factors such as the stigma associated with HIV and AIDS and the limited time that physicians have to spend with patients, religion and motivational counselling can provide a patient with individual empowerment and allow him or her to better understand his or her mental or physical health issues. Spirituality has the potential to help traumatised people to go beyond the self, to give themselves over to something benevolent, something that helps them renew their trust in people, regain connection, and develop a positive identity (<http://www.heal-reconcile-rwanda.org/lec-needs.htm>). In addition, spirituality, is the last thing a person clings to in times of great difficulty and suffering, when hope seems to be far away, as in the case of HIV and AIDS.

### **5.3.3.2 Category 2: Spirituality as a source of conflict with the taking of ART**

Although spirituality may be a source of support for PLWHA, in this study the researcher found that it may be a source of conflict to the sufferer. Although most of the participants (21) felt that spirituality offered them support, some (3) felt that spirituality was a source of conflict in the taking of their treatment. Two subcategories emerged from this category, namely: (1) the conflict of spirituality and ART may result in a change of religion; and (2) the abandoning of ARVs.

- **Spirituality clashes with the taking of ART, resulting in a change of religion**

One participant had to change his religion from Christianity to Islam because he discovered that most Christian pastors discourage the use of ARVs and insist on prayer. Meanwhile he believes that PLWHA need the drugs for their physical health, while spirituality takes care of their emotional health. This was his response:

*Most Christian pastors insist on praying and healing an individual with HIV. They [the pastors] usually say, "We will pray for you and you will be healed, if you bring your tablets, so that we can burn them." One thing that people need to understand is that in church we are offered spiritual healing, and not physical healing. Physical healing is taken care of by medicine, and I will never stop taking these pills [ARVs], because they are the reason that I am still alive.*

The above response corresponds with the findings of Cichocki (2007), who did a study on the role of religion and spirituality in HIV and concluded that, while physical problems can be treated with medicine, emotional impact has no solutions. While some PLWHA turn to their family and some seek counselling from doctors or mental health professionals, sadly, others turn to drugs or alcohol. For many PLWHA, however, support comes from spirituality and religion (<http://www.aids.about.com/od/spirituality/a/religion.htm>). According to the above author,

religion helps PLWHA, by giving new meaning to life. Illness becomes part of the “new you”, and spirituality answers questions.

The study revealed that there is not much difference in the way that Christianity and Islam view HIV and AIDS and its treatment. This is supported by Balogun (2009), who states that, although Christian religious bodies are taking the lead in religious campaigns against HIV and AIDS worldwide, Islam is not opposed to antiretroviral treatment of HIV and AIDS.

- **Spirituality conflicts with the taking of ART, resulting in the abandoning of ARVs**

While conflict between spirituality and the taking of ART caused some PLWHA to change their religion, it became clear that such conflict may also result in the abandoning of ARVs. In this subcategory, two participants stated that they once stopped ARVs because:

*Some church members and pastors have caused many people to stop taking their tablets and depend on prayer [alone], and we have lost many people who have stopped taking the tablets and have died. They [PLWHA] don't understand that we pray, so that the drugs can work.*

*I learned the hard way. I stopped the drugs because I believed I was healed. I got sick and was lucky I responded well after I started taking them again. I will never stop the drugs again.*

While most studies see religion as having positive outcomes, other studies state that it may conflict with the taking of prescribed medical treatment. Koenig (2004:1194) states that religious beliefs may affect medical decision making, generate beliefs that conflict with medical care, induce spiritual struggles that create stress and impair health outcomes and interfere with disease detection and treatment compliance, and conflict

with treatments prescribed by a physician. In addition to the above, Koenig revealed that certain Christian groups may have beliefs against taking drugs or receiving medical procedures, preferring to pray for healing or perform other religious rituals. This is true in Swaziland, as some Christian pastors insist on prayer and healing, and not using drugs.

Cotton, Tsevat, Szaflarski, Kudel, Sherman, Feinberg, Leonard, and Holmes (2006:14) did a study with 347 adults with HIV. Twenty five percent of the participants reported being more religious since becoming infected with HIV, while 25% reported that they felt alienated by a religious group, and others had to change their place of religious worship because of HIV and AIDS. This alienation is partly due to the initial response of Christians to HIV and AIDS, which was condemnation of those infected. PLWHA were taken as sinners deserving punishment and death, and some still are.

The negative influence of religion is confirmed by Flannelly, Ellison, and Strock (2004:1232), who believe that religion may cause coping styles in which individuals surrender control or responsibility of problems to a higher power. Furthermore, Pargament et al. (2000:519) state that it is important to note that although religion and spiritual resources hold particular value for people with HIV, it is also important to note that religion and spirituality may present a source of pain and struggle for some with HIV. With some religions, there is outright prohibition of distribution of condoms (Dapaar 2009).

While researchers often refer to the importance of dealing with the spiritual and emotional needs of HIV-infected clients and their loved ones, this process probably remains one of the most neglected aspects of counselling, especially within the context of HIV and AIDS (Van Dyk 2003:310). Although it is important for counsellors not to force their own religious views onto their clients, it is probably more common for counsellors to either totally ignore the religious needs of clients, or simply refer clients to a rabbi, priest, minister, or imam, as the case may be, and unfortunately many religious

leaders cannot counsel clients, because they themselves are ignorant of the disease (Van Dyk 2003:310-311).

Some religions are concerned with what they call the ethical dilemma of ARVs prolonging life, rather than God prolonging it. They are concerned that religion is losing ground in Africa because of biomedical science, and that the active involvement of religious bodies in the roll-out of ARVs is contradictory to African ideology (Kalipeni 2009).

Concerning the question of who is in a better position to offer spiritual health, most of the participants in this study (20 of them) stated that although religion is important, they felt that nurses should concentrate on their job of giving medication and education, and that the job of caring spirituality should be left to the churches. Andrews and Boyle (2003:436), however, believe that nurses should also offer spiritual nursing care. In addition, Potter and Perry (2005:95) state that nurses must understand clients' spiritual dimensions to involve them effectively in nursing care. Ross (1994), in Kinghorn and Gamlin (2002:88), insists that spiritual care should be a responsibility of nursing, and not an optional extra, and that nurses are in a position that enables them to offer spiritual care. Maughans (1996), in Kinghorn and Gamlin (2002:87), recommends that health care professionals should consider spirituality as a potentially important component of every patient's wellbeing, and that they should consider addressing spirituality with patients early and often and respect patients' autonomy and privacy of spiritual beliefs and practices. The research findings that spirituality is important were observed at the study centre, as morning prayers were said before consultation started.

Tsevat (2006:S1) recognises the importance of religion. He has discovered that it is an ignored aspect of QOL and asserts that an important yet often neglected facet of QOL, particularly for those facing chronic illness or life-threatening illness, is spirituality/religion. In support of his argument, the author goes on to state that numerous studies have examined QOL, but that few of them have examined the role

that spirituality plays in QOL of PLWHA. The above assertion is supported by Pargament et al. (2001:497), Siegal and Schrimshaw (2002:91), and Flannelly et al (2004:1231).

In addition, Drew (1996:404) observes that spirituality is rarely central in any intervention programme and is given little consideration. Supporting this finding, Andrews and Boyle (2003:46) claim that although spiritual needs are recognised by many nurses, spiritual care is often neglected. These authors posit various reasons cited for nurses' failure to provide spiritual care. One main reason posited for why nurses neglect patients' spiritual care is that they view religious and spiritual needs as a private matter concerning an individual and his or her Creator. Nurses sometimes lack knowledge about spirituality and the religious beliefs of others, hence they mistake spiritual needs for psychological needs, and they view meeting the spiritual needs of clients as a family or pastoral responsibility, not a nursing responsibility.

#### **5.3.4 Low socio-economic status of PLWHA on ART**

The socio-economic domain deals with social support, community roles, community integration, participation, and employment. In this domain only one category emerged from the data analysis, namely lack of financial resources for PLWHA. Table 5.5 outlines the themes, categories, and subcategories of the socio-economic domain.

**Table 5.4: Themes, categories, and subcategories of the socio-economic domain**

<b>Theme</b>	<b>Category</b>	<b>Subcategory</b>
<b>5.4.4 Low socio-economic status of PLWHA</b>	5.4.4.1 Lack of financial resources for PLWHA	<ul style="list-style-type: none"> <li>Lack of financial support, due to the poor economic situation in Swaziland</li> </ul>

#### **5.3.4.1 Category 1: Lack of financial resources for PLWHA**

Twenty participants claimed that due to their low socio-economic status, they were unable to meet certain expenses, such as travelling expenses, and food. This in turn affects their QOL. One subcategory was identified within this category, namely the lack of financial support, due to the poor economic situation in Swaziland.

- **Lack of financial support, due to the poor economic situation in the country**

Participants mentioned that because poverty was pervasive in Swaziland, it was difficult to get financial assistance from family and friends:

*The situation in Swaziland is survival of the fittest. No one is assisting anyone, because everyone is poor and is struggling to feed their family.*

*There is no compassion for anyone anymore. Everyone is minding their own business. No one cares about us. Not even government cares about us.*

The low socio-economic status of Swaziland's population is not a new phenomenon. The majority of the people of Swaziland (69%) are classified as poor (living below the poverty line of €128.60 (US\$22) per month, or less than US\$1 a day) (Swaziland Amnesty International Report 2007; Swaziland-African Economic Outlook 2008; Swaziland Budget Speech 2008-2009; Second National Multisectoral HIV and AIDS Strategic Plan of 2006-2008; Swaziland National Health Policy 2007). The economy is very small and susceptible to external shocks and is currently facing declining long-term growth, rising poverty, and major social challenges. Gross Domestic Product (GDP) growth has continued to decline, from 2.1% in 2004 to 1.8% in 2005 (World Bank 2006).

Although Swaziland's health sector funding has improved from 7.9% in 2007-2008, to 10.6% in 2008-2009, and 17.7% in 2009-2010 (which is above the 15% minimum stipulated by the Abuja Declaration of 2001) the problems of poor socio-economic status, poverty, and hunger still exist. According to Poverty Reduction Strategy and

Action programme (PR SAP) (2006:3), the poor in Swaziland are those without adequate income to buy even the minimum amount of food required to sustain a normal, active life (set at 2,100 calories per person per day), and to acquire basic non-food requirements for a decent living. This is referred to as income poverty. Income poverty in Swaziland increased from 66% in 1995 to 69% in 2001. The poverty rate in rural areas is 76%, and in urban areas it is 50%. In terms of regions, in 2001 the rate of poverty was greatest in Shiselweni, at 76%, followed by Lubombo, at 73%, and Manzini, at 70%.

According to the Swaziland-African Economic Outlook (2008), Swaziland's economic growth has declined, from 3.5% in 2007 to 2.6% in 2008. This report also observed that income distribution is highly skewed, with 54.6% of income going to the richest segment of the populace, which accounts for a mere 20% of the population, and 4.3% going to the poorest segment. Low socio-economic status may affect a client's level of health by increasing the risk for disease and influencing how or at what point the client enters the health care system. An individual's compliance with the treatment that is designed to maintain or improve health is also affected by economic status (Potter & Perry 2005:95). This is true for Swaziland. In this regard, Von Wissel observed that Swaziland has a worryingly high default rate for ARV treatment, and that about 31% of patients drop out of treatment in their first year of medication, as a result of low socio-economic status (<http://www.aegis.com/news/IRIN/2008/R08925.html>).

From the participants' inputs and literature, it is evident that low socio-economic status has a negative impact on HIV and AIDS and QOL. With low socio-economic status, many people quickly develop full-blown AIDS, will not be able to work, and will require medical care. This will cause further deterioration of the economy. Children will have to look after the sick, they will be deprived of education and will engage in risky behaviours, or they will be abused for financial gain and will contract HIV and AIDS and further depress the economy.

Participants mentioned that travelling to the clinic for refills and treatment of some opportunistic infections was costly for them. The cost ranged from €20 (US\$2.70) upwards, with return journeys of 70 km and more. The cost of transportation for monthly clinic visits compromises both ART adherence and access to care. Interventions to address this barrier will be important in ensuring the success of ART programmes in sub-Saharan Africa (Tuller, Bangsberg, Senkungu, Ware, Emenyonu & Weiser 2009) (<http://www.ncbi.nlm.nih.gov/pubmed/19283464?>).

The participants in the study revealed that with their current low socio-economic status, it becomes very difficult to adhere to the ART medication. A study done by Chhagan, Luiz, Mohapi, McIntyre and Martinson in 2007 on the socio-economic impact of antiretroviral treatment on individuals in Soweto, South Africa found that with an overall increase in mean personal and household income following commencement of ART, and mean personal income rising 53% over baseline income, antiretroviral treatment increased individuals' capacity to seek employment. Unemployed individuals were actively seeking work, and patients noted an improvement in wellbeing, with fewer to no episodes of illness and improved QOL within three months of starting ART (<http://www.hsr.e-contentmanagement.com/archives/vol/17/issue/1/articles/2307/the-socioeconom>). Consistent with these findings, a cross-sectional study conducted by Weiser et al. (2003:281) on barriers to antiretroviral treatment adherence for patients living with HIV and AIDS in Botswana concluded that financial constraints were the most significant barrier to ART adherence.

### **5.3.5 Cognitive challenges faced by PLWHA**

Cognitive abilities determine an individual's capability to reason, use knowledge, and make decisions. An individual's definition and understanding of health and illness and the capacity to seek appropriate resources or health care depend on cognitive abilities. Cognitive abilities shape the way a person thinks, including the ability to understand

factors involved in illness, and to apply knowledge of health and illness to personal health practices (Potter & Perry 2005:164). Categories that emerged from the data analysis were (1) poor understanding of ARVs; and (2) negative thoughts about HIV and AIDS and ART. Table 5.6 represents a summary of the themes, categories, and subcategories of the cognitive domain.

**Table 5.5: Themes, categories, and subcategories of the cognitive domain**

Theme	Categories	Subcategories
<b>5.4.5 Cognitive challenges faced by PLWHA</b>	5.4.5.1 Poor understanding about treatment	<ul style="list-style-type: none"> <li>Misconceptions about HIV and AIDS and ARVs, and difficult-to-pronounce names of ARV drugs</li> </ul>
	5.4.5.2 Negative thoughts about HIV and AIDS and ART	<ul style="list-style-type: none"> <li>Being constantly reminded of one's condition</li> <li>Shortage of ARVs in clinics</li> </ul>

#### ***5.3.5.1 Category 1: Poor understanding about treatment***

Concerning knowledge of the pharmacodynamic action of ARVs, six participants were not knowledgeable about the way ARVs acted against the HI viruses in the body, that is, their inhibiting action on the enzymes used in the replication of the HI virus. One subcategory emerged from this category, namely that misconceptions about HIV and AIDS and ARVs still exist in Swaziland, and that the difficult-to-pronounce names of the ARV drugs contribute to patients' poor understanding about treatment.

- **Misconceptions about HIV and AIDS and ARVs, and difficult-to-pronounce names of ARV drugs**

The study revealed that some participants still had misconceptions about HIV and AIDS and ARVs. Misconceptions were revealed in the study, as two participants claimed to have been cured by faith healers and traditional healers. One participant commented that:

*We are given some education before we start the drugs, but we cannot learn everything within a short time. Education needs to be strengthened and made continual, by means of radio, TV, and newspaper [messages].*

Concerning knowledge of the names of the ARV drugs, almost all of the participants (20 of them) did not know by name the drugs that they were taking. This may be due to the difficult-to-pronounce names that have been given to the drugs. These names are difficult to pronounce even for health professionals. One participant responded as follows:

*The names of the drugs are difficult [to pronounce]. I do not know them [the drugs] by name. Anyway, it is not for us to know them, but we have to take them correctly.*

A participant that had excellent knowledge about HIV and AIDS, but had difficulty remembering the names of the drugs, commented that:

*I do not know by name the two drugs that I am taking. The names of these drugs are difficult [to pronounce]. I only know zidovudine. It's like I am calling the king of demons (laughing). Just listen to that! Zidovudine! What is that? Why did they give it a difficult name like that?*

The researcher observed that on Mondays, Wednesdays, and Fridays, clients received one hour of health education, with the focus on HIV and AIDS, ART, diet, and adherence issues, and on Tuesdays and Thursdays they received two hours of health education. Although clients received HIV and AIDS-related education on the above-mentioned days, the research study showed that misconceptions still existed among PLWHA. The researcher feels that there is an urgent need to scale up community awareness of HIV and AIDS and ART.

The need for education was also recognised by SADC, of which Swaziland is a member state, in its 2003 Declaration on HIV and AIDS. SADC claimed that there was a need to scale up the role of education, to form partnerships with all key stakeholders, including the youth, women, parents and the community, health care providers, traditional health practitioners, nutritionists, and educators, and to integrate HIV and AIDS education into both the ordinary and extraordinary curricula at all levels of education (SADC 2003). With education, PLWHA can be empowered to improve their QOL. This study clearly indicates that the misconceptions that PLWHA have about HIV, AIDS and ART negatively influences their QOL.

#### **5.3.5.2 Category 2: Negative thoughts about HIV and AIDS and ART**

Because of the stigma and discrimination that have been engendered by HIV and AIDS, PLWHA may have negative thoughts about the disease and its treatment. When the participants were asked what was constantly on their minds concerning the illness and the drugs, most of them (16) did not have any negative thoughts, but some of them (8) had thoughts that were constantly troubling them. The thoughts that were constantly troubling the participants were as follows: (1) their having to take ARVs was a constant reminder to them that they had the HI virus, and (2) a shortage of ARVs, which could result in drug resistance.

- **Constantly being reminded of their condition by their having to take ARVs**

In this regard, one participant commented that:

*Even if I try to forget, it is constantly in my mind that I am infected, and that it [HIV] is not curable. Even when I want to forget, the papers and the radio are constantly talking about it, and I cannot take it out of my mind. It's like I am already living under the mercy of the referee, who can blow the whistle at any time.*

- **A shortage of ARVs, which could result in drug resistance**

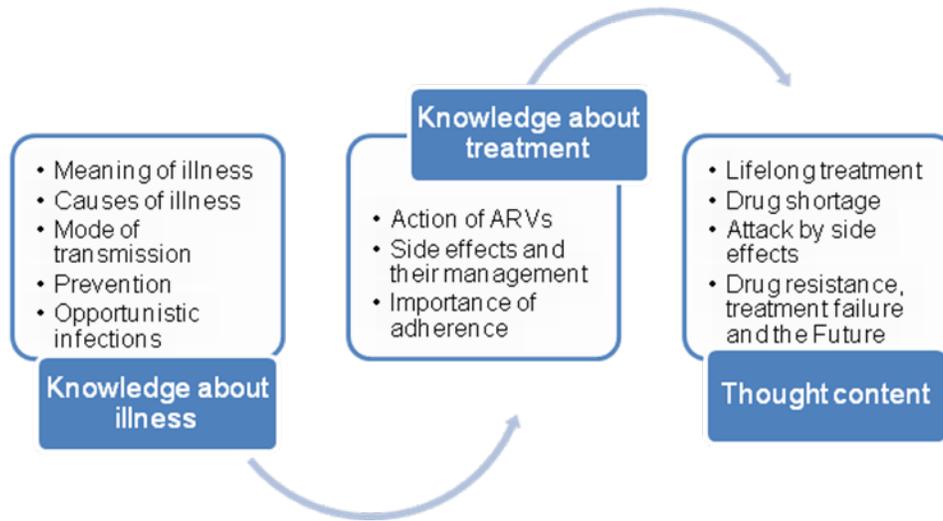
One participant was concerned about whether measures were being taken to ensure a constant supply of antiretroviral drugs:

*I am constantly thinking about the shortage of these drugs. I heard over the radio that government can no longer afford them [ARVs], because they are expensive. What will become of us [PLWHA on ART] now, since we were educated that once you start them, you should not stop? Maybe those who were not put on the drugs are lucky.*

On being asked what measures the participant thought could be taken by government to ensure a constant supply of the drugs, he suggested that:

*Other spending should be reduced, such as the national celebrations and [expenditure on] other drugs that are not important, so that we have enough money for ARVs. This is our lives, and we [PLWHA on ART] are many.*

Constantly having negative thoughts about HIV and AIDS, and ART negatively influences QOL. The researcher developed a diagram (Figure 5.2) that depicts the cognitive domain of PLWHA in Swaziland who are on ART. The diagram suggests that having proper knowledge about HIV and AIDS makes it easier for PLWHA to understand about treatment and have positive thoughts about HIV and AIDS and its treatment.



**Figure 5.2: A diagram depicting the relationship between knowledge about illness, knowledge about treatment and the thought content of PLWHA in Swaziland who are on ART**

### 5.3.6 An unfavourable environment for PLWHA

According to Gillespie and Kadiyalla (2005:11), HIV and AIDS is environmentally driven. Louis Pasteur (1860), in Gillespie and Kadiyalla (2005:11), identified the importance of the environment in every illness and declared that “the microbe is nothing, the terrain is everything”. His observation succinctly captures the power of the environment, which encompasses everything from the microbial environment, represented by the individual’s nutritional and health status, to the macro-environment of policy, culture, and economy (Gillespie & Kadiyalla 2005:11). The environment of PLWHA includes health care systems, support systems, culture, policies, and rights (see Figure 5.3).

Categories that emerged from the data analysis were: (1) unsatisfactory health care delivery systems; (2) the negative influence of culture on HIV and AIDS and ART; and (3) violation of the rights of PLWHA. Table 5.7 provides a synopsis of the themes, categories, and subcategories of the environmental domain.

**Table 5.6: Themes, categories, and subcategories of the environmental domain**

Theme	Category	Subcategories
<b>5.4.6 An unfavourable environment for PLWHA</b>	5.4.6.1 Unsatisfactory health care delivery systems	<ul style="list-style-type: none"> <li>• Lack of privacy due to mixing of clients in consultation areas</li> <li>• A shortage of doctors and nurses, resulting in long queues of PLWHA</li> <li>• Concomitant use of traditional and Western health care systems</li> </ul>
	5.4.6.2 Negative influence of culture on HIV and AIDS, ART, and QOL	<ul style="list-style-type: none"> <li>• Swazi cultural practices discourage ART adherence and encourage the spread of HIV and AIDS</li> </ul>
	5.4.6.3 Violation of the rights of PLWHA	<ul style="list-style-type: none"> <li>• The belief that PLWHA should be known and branded</li> </ul>

#### **5.3.6.1 Category 1: Unsatisfactory health care delivery systems**

When the participants were asked how satisfied they were with the health care they were receiving, they all mentioned that they were not satisfied, as there were some problems that needed urgent attention. These include: (1) lack of privacy due to mixing of clients in consultation areas; (2) a shortage of doctors and nurses, resulting in long queues; and (3) concomitant use of traditional and Western health care systems.

- **Lack of privacy due to mixing of clients in consultation areas**

Five of the participants were not happy about the lack of privacy at the clinic. One of them mentioned that:

*The consultation area is public, and there is no privacy. Even if you want to reveal your secrets, it is difficult. You are asked a sensitive question in front of all the others, and you are ashamed to answer. You end up leaving with your problems [unsolved].*

Another participant, who was concerned about the mixing of patients, suggested that:

*If only we were not mixed, like those who have come to collect their drugs should be in one area, and those [who have come] for consultation [should be] in another area, because this will also reduce the congestion.*

When the researcher suggested that patients could be being mixed on the grounds of shortage of space, the participant was quick to suggest that:

*They can even ask for space from the hospital, because a lot of patients have been moved from the hospital to the VCT centre.*

The researcher observed that space shortage was indeed a problem faced by the clinic. It was observed that there were only four rooms that were originally designed for consultations with patients. As a result, the nurses' duty room was also used for consultations, and, by the nature of the room, confidentiality and privacy were not assured. ARVs were dispensed in a separate room (a container), because of the space shortage at the clinic.

- **A shortage of doctors and nurses, resulting in long queues**

While five of the participants were concerned about a lack of privacy, 11 of the participants were concerned about long queues. Two participants had this to say:

*Every time I come here I have to ask for permission from my employer and promise to come back [to work] soon. Now, with the long queues, it is impossible*

*to come back to work soon. We need more nurses to work here, because we will end up not taking the drugs as a result [of these long queues].*

*I was supposed to collect my medication last week Friday, but I could not because of the long queues. I waited for many hours without being attended to, such that I gave up and went home, because I was tired and hungry.*

Staff shortages, which result in work overload, were noted by the researcher. The clinic was short-staffed, with only seven nurses to take care of all these patients every day. Understaffing is a problem that results in reduced quality of nursing care, and may jeopardise patient safety.

Staff shortages are a problem not just at the study centre, but in Swaziland as a whole. This is confirmed by a study carried out by Mkhabela (2006:70), which found that there were staff shortages in VCT centres in Swaziland. Staff shortages are one of the common problems experienced by most health agencies in developing countries such as Swaziland. Staff shortages are accompanied by overcrowding. Overcrowding makes it difficult for a short-staffed facility to provide quality care, which often leads to frustration and stress for the nurses (Mkhabela 2006:70).

The researcher also observed that there were overwhelming numbers of PLWHA who were attending the clinic. This is attributed to the fact that the prevalence of HIV and AIDS has increased in Swaziland, and the clinic is in the hub of Swaziland. This results in long queues and work overload for the nurses working in this centre. The estimated number of patients seen on any one day is 300 and includes pre-ART clients and those already on ART.

Existing human resource problems in Swaziland have been exacerbated by HIV and AIDS. In Swaziland both the quantity and quality of labour is being adversely affected by AIDS, as highly trained and educated human resources become infected, are ill for a long time, and eventually die Ministry of Health and Social Welfare(MOHSW 2004:6).

Workloads have increased, as a result of the growing demand for services such as counselling and testing, and prevention and treatment of opportunistic infections.

There has been an increase in the number of programmes addressing the HIV and AIDS epidemic in Swaziland, yet the numbers of nurses have not been adequately increased. Poorly planned HIV and AIDS treatment and care upscales have often had a detrimental impact on VCT services. In 2004, the MOHSW, with the assistance of the WHO, conducted a situational analysis of the health workforce in Swaziland, and revealed gross staff shortages, stating that there was an imbalance between the supply of and demand for nurses in the country, and that the ratio of nurses to members of the population was 28:10,000. According to the situational analysis, the nurse: patient ratio was 1:356, and the doctor: patient ratio was 1:5,953. This shows that health professionals across all cadres are still in short supply. The country competes for health professionals in the international markets.

A study by Kober and Van Damme (2006:4) of the public sector nurses in Swaziland concluded that the lack of human resources for health is increasingly being recognised as a major bottleneck to scaling up antiretroviral treatment, particularly in sub-Saharan Africa. Among the causes of human resource shortages are emigration and attrition as a result of HIV and AIDS. The report estimated that by the year 2010, the nursing workforce would be reduced by 40%. The report revealed that a combination of measures, such as an increase in training capacity in nursing schools, and the introduction of retention measures, could reverse the trend of shortages of nurses.

Long queues, extensive waiting times, and shortened consultation times are among the factors affecting quality of care and subsequently affecting QOL. These problems were mentioned by participants in the study. The researcher is of the idea that there is a need for quality assurance programmes to ensure quality health service delivery, as well as a monitoring and evaluation system that can track progress in service provision.

In order to deal with staff shortages and overcrowding in Swaziland, decentralisation of ART services is urgently needed. Poverty and the rising cost of transport have made the decentralising of ARV treatment an urgent priority. Decentralisation must take place together with capacity building. The major difficulty is that most clinics are staffed solely by nurses, who are not authorised to prescribe medication, and there is a need to implement the process of task shifting, in which nurses are trained to prescribe and dispense ARVs (Okello 2008) (<http://www.aegis.com/news/IRIN/2008/IR080925.html>). Swaziland needs to develop the human resource capacity of the health sector, to adequately support the health sector response to HIV and AIDS, to provide ART services to all people in need of treatment, to develop and update national treatment guidelines, and to establish mechanisms for getting PLWHA on ART involved in ART literacy training (HSRP 2006-2008).

- **Concomitant use of traditional and Western health care systems**

The health care system of Swaziland consists of the formal and informal health care systems. The formal health care system is based on Western medicine and consists of public and private health care services, including rural health motivators. The informal health care system consists of traditional health practitioners, community and family caregivers, PLWHA, and other unregulated service providers. In both of these health care systems, governments have a legal, moral, and ethical duty to protect the public from harm (Ernst 2005) (<http://www.medicinescomplete.com/journals/fact/current/fact0803a02t01.htm>).

Concerning the concomitant use of traditional and Western health care systems, most of the participants (19) were against the use of traditional medicine. These are some of their comments:

*How do we allow such people to treat people living with AIDS, while they are killing them? Is there no law that these people have to follow? Because they are deceiving people when they claim that there is a cure for HIV and AIDS.*

*I had to defy my father who insisted that I use traditional medication. Now we are not on good terms, because he insist that the [ARV] tablets will kill me, yet without the traditional medication I will improve very fast, and I don't tell him if I have any side effects of the drugs [ARVs] or any opportunistic infections.*

Some five participants admitted to using traditional medicine:

*When you are sick, you will do anything in order to get well. You will eat anything if they say it will make you well, because you do not know which is which. Even if they say you have to get down and eat the green grass like a cow, you will do it. So I am not against traditional medicine. We are desperate, you know.*

*I do use herbs most of the time. I don't think there is any harm in that, since they complement the drugs [ARVs]. The herbs work. We cannot deny that. Herbs are part of our Swazi culture.*

The above responses indicate that some PLWHA rely on both the traditional and the Western health care systems. Swazi culture believes that ARVs belong to a Western class of solutions, which one could call biomedical, or technological. According to Czerny (2009), the Western biomedical model does not provide all the answers (<http://www.jesuitaids.net/go.aspx?ID=4&B2=PO=127&TL=1>), and, as such, traditional medicines are considered to fill in the gaps.

Many studies have indicated that there are problems inherent in the existence of the two health care systems. There is no drug authority council regulating the informal health care system in Swaziland. The service providers in the informal health care system are not regulated by the Ministry of Health (MOH), and, as such, the MOH has little or no control over them. The Swaziland National Health Policy (2007:13) states that the practice of traditional medicine and other alternative health care practices should be regulated by the Complementary and Alternative Medicine Practice Act, which has not yet been promulgated. Ernst (2005) is of the view that complementary and alternative

medicine (CAM) practitioners should build up a base of evidence with the same rigour as is required of conventional medicine, and that every therapist working in CAM should have a clear understanding of the principles of evidence-based medicine and health care (<http://www.medicinescomplete.com/journals/fact/current/fact0803a02t01.htm>).

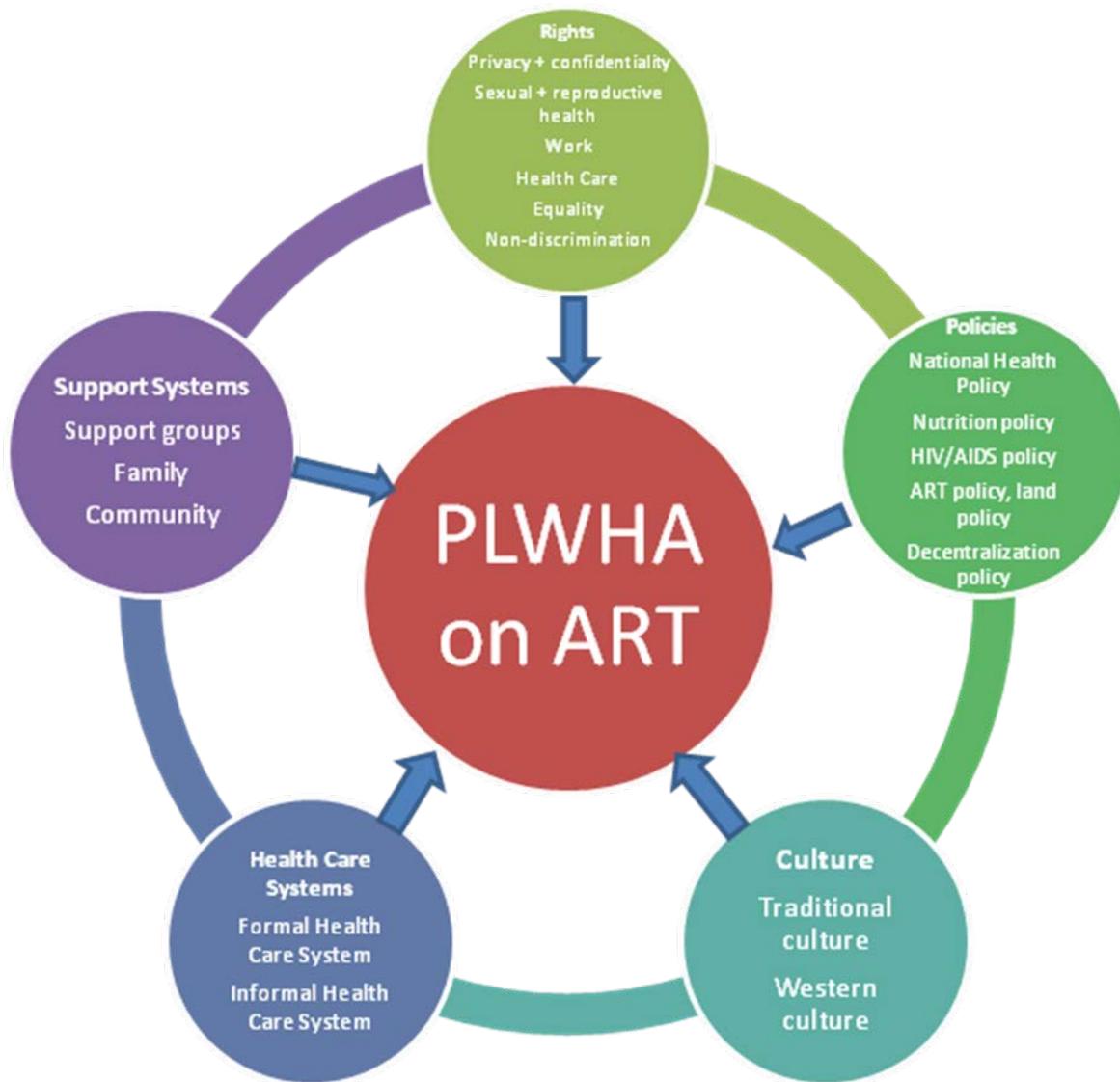
Complicating the matter further is the fact that Swaziland has no programme for providing HIV and AIDS education to traditional healers and faith-based healers, many of whom discourage people from taking ARVs. The traditional health system and the other unregulated health services have wide acceptance among PLWHA, because of the reasons stated earlier, in Chapter 4. There are over 8,000 traditional health practitioners in Swaziland, and over 80% of Swazis use the traditional health care system. HIV-positive people are abandoning ARVs in favour of traditional medication, according to the National Emergency Response Council on HIV and AIDS (NERCHA) for 2009 to 2014.

The researcher is of the opinion that traditional health practitioners can be used positively in Swaziland. Since traditional health practitioners have wide acceptance in Swaziland, their involvement can be used positively in a multisectoral response to HIV and AIDS. Traditional health practitioners can support STI and HIV prevention, care and treatment, they can assist in identifying signs and symptoms of HIV infection among their clients and encourage them to go for testing and counselling, they can encourage PLWHA on ART and tuberculosis (TB) sufferers to adhere to their treatment, and they can provide ongoing counselling.

In order to promote harmony between traditional healers and modern medical practitioners, the MOH has developed a draft framework for collaboration between the health sector and traditional health practitioners. The ministry has also reviewed the Swaziland National Pharmaceutical Policy (SNPP), to make provision for the establishment of a Medicines Regulatory Authority and a Pharmacy Council that would be responsible for the regulation of the pharmaceutical profession and all aspects of

medicine, including traditional remedies and alternative therapies (Multisectoral Strategic Framework for HIV and AIDS 2009-2014:48).

According to the Multisectoral Strategic Framework for HIV and AIDS (2009-2014:49), the following remains to be done: a framework must be finalised for cooperation and collaboration between traditional health practitioners and the health sector; the establishment of a regulatory body for the practice of traditional health practitioners must be facilitated; and a liaison office for traditional health practitioners must be set up in the MOH. In addition, there is a need to strengthen the capacity of traditional practitioners to provide quality services to their clients in respect of HIV/TB co-infection, as agreed between these practitioners and the MOH, and to facilitate the registration of all traditional health practitioners in the country. Figure 5.3 graphically represents the environmental component of PLWHA in Swaziland who are on ART. The diagram shows that the QOL of PLWHA in Swaziland is directly influenced by policies, health care systems, culture, support systems, and rights.



**Figure 5.3: A graphic representation of the environment of PLWHA in Swaziland who are on ART**

#### **5.4.6.2 Category 2: The negative influence of culture on HIV and AIDS, ART, and QOL**

Some 12 participants mentioned that Swazi culture has a negative influence on the way Swazi people view HIV and AIDS and ART. They mentioned that even after intensive education, harmful traditional cultural practices still exist in Swaziland. One main subcategory was identified from this category, namely that Swazi cultural practices discourage ART adherence and encourage the spread of HIV and AIDS.

- **Swazi cultural practices discourage ART adherence and encourage the spread of HIV and AIDS**

Concerning the relationship between culture and QOL, this is what the research participants had to say:

*Even if you are educated about HIV and AIDS and the drugs [ARVs], there is a lot that is being said around us that disturbs us, because we are traditional Swazis, and we are still attached to our traditions. Sometimes I feel tempted to take traditional medicine, because when we were young our parents relied mostly on herbs.*

One participant, who was in a polygamous relationship and was concerned that such a relationship was disadvantageous to her, commented that:

*I take care of myself. I insist that he take care of himself, but I do not know what is happening with his other wives. I cannot call a meeting for all of us so that we can take care of ourselves. All I do is keep quiet and hope that I will be fine.*

Another participant stated that:

*We Swazis still believe that a woman's role is to bear children continuously and that a man's role is to impregnate multiple partners, which is why polygamy is strong. It is a desired status if a Swazi has a minimum of five children. HIV and*

*AIDS is not considered. Times have changed, but people have not changed. This encourages the spread of the virus [HIV].*

In Swaziland, there is only one ethnic group, namely the Swazis, who have a common culture and similar and strong traditions. The role of the family structure remains the mainstay of Swazi society. The Swazi people are a patriarchal society, and male superiority influences all social, political, cultural, and economic decisions. In Swazi culture, decision making has traditionally been a male prerogative. Family decisions therefore lie with the man. Swazi men defend polygamy as a cultural necessity. Swazi culture and traditional practices have endured the test of time and influence the behaviour, attitudes, and health outcomes of the Swazi people in varied ways. A 2002 UNDP report found that culture and patriarchy contribute to the spread of HIV AND AIDS. The report found that in addition to culture and patriarchy, other cultural practices that place Swazi people at risk are Swazi society's approval of multiple sexual partners for men, polygamy, arranged marriages, and widow inheritance.

The study revealed that as the Swazi cultural practices discourage ART adherence and encourage the spread of HIV and AIDS, QOL is negatively affected. This is based on the fact that some definitions of QOL have recognised the importance of cultural influence on QOL. Clinch and Schipper (1993), in King and Hinds (1998:42), have suggested that the cultural setting is a major determinant of the definition of QOL.

### **5.3.6.3 Category 3: Violation of the rights of PLWHA**

The Swaziland National Health Policy (2007:11) states that fundamental human rights will be respected in the course of provision of all health services. The upholding of human rights and fundamental freedoms for all, including the prevention of stigmatisation and discrimination of PLWHA, is a necessary element in our regional response to the HIV and AIDS pandemic, which would encompass, inter alia, access,

education, inheritance, employment, health care, social and health services, prevention support, treatment, and legal protection, while respect for privacy and confidentiality would be upheld, and strategies would be developed to combat stigma and social exclusion connected with the pandemic (SADC 2003).

One subcategory emerged from the above category, namely the belief that PLWHA should be known and branded. All participants mentioned that most of the time their rights were violated, in the sense that some employers have set the prerequisite of HIV status disclosure for employment, and some influential leaders feel that PLWHA should be branded on their buttocks, so that they don't infect others:

*One Member of Parliament mentioned that we [PLWHA] should be branded on our buttocks, so that we are easily identified and do not infect others. This means violating my right to my illness. We should emphasise that everyone must protect himself or herself and not expect to be protected by HIV branding.*

*Some people have the idea that people with AIDS should be [publicly made] known. Why us [PLWHA] now, when there are a lot of illnesses that are kept confidential? This disease should be treated like other diseases. You go anywhere to look for work, and you are asked your [HIV] status. Why?*

The study showed that the right to confidentiality and privacy was not respected at all times at the study clinic, as the consultations were sometimes conducted in the nurses' duty room. This study clearly indicates that the rights of PLWHA in Swaziland are sometimes violated, yet the concept of individual rights is important in QOL appraisal (Schalock 2000:118).

A study by Kohi, Makoe, Chirwa, Holzemer, Rene, Phetlhu, Uys, Naidoo, Dlamini, and Greeff (2006:404) on HIV and human rights revealed that the human rights of people living with HIV and AIDS are violated in a variety of ways, including the absence of health care services, or denial of access to adequate health care services, denial of

home care, termination of employment, or refusal to employ, denial of the right to earn an income, produce food, or obtain a loan, and verbal and physical abuse.

A study done in Tanzania by Roura et al. (2009:308) on the effects of antiretroviral roll-out and stigma found that the general perception among community leaders was that ART users regained health, they increasingly engaged in sexual relations, and they spread the disease. The leaders recommended that ART recipients be given drugs for impotence, that they be marked with a sign stating that they had HIV, and that they be placed in isolation camps.

Governments and health professionals need to address these issues to ensure the human rights of all PLWHA. PLWHA should have the same basic rights and responsibilities as those that apply to all citizens of a country. This means that PLWHA have the right to confidentiality and privacy about their health and HIV status (Van Dyk 2003:405). The UNAIDS Executive Director Pilot Speech to the 59th Session of the United Nations High Commissioner for Refugees (UNHCR) in 2003 states that

Human rights are fundamental to the response to HIV for three reasons: *ethical*, because all human beings have a right to health, to life and all other human rights; *legal*, to implement the International Declaration on Human Rights and the many other international and national laws and guidelines on human rights, and for *pragmatic* reasons, because it is beyond doubt that a human rights based response, which empowers our whole community to avoid infection, and which treats those with HIV with respect and inclusion and aims to properly manage their health, is significantly more effective in reducing the spread of HIV than a response of silence, discrimination or exclusion (<http://www.napwa.org.au/2005/11/18/declaration-of-rights-for-people-living-with-hiv-aids>).

## 5.4 CONCLUSION

This chapter presented the findings based on individual semi-structured individual interviews and FGDs with PLWHA in Swaziland who were on ART. The study revealed that though ART improves some aspects of the lives of PLWHA, there are nevertheless many challenges that are faced by PLWHA in Swaziland that lowers their QOL. These challenges include an inability to meet nutritional needs for ART adherence and ART success, non-adherence to ART, disfiguring side effects of ARVs, inconsistent condom use, stigma and discrimination, difficulty coping with HIV and ART, low self-esteem, conflict caused by spiritual leaders, a desire to have children, low socio-economic status, poor understanding of HIV, AIDS and ART, unsatisfactory health care delivery systems, and violation of the rights of PLWHA. Based on the above identified challenges, the researcher therefore concludes that PLWHA in Swaziland who are on ART have a poor QOL. This finding was discussed with reference to relevant literature.

The vision of the Swaziland Ministry of Health is that with the help of ART, by the year 2015 the people of the Kingdom of Swaziland will have reversed the trend of the AIDS epidemic, resulting in improved QOL, which will be characterised by reduced HIV and AIDS-related morbidity and mortality (MOHSW 2006-2008). However, this vision cannot be realised without the adherence of PLWHA to ART. The MOH needs to attend to the challenges identified by the participants in the study, if it hopes to improve the QOL of PLWHA.

The government of Swaziland has initiated many programmes, drafted many policies, signed many declarations, attended many summits, made many commitments, and set many goals to realise the vision of the MOH by the year 2015. What is needed now is implementation and strengthening of the above initiatives by all sectors. There is a need to strengthen the multisectoral approach to the epidemic, where each sector will play its role and the combined effort will result in the improvement of the QOL of PLWHA. The health sector alone cannot win the battle against HIV and AIDS without the contributions

of social scientists, epidemiologists, public health specialists, nutritionists, the agricultural sector, and the economic sector, among others. In this way alone will HIV and AIDS-related morbidity and mortality be reduced and the QOL of PLWHA be improved.

As a commitment to improving the QOL of PLWHA on ART and realising the vision of the MOH, the researcher has developed guidelines that can be used to empower PLWHA, so as to promote adherence to ART and improve the QOL of PLWHA. These empowerment guidelines are discussed in the following chapter.

## **CHAPTER 6**

### **NURSES' GUIDELINES FOR PEOPLE LIVING WITH HIV AND AIDS WHO ARE ON ANTIRETROVIRAL THERAPY**

#### **6.1 INTRODUCTION**

The previous chapter presented the findings of the study based on in-depth individual interviews and focus group discussions (FGDs) with people living with HIV and AIDS (PLWHA) in Swaziland who are on ART. The findings of the study revealed that there are challenges that are faced by PLWHA in Swaziland who are on ART. These challenges have a negative influence on QOL. It is therefore vital that these challenges be addressed to improve the QOL of PLWHA in Swaziland who are on ART.

This chapter provides guidelines that can be used to empower PLWHA so as to improve their QOL. The chapter describes how the guidelines were developed and evaluated. These guidelines were formulated in cognisance of the fact that nurses in Swaziland are limited by their scope of practice and, as such, the guidelines do not have the component of prescribing ARVs, but the focus is on nursing care of PLWHA in Swaziland who are on ART. Currently, Swaziland uses the National Guidelines for Antiretroviral Treatment and Post-Exposure Prophylaxis for 2006. These guidelines deal with ARV prescription, but do not offer much guidance on nursing care. The researcher's guidelines are the first to focus on nursing care. These guidelines are a result of the researcher's commitment to the improvement of the QOL of PLWHA. They were developed from the data collected by the researcher in the form of observations, in-depth individual interviews, FGDs, and the literature reviewed.

## 6.2 CONCEPTUAL FRAMEWORK

In order to develop guidelines to empower PLWHA and to improve their QOL, the researcher developed a conceptual framework (see Figure 6.1) based on a survey list of Dickoff et al. (1968:420-423), which outlines six aspects of activities necessary for the development of a theory for a practical discipline such as nursing. According to Dickoff et al. (1968:420-423), there are six questions about any nursing activity. The activity in question in this thesis involves the empowerment of PLWHA in an attempt to improve their QOL. These six questions are briefly described in the sub-sections below:-

- **Purpose or terminus:** *What is the goal of this activity?*

The purpose addresses the end point or accomplishment of the activity. To regard activity for the aspect of terminus is then to consider the activity from the point of view of what is accomplished by the goal of this activity.

The purpose of these guidelines was introduced by the researcher in Chapter 1. The guidelines are important for the empowerment of PLWHA in Swaziland who are on ART and their families. The process of empowerment will allow PLWHA to make informed health care decisions and to increasingly feel in control of their own lives. PLWHA will be more responsible for their health, and thus their QOL will be improved.

- **Agency:** *Who or what performs the activity?*

The agents in the context of this study are nurses working with PLWHA in all health care settings. In these guidelines, they are viewed as people responsible for empowering PLWHA in Swaziland who are on ART.

- **Patiency or recipiency:** *Who or what is the recipient of the activity?*

In these guidelines, the recipients of this activity are PLWHA in Swaziland who are on ART as well as their families.

- **Framework (context):** *In what context is the activity performed?*

The empowerment of PLWHA and their families takes place in all ART service delivery institutions in Swaziland. These include the national and regional hospitals, primary health care facilities, and community-based services.

- **Dynamics:** *What is the energy source for the activity-whether chemical, physical, biological, mechanical, or psychological, etcetera?*

The energy source, or motivating factor, for the activity is to realise the vision of the Ministry of Health, that by the year 2015 the people of the Kingdom of Swaziland will have reversed the trend of the AIDS epidemic, resulting in improved QOL, which will be characterised by reduced AIDS-related morbidity and mortality. In order to realise the above vision, PLWHA who are on ART need to be in control of their lives and have an improved QOL.

The study revealed that PLWHA in Swaziland who are on ART have many challenges that have a negative impact on their QOL. It was also concluded from the study findings that PLWHA are powerless to deal with these challenges most of the time. PLWHA cannot achieve their full health potential unless they are able to take control of these challenges, so that they can improve their health status.

- **Procedure:** *What is the guiding procedure, technique, or protocol of the activity?*

The guidelines for PLWHA who are on ART, their families, and community are the guiding procedure, technique, or protocol for the activity. The rationale for including families and the community is that the process of empowerment exists at three levels. These levels are the personal, family, and community level. Figure 6.1 depicts a framework for the empowerment of PLWHA in Swaziland who are on ART (adapted from Dickoff et al. 1968:420-423).

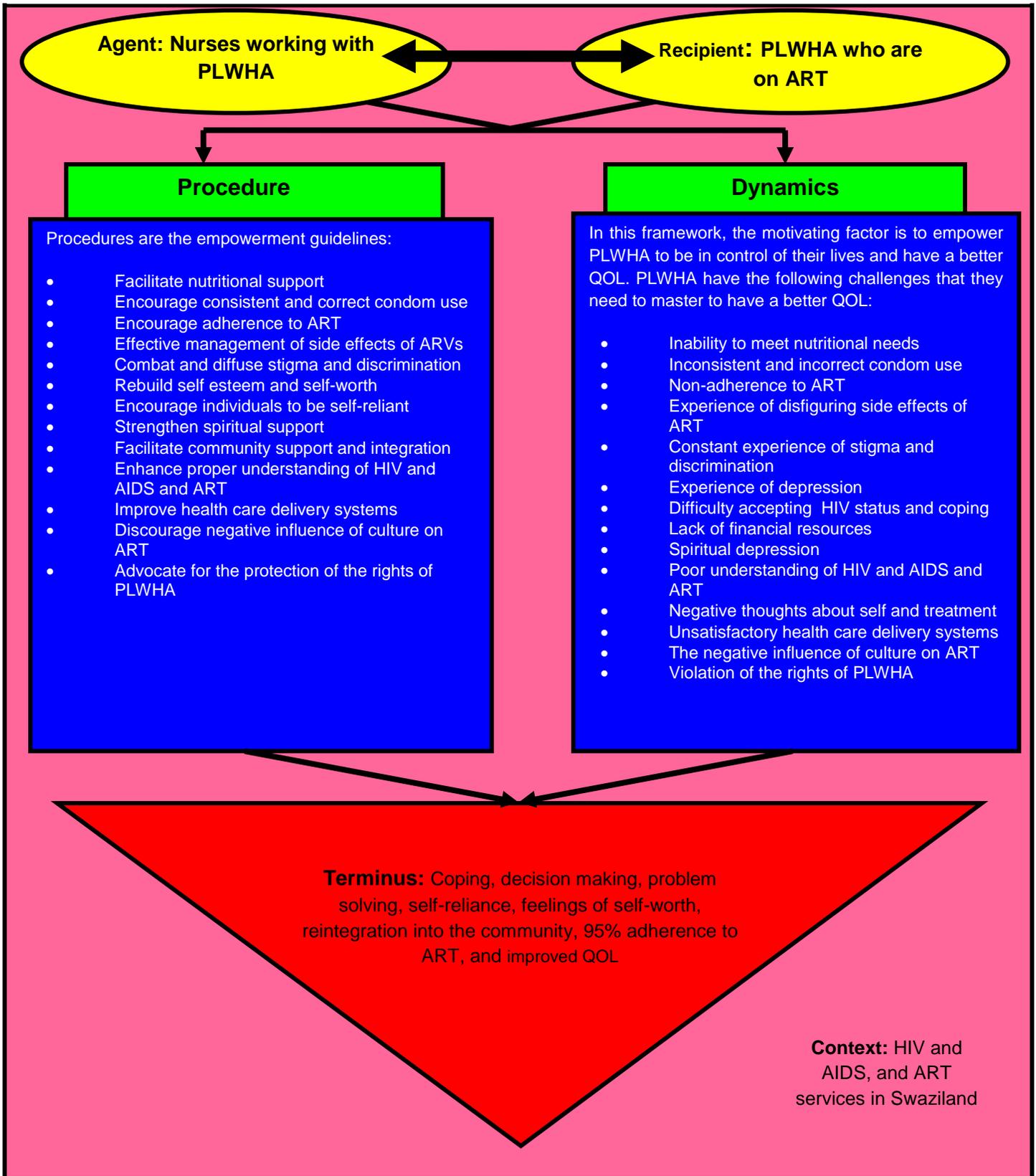


Figure 6.1 A framework depicting the empowerment of PLWHA in Swaziland who are on ART (adapted from Dickoff et al 1968:420-423).

### **6.3 DEVELOPMENT AND DESCRIPTION OF THE GUIDELINES**

The study revealed that there are many challenges that are faced by PLWHA in Swaziland who are on ART. These challenges have a negative impact on the QOL of PLWHA. These challenges are food shortages, fear of disclosing their HIV-positive status, disfiguring side effects of ARVs, inconsistent and incorrect condom use, a desire to start a family and have children, stigma and discrimination, poor understanding of HIV and AIDS and ARVs, un-acceptance of their HIV-positive status, poor health care delivery systems, violation of the rights of PLWHA, negative cultural influences, and the negative impact of some religions on HIV and AIDS and ART.

From the study findings, it was concluded that PLWHA who are on ART are powerless to deal with the above challenges that they face in their daily lives of coping with the illness and ART. This is because most of these challenges are almost beyond the control of PLWHA for example, the political, cultural, and economic influences. This is consistent with the sentiments of Duboise and Miley (1996:210), who states that contextual factors, such as economic and political structures, values and beliefs, and role definitions, directly or indirectly inhibit the empowerment of PLWHA. This, however, does not mean that these influences cannot be addressed to empower PLWHA. It is therefore, the commitment of the researcher to develop guidelines that will empower PLWHA who are on ART to be in control of their lives and to deal effectively with the challenges mentioned above.

The literature is replete with definitions of empowerment. Empowerment is an abstract concept derived from the word “power” meaning “to be able”. To empower, then, means to enable, or to give authority to (Oxford Advanced Learner’s Dictionary 2005:421). Whitmore (1988:13) defines empowerment as an interactive process through which people experience personal and social change, enabling them to take action to achieve

influence over the organisations and institutions that affect their lives, and the communities in which they live. She bases her definition on the assumptions that individuals understand their own needs better, all people possess strengths which they can build, empowerment is a lifelong endeavour, and personal knowledge and experience are useful in coping effectively.

Rappaport (1984:1) associates empowerment with personal control and defines it as “a way that people, organisations and communities gain mastery over their lives”. Expanding on the issue of personal control, Rodwell (1996:309) suggests that empowerment is a helping process where groups of individuals are enabled to change a situation, and they are given the skills, resources, opportunities, and authority to do so, it is a partnership which respects and values self and others, aiming to develop positive beliefs in self and the future.

Swift and Levin (1987:71) take a broader view in defining the concept of empowerment. They define empowerment as both a process and a goal. As a goal, empowerment defines an end state of power achieved. In this sense, individuals, groups, organizations, and communities alike may strive for empowerment. As a process, empowering implies facilitating, enabling, fostering or promoting the capacity for competent adaptive functioning.

Empowerment has several desired outcomes that can be of benefit to PLWHA who are on ART. Some of the outcomes of empowerment are increased control, the acquisition of instrumental behavior, self-awareness, finding meaning, strengthening social skills, securing resources, and competence (Mkhabela 2006:86). For the purpose of this study, empowerment is defined as processes whereby PLWHA who are on ART achieve increasing control of various aspects of their lives and participate in the community with dignity.

According to Burns and Grove (2005:46), theories and instruments are developed on the basis of assumptions that may or may not be recognised by the researcher. With this in mind, these guidelines, therefore, were developed based on the following assumptions about empowerment in the field of social work (Dubois & Miley 1996:212):

- Empowerment is a collaborative process, with PLWHA and the health care practitioner working together as partners;
- The empowering process views PLWHA as competent and capable, provided they are given access to the necessary resources and opportunities;
- PLWHA must perceive themselves as causal agents, able to effect change;
- Competence is acquired or refined through life experience, particularly experience affirming efficacy, rather than from circumstances where one is told what to do;
- Situations evolving from the particular situation are necessarily diverse and emphasize complexities of multiple contributing factors in any problem situation;
- Informal social networks are a significant source of support for mediating stress and increasing one's competence and sense of control;
- PLWHA must participate in their own empowerment "knowledge mobilizes action for change" (Swift & Levin 1987:81);
- Empowerment involves access to resources and the capacity to use those resources in an effective way;
- The empowering process is dynamic, synergistic, ever-changing and evolutionary, problems always have multiple solutions; and
- Empowerment is achieved through the parallel structures of personal and socio-economic development.

### **6.3.1 Guiding principles for the development of the guidelines**

The guidelines were developed based on three approaches to QOL. These are the holistic approach, the human rights-based and the Greater Involvement of People Living

with HIV and AIDS (GIPA) approach. The researcher is of the opinion that these three principles are basic to the development of the empowerment guidelines of PLWHA who are on ART. These approaches are discussed below:-

#### **6.3.1.1 *The holistic approach***

These guidelines recognise the importance of taking a holistic approach when dealing with the issues and needs of PLWHA who are on ART. Based on the holistic approach, these guidelines foster the empowering of PLWHA, paying special attention to their physical, psychological, spiritual, socio- economic, cognitive, and environmental needs. These are the domains of QOL that were identified from the workshop and also by PLWHA in Swaziland who are on ART. These domains are considered relevant in the care of PLWHA in Swaziland who are on ART.

#### **6.3.1.2 *The human rights-based approach***

In the human rights-based approach, every person with HIV or AIDS must be acknowledged, both as a person and as a holder of human rights. The guidelines are thus congruent with values and beliefs about humanity, and the dignity and autonomy of PLWHA. They are based on respect, protection, and fulfillment of the rights and dignity of PLWHA in Swaziland who are on ART, as well as their families. Respecting, protecting, and fulfilling the full range of human rights is vital to reducing the rate of HIV infection, expanding access to care, and treatment and mitigating the impact of the AIDS epidemic ([data.unaids.org/pub/report/2007/jc1367](http://data.unaids.org/pub/report/2007/jc1367)).

### **6.3.1.3 The Greater Involvement of People Living with HIV and AIDS (GIPA) approach**

The GIPA approach was identified as important in 1994 at the Paris AIDS summit. The GIPA Declaration states that the greater involvement of PLWHA is “critical to ethical and effective national responses to the epidemic” (<http://www.aidsallianceindia.net>). In order for PLWHA to be self-empowered, they have to be involved in all aspects of health care. This approach was adopted by Swaziland. Findings from the study revealed that PLWHA are not always involved in the issues concerning HIV and AIDS, thus the researcher is of the opinion that guidelines for empowerment should stress greater involvement of PLWHA in their care. This is important, based on the understanding that PLWHA who are on ART are the ones that have the experience of being on ART and, as such, they are the masters of their own destinies. The researcher believes that PLWHA understand their own needs far better than anyone else, and consequently, they should have the power to act upon their needs.

In addition, the guidelines overcome the imbalance of power created by nurses and other health care workers having control over ART services. Hence, there will be an element of partnership, meaningful involvement, and participation of PLWHA. The fact that nurses are experts and have access to information, as well as control over services offered, makes them “power holders”, which leads to the recipients of their services (PLWHA), feeling powerless, and the implication of an imbalance of power between the two parties (Weis, Schank & Matheus 2006:24). These guidelines aim to foster partnerships, so that both nurses and PLWHA can nurture and sustain this collaboration. This is congruent with the views of Ellis Stoll and Popkess-Vawter (1998); Hewit-Jaylor (2004), and Shearer and Reed (2004) in Burkhardt and Nathaniel (2008:469), who state that empowerment is a participative process or partnership between a nurse and a patient, which supports patient wellbeing and facilitates the changing of unhealthy behaviors. These transformational empowerment guidelines

therefore attempt to create a balance of power between nurses and PLWHA in Swaziland who are on ART.

### **6.3.2 Empowerment guidelines for PLWHA**

The following section explains the empowerment guidelines for PLWHA in Swaziland who are on ART. These guidelines were aligned with the Swaziland National Health Policy (2007), the Swaziland National Strategic Framework (NSF) for HIV and AIDS (2009-2014), the Swaziland National HIV and AIDS Policy (2006) and the Swaziland National Palliative Care Policy (2010).

#### **6.3.2.1 *Guideline: Enhance nutritional support***

Participants in the study disclosed that they could not provide for their nutritional needs and the nutritional needs of their families because of poverty and unemployment. The issue of meeting the nutritional needs of PLWHA in Swaziland who are on ART has not been adequately addressed. This is of particular concern, as nutrition is important for adherence, immunological development, treatment success and improved QOL (Gillespie & Kadiyalla 2005: VI). In view of the critical importance of an adequate and balanced diet among PLWHA, nutritional assistance should be an important component of HIV intervention programmes. This may take the form of nutritional assessment and counseling, and increasing access to food, either directly or indirectly, by facilitating income-generating projects.

- Nutritional assessment and counseling:-
  - All new ART patients should be screened by nurses to determine those at risk of poor nutrition. Assessment is conducted to ascertain a baseline nutritional status and to determine the nutritional needs of the patient, so as to offer tailored nutritional assistance, treatment, and management

based on the results of the assessment. Factors that affect food intake include food availability, appetite, eating patterns, medication side effects, traditional food taboos, lifestyle( that is, whether the patient smokes or drinks, his or her amount of physical activity, his or her intake of caffeine, and whether he or she uses of recreational drugs), psychological factors( such as stress, and depression), stigma, and economic factors. The focus of nutritional assessment is to use the information obtained from anthropometric, biochemical, clinical, dietary, and environmental (ABCDE) measures to provide the appropriate treatment, care, and nutritional support. (<http://www.users.erols.com/dentnut/nutdent>):

- Anthropometric measures: weight, height, hip and waist circumference, and skin folds.
  - Biochemical measures: CD4 cell count, enzymes, haemoglobin, glucose, albumin, iron and certain lipids.
  - Clinical measures: a physical examination of eyelids, the hands, the fingers, the hair, and the mouth.
  - Dietary measures: food and nutrient intake, 24hour recall.
  - Environmental measures: the psychosocial and economic environment that affect nutritional status.
- Nutritional status assessment and counselling should be done during every visit, until the patient is nutritionally secure. All those eating from the same pot as the patient should also be screened for their nutritional status because they too require nutritional assistance.
  - Nutritional supplementation:

The study showed that some PLWHA who are on ART are so poor that even the corn soya that is sometimes provided at the clinic is consumed by every member of the family. The researcher is of the opinion that every family member of a person who is on

ART who does not have enough food should be supported. This is based on holistic care principles. Nutritional care and support interventions and strategies should be based on the results of nutritional assessment. Nutritional supplementation should be offered to those who are food insecure. Food security means when all people at all times have physical and economic access to sufficient amounts of safe and nutritious food to meet their dietary needs and food preferences for an active and healthy life (Poverty Reduction Strategy and Action programme (PRSAP) 2006:93).

The following strategies should be used by nurses for nutritional supplementation:

- All those who are found to be lacking proteins, minerals and vitamins should be provided with enough corn soya and multivitamins every visit. Sufficient corn soya should be provided for both patients and their dependants. This intensive feeding regimen should continue until the patient is food secure. Thereafter, the rations it can be reduced. All those with a CD4 cell count below 500 should also be given the corn soya and multivitamins. Corn soya is rich in proteins. Multivitamins are essential for chemical reactions in the body.
- PLWHA should be involved in training on income-generating projects and farming to ensure long term food security through the use of *tinkhundla* (traditional administrative units) development funds.
- Individuals should be encouraged to be self-sufficient: Socio-economic status is related to health. Lack of money affects the quantity and quality of resources that can be bought, and therefore affects health. Improvement in health status depends on socio-economic factors. What needs to be assessed includes financial status, employment, financial support and the number of dependants.
- Information should be provided about proper diet that is based on a variety of foods that are locally available and acceptable to the patient.

### **6.3.2.2 Guideline: Encourage consistent and correct condom use**

Consistent condom use means using a condom for every act of penetrative vaginal or anal intercourse. Consistent condom use reduces the chances of HIV transmission by 80%. The study revealed that there is a low rate of condom use among PLWHA in Swaziland who are on ART, yet the major mode of transmission of HIV is through unprotected sex. There is a misconception among PLWHA that once they have been put on ARVs, there is no need for protection when having sexual intercourse. The researcher is of the opinion that the promotion of condom use should be given the same priority as nutrition.

Condom use promotion strategies may include any of the following:

- Advocate for behaviour change. Unlike some other infectious diseases, the transmission of HIV is mediated directly by human behaviour. Changing one's behaviour will mean that each individual will be responsible for his or her own health, and, thus will be able to use protective measures, such as condoms effectively. Nurses should advise PLWHA who are on ART to use condoms to prevent re-infection and drug resistance.
- Change norms about sexual behaviour and condom use. As long as cultural norms encourage high risk sexual behavior, and discourage condom use, people are unlikely to use condoms as much as they should. Whether an individual practices safe sex, or uses condoms, is determined, not only by his or her knowledge, but by the social norms and cultural practices of the society in which he or she lives. Nurses should offer education that is aimed at changing individual behaviour and increasing condom use by addressing community norms and other behavioural obstacles to condom use. The use of condoms should become a community norm and an expected practice. Educational programmes also need to focus directly on changing men's behaviour towards the use of condoms, as men have more power in most relationships. Women's

self-esteem and insistence on the use of condoms should be strengthened, as well as their skills in negotiating and communicating with men.

- Create a positive image of condoms. Nurses should offer education that aims at changing negative perceptions of condoms to help increase their use.
- Discourage bad labels given to condoms. For example, the female condom in Swaziland is called *umkhumbi* (boat). This word does not sound good when applied to the condom.
- Promote condom use. Nurses should use condom promotion strategies that focus on normalisation of condom use while addressing barriers to condom use. Promotion can inform people about condoms and change their health behaviour. Promotion of condoms can also do more than warn about the risks of HIV infection, or teach how to use a condom. It can engage people's interest, reach them emotionally, and persuade them that using condoms is easy, important, convenient, and a social norm.
- Offer condom use counseling. By counseling PLWHA who are on ART, nurses provide assurance that condoms effectively prevent STIs, pregnancy, and HIV.
- Provide greater access to both male condoms, and female condoms. Strengthen existing structures for condom distribution, as well as for the monitoring and evaluation of whether condoms are being used consistently and correctly.
- Develop focused information, education, and communication (IEC), for promoting condom use among PLWHA.
- Sensitise health workers to condom use. Nurses should be role models in condom use. They must practice what they preach.
- Promote social marketing, as it is the most effective strategy for condom use promotion. This strategy not only helps to increase the acceptability of condoms, but also provides easy access to the uses, while increasing the sustainability of condom use promotion.

- Use influential people as condom promoters. Nurses can lobby influential people as condom promoters. If influential people can advocate condom use, it can be easy for all individual to accept condoms.

The study revealed that some participants do not use condoms because of the desire to have children. Nurses should change their mind-set that having HIV and AIDS means no children and no family. Very young people are getting infected or were infected at birth. To these people life needs to continue. Fertility choices in the context of HIV are complex (Southern African HIV Clinician Society 2008:24) and sensitive, however it is the choice of the client to have children or not to have them. Pregnancy or desire to become pregnant should not preclude the use of ART. All women have the right to determine the course of their sexual and reproductive lives, and to have access to information related to HIV.

The following strategies can be used by the nurses to support PLWHA who desire to have children:

- Offer information and guidance to those PLWHA who desire to have children. Information should be provided that helps people protect their reproductive health and their right to make choices. It should be explained that the risk of mother-to-child transmission of HIV, is high with CD 4 below 350. Initiation into ART will have an impact on the health of the mother and child. A stable, maximally suppressed viral load prior to conception is recommended for HIV-infected woman who are on ART and who wish to become pregnant. There has to be a balance between fertility choices and reduction of HIV transmission.
- Provide counseling and support to HIV-discordant couples. Discordant couples are couples where one partner is HIV-positive and the other is HIV-negative. HIV-discordant couples who wish to have a child need to balance the chances of conception against the risk of HIV transmission.

### **6.3.2.3 Guideline: Encourage adherence to ART**

Non-adherence has a strong and direct effect on disease progression and survival in PLWHA. For the full benefits of ART to be realised, an adherence rate of 95-100% is required (Steel et al. 2007:4). This means that patients should not miss more than three tablets from a prescription of 60 tablets a month. The study revealed that none of the participants has reached the 95% adherence rate necessary for maximising the benefits of ART, as all of them reported missing more than three doses in a month. The main reasons for missing doses cited by most of the participants were secrecy about their HIV status, forgetfulness, having a busy schedule, unavailability of food and the tiresome routine of taking the same drugs at the same time for the rest of their lives. Health providers have a significant responsibility to assessing the risk of non-adherence to devise interventions to optimise adherence.

Strategies to improve adherence that can be used by nurses include the following:

- Use of a multidisciplinary approach to adherence. Nurse managers can utilize other partners in a collaborative effort to reinforce adherence messages. These include:- pharmacists, peer educators, volunteers, case managers, nurse practitioners, health planners, policy-makers, research nurses, drug counsellors, clinician's assistants, and church leaders.
- Develop collaborative relationships with church leaders or faith-based organisations, traditional leaders, and traditional healers in the management of HIV and AIDS and ART. The parties mentioned above are easily accepted by PLWHA.
- Assess patients for readiness for ART before initiation into ART. Patient readiness for therapy is as important as the medical indication for commencing therapy (Southern African HIV Clinicians Society 2008:19). Patients should be assessed by the nurses if they are emotionally ready to adhere, as the effectiveness of ART depends on an adherence rate of at least 95%. A patient

who is not ready should be given the necessary assistance before initiation. This requires collaboration between nurses and doctors.

- Assist patients that have been initiated into ART to complete a personal adherence plan. The plan should include the identification of a treatment supporter that will assist the patient to take the drugs. The treatment supporter will be charged with checking on the patient at least once a week recording the doses of the tablets taken by the patient on a daily treatment record. The treatment supporter should receive sufficient orientation on ARV adherence before the patient is initiated into ART. Recruit family and friends to support the treatment plan, develop adherence support groups, and add adherence concerns to the agendas of other support groups.
- Sustain patients' motivation to adhere. Patients need to be supported, not blamed, when they do not adhere, because not all adherence problems are patient-related. For example, in availability of food, stigma and discrimination and side effects of the ARV drugs can cause the patients not to adhere.
- Adopt and adapt the elements of the directly observed treatment (DOT) tuberculosis (TB) control framework for ART delivery. The elements of DOT are political commitment, diagnostic facilities, adequate supply of drugs, directly observed treatment and accountability. These elements have proved effective in the management of TB, and can be used for managing ART.
- Adherence should be monitored aggressively and on an ongoing basis. Assess and strengthen those factors that contribute to adherence. Assess for those factors that might cause non-adherence and deal with them before ART initiation.
- Effectively manage of side effects of ARVs and opportunistic infections. The study showed that the manifestation of side effects is one cause of non-adherence to ART. The researcher is of the opinion that prompt management of side effects of ARVs by nurses can improve the QOL of PLWHA who are on ART.
- Provide counseling where the patient expresses any desire to stop change, or mix medications. The study revealed that some PLWHA stop medications due to

side effects, or they mix ARVs with other medications because these other medicines are widely marketed and available. The patient's wishes should be respected by every health care team member, however information should be provided on the clinical, immunological, and virological consequences of stopping, changing or mixing ART medication with other medications. Patient should be encouraged to discuss with the nurse any desire to stop, change, or mix the ARV drugs with other medications or nutritional supplements. The use of herbal products should be discouraged because of potential harmful interactions with the ARV drugs. It should be explained that concomitant use of traditional medicine and ARVs cause harmful interactions. Discussion of dangers such as these should form part of routine counselling about ART. Patients should be encouraged to go for another HIV test if ever claim to have been cured by prayer. Nurses should not dispute the fact that all things are possible to them that trust in God, and that miracles do happen, but patients should be encouraged to confirm claims of having been cured by being tested again for HIV. This approach will prevent possible conflict between nurses caring for PLWHA and some spiritual leaders.

- Ensure that patients are retained in ART. The study found that some patients that are put on ART are lost to follow-up yet long-term retention of patients on ART is essential for ART success. There should be effective and efficient patient tracing procedures, good monitoring systems and early detection systems for defaulters. In implementing these procedures and systems, nurses can work together with community networks in the patient's place of residence, social workers, and home-based care givers. For tracing of patients, a box file system is recommended. In this system, the clinic has 12 boxes, each box representing a different month of the year. If a patient is due for consultation in the month of June, his or her card is put in the box of June. In this way it will be easy to determine if the patient did not show up for his or her consultation, if his or her card is still in the box by the end of June. The patient will be contacted

immediately and encouraged to attend consultations. This will avoid the problem of unnecessary defaulting.

#### **6.3.2.4 Guideline: Combat and diffuse stigma and discrimination**

Although some participants stated that ARVs have helped reduce stigma and discrimination associated with HIV and AIDS, some participants mentioned that ARVs have increased stigma and discrimination. This shows that stigmatisation of and discrimination against PLWHA is still pervasive in Swaziland, and it is a major cause of non-adherence to ART and consequently lowers QOL. It was also identified that stigmatisation of and discrimination against PLWHA in Swaziland leads to PLWHA being afraid to disclose their HIV-positive status, failure to use risk-reduction practices, and social isolation. Stigma and discrimination is at the heart of many failed efforts to deal with HIV and AIDS over the years, and many HIV prevention, care, support, and treatment interventions have not been that effective, as a result of HIV-related stigma (World Council of Churches 2005). The reduction of HIV and AIDS-related stigma in the media, health institutions, workplaces, religion, families, and communities is very important.

The following strategies can be used by nurses to reduce HIV and AIDS-related stigma and discrimination:

- Nurses should be role models for reducing stigma and discrimination. The study revealed that nurses themselves are the perpetrators of stigma and discrimination. In order for society to see the consequences of stigma, and the need for it to be eradicated, nurses should be at the forefront of any stigma reduction strategy.
- Create an environment that enables caregivers to move beyond illness and stigma to compassionate care. Nurses should create a climate of love, acceptance, and support for PLWHA.

- Promote communication that respects the client's dignity and self-worth and that reflects empathy and affirms the client's choices and right to self-determination.
- Address both the consequences and the causes of stigma at both individual and community level, for example, social and gender inequality, poverty, and any form of prejudice.
- Empower individuals and communities to sustain any stigma-reduction strategies by strengthening skills and knowledge, building self-acceptance, and enhancing the acceptance of PLWHA.
- Sensitise key professionals and community leaders to the consequences and the causes of HIV and AIDS-related stigma and discrimination.
- Ensure provision of quality care, by using the holistic, GIPA and QOL approaches. This means attending to the physical, psychological, spiritual, socio-economic, cognitive, and environmental needs of PLWHA.
- Strengthen self-support groups. PLWHA can cope well with the assistance of support groups, as they create a sense of safety in numbers.
- Facilitate greater involvement of PLWHA. This will increase the visibility of PLWHA as productive members of society. PLWHA need to be involved in all levels of HIV and AIDS issues. PLWHA need to be involved as decision makers (participating in decision-making or policymaking bodies, where their inputs are valued), as experts (where PLWHA are acknowledged as the main source of information about HIV and AIDS), as implementers (where PLWHA play an instrumental role in interventions), and as speakers (where PLWHA are used as spokespersons in campaigns to change behaviour).
- Avoid HIV and AIDS stand-alone health care settings. Such settings make it possible for PLWHA to be easily identified and stigmatised.
- Avoid using bad labels for PLWHA and ARVs. Nurses should be role models of stigma reduction by using proper language when dealing with PLWHA. Nurses should stop calling PLWHA "victims" or "AIDS cases" or "AIDS sufferers", but "survivors". If this is done in the case of cancer, it can be done for HIV and AIDS.

Only call them “victims” when they are dead. Calling PLWHA “victims” while they are alive implies that they are powerless, with no control over their lives. Nurses should avoid calling some PLWHA “innocent victims”. This implies that other PLWHA are not innocent, but are guilty of what has befallen them. Terms such as “full-blown AIDS” and “high-risk group” should be avoided. Saying that a person has “full-blown” AIDS makes it sound as if there are those that only have “half-blown” AIDS. The term “high-risk group” implies that membership of a particular group, rather than a particular behaviour, is the significant factor in HIV transmission. Use conciliatory vocabulary, rather than confrontational, destructive, or condemnatory vocabulary, for example, nurses should talk about a “response to HIV and AIDS”, rather than a “fight against HIV and AIDS”. Refrain from describing HIV as a “scourge”, or a “plague”. HIV is an infection.

- Provide a secure and friendly environment where members have access to resources, support, and counselling.
- Help to link clients to needed services for economic and social support.
- Provide referrals to other care and programmes, to ensure continuity of care.
- Encourage disclosure of HIV status. Disclosure of HIV status should be strongly encouraged, as this has been shown to be an important determinant of adherence. Disclosure can reduce HIV-related stigma. Help the patient to make decisions about disclosure to friends, family, and the community.
- Help the patient effectively manage depression. Depression can be caused by the virus itself, or it can be caused by stigma and discrimination. Depression can lead to lack of self-worth and despair. Care must be taken to identify those patients that are at risk of developing depression, those that are experiencing difficulty with interpersonal relationships, those that are failing to cope, and those with a poor self-concept.
- Sustain patients’ hope. Research findings indicate that some PLWHA lose hope because of the invasive nature of the infection and society’s reaction to it. Hope has several components: future orientation, the setting of goals, the taking of action to meet those goals, and the importance of interpersonal relationships.

Therefore, fostering hope, and inspiring realistic hope, is important, for without hope, there is despair (Soeken & Carson 1987, in Magenuka 2006:157). To sustain hope, nurses should be future-oriented when dealing with PLWHA.

- Provide clear and accurate information about HIV and AIDS. This will help dispel myths about HIV and AIDS and ART.
- Facilitate the perception of having control over the situation. Enhancement of patients' feelings of control will help them perceive their ability to cope with other demands more positively (Chen, Boore & Mullan 2005:256). There is a need for psychological counselling and support. Counselling therapy should assist patients in coping and should teach them healthy adaptive behaviour. Counselling therapy uses the principles of grief work and supportive psychotherapy and aims to promote patients' best psychological and social functioning, by restoring and reinforcing their ability to manage life (Judd & Brown 1988:422). People understand their own needs better than anyone else, and, as a result, should have the power both to define them and act upon them.
- Adhere to the professional code of ethics, for example, maintaining privacy and confidentiality in all health care settings.

#### **6.3.2.5 Guideline: *Build the self-esteem and self-worth of PLWHA***

It was discovered that PLWHA had low self-esteem due to the infection, and the stigma and discrimination attached to the infection.

Some of the strategies to build self-esteem that can be used by nurses are:

- Encourage the patient to share his or her thoughts and feelings.
- Assist the patient to change view of self from being a victim to being a survivor of HIV.
- Assist the patient to be in control of his or her situation.
- Help the patient to develop and maintain a positive self-concept.

### **6.3.2.6 Guideline: Strengthen spiritual support**

The study found that for some PLWHA, spirituality served as a great source of emotional and material support, and a source of strength to carry on, while the spiritual aspect of some PLWHA was weakened. Spirituality is linked to health. Religiosity and faith significantly influence adherence. Nurses must envision spirituality as a powerful resource for holistic care (Delgado 2007:233). Nurses can implement a number of interventions based on an awareness of the importance of the meaning of life, and spiritual practices that reflect one's connection to self, others, and a belief in the existence of spiritual powers outside of the self (Scarinci et al. 2009:75).

Below are some of the interventions that nurses can implement:

- Assess the spiritual beliefs of PLWHA. The spiritual beliefs of the patient should be assessed and known, so that the patient can be given the necessary spiritual care. Spiritual assessment can provide nurses with information about how patients view life, death, and health concerns (Burkhardt & Nathaniel 2008:453).
- Create and sustain the hope of PLWHA by explaining that the HIV and AIDS situation is now better than it used to be. Assist PLWHA to believe in possibilities.
- Instil a feeling of increased inner strength and personal awareness and acceptance of the world, manifested by inner peace.
- Instil a feeling of satisfaction with life. Instil a sense of wellbeing that transcends the physical and emotional aspects of HIV.
- Engage in life. One of the sustaining elements of spirituality is that it can engage people in life. Faith can motivate PLWHA to take the extra care needed for healing and sustaining their lives.
- Show love, understanding, and compassion.
- Facilitate self-forgiveness. The study showed that some PLWHA blame themselves, as they think that they are responsible for their suffering. The first

step to healing is self-forgiveness. Nurses can facilitate this remedy by explaining to the patients that HIV infection is not a result of a person's irresponsibility, and they should not blame themselves.

- Restore a sense of wholeness to broken relationships between the patient and those near to him or her.
- Build a sense of trust and caring, and show unconditional love to those regarded by society as outcasts.
- Establish a spiritual intervention programme for education, support, counselling, and income generating.
- Spiritual leaders can make intercession for people infected and affected by HIV and AIDS at health facilities and in communities where there are many PLWHA.

#### **6.3.2.7 Guideline: *Facilitate community support and community integration***

The study revealed that because of the stigma attached to HIV and AIDS, PLWHA are ostracised by family members and the community.

Some of the measures that can be used to support community integration are the following:

- Involve the family, friends, the community, and significant others. According to Van Dyk (2003:326), the magnitude of the HIV and AIDS crisis has inevitably meant that both the family and the community have to become involved in most care programmes. The family is the most important support structure for PLWHA. The family, the community, and patient organisations are key factors for success in improving adherence and, as such, they should be involved.
- Increase the provision of home-based care. Because of poverty, some patients fail to meet their appointments. This calls for nurses to visit the patients at their homes.

- Provide ongoing support and monitoring. Nurses should provide access between visits for questions or problems, and monitor ongoing adherence intensively per visit or during periods of suboptimal adherence.

#### **6.3.2.8 Guideline: Enhance proper understanding of HIV and AIDS and ART**

The study revealed that there is a lack of understanding of HIV and AIDS and ARV drugs, and that this is another cause of non-adherence, yet ART is an empowering tool for people to live longer and have a life with quality.

The following are strategies that can be used by nurses to enhance a proper understanding of HIV and AIDS and ART:

- Assess HIV and AIDS and ART knowledge. This must be assessed before ART initiation. The assessment should be ongoing, as there is much misinformation in the client's environment that may have a negative impact on adherence.
- Provide correct information, and correct any misunderstandings and misbeliefs about HIV and AIDS, ARVs, and adherence. Nurses should serve as educators and information sources, with ongoing support and monitoring. Education should be offered for a month before initiation into ART, and there should be evaluation of this knowledge. It must be emphasised that HIV is now a chronic and manageable condition. Education should include family members and treatment supporters. The following factors should be explained in simple language:
  - What HIV is;
  - What AIDS is;
  - What ARVs are, and their importance;
  - What adherence means;
  - Why patients need to adhere;
  - The consequences of not adhering; and

- Immune Reconstitution Inflammatory Syndrome (IRIS). This means a spectrum of clinical signs and symptoms resulting from restored ability of immune response, that is associated with immune recovery (National Guidelines for Antiretroviral Treatment and Post-Exposure Prophylaxis 2006:29).

#### **6.3.2.9 Guideline: Discourage negative thoughts about HIV and AIDS and ART**

The study revealed that some PLWHA have negative thoughts about themselves, the infection, and the ARV drugs.

The following strategies can be used to change negative thoughts about the infection and the drugs:

- Establish trusting relationships with patients. This is crucial for ensuring confidentiality and privacy. Breach of confidentiality can lead to mistrust and avoidance.
- Have non-judgemental attitudes towards patients, and offer them assistance. Patients are likely to confide truthfully in someone that they trust with the information.

#### **6.3.2.10 Guideline: Improve health care delivery systems**

Data collected show that the Swazi formal health care delivery system is not satisfactory. As stated by the participants in the study, and as observed by the researcher, factors that contribute to the Swazi formal health care delivery system being unsatisfactory are the lack of privacy, the mixing of patients in one consultation area, shortage of space, a shortage of nurses and doctors, long queues, and the clash of the traditional health care system and the modern health care system.

The following are strategies that can be used to improve health care delivery systems:

- Assess the use of traditional medicine. The study revealed that some PLWHA use traditional medicine, as they do not believe in the efficacy of ARVs. Nurses should assess the use of traditional medicine, as concomitant use of traditional medicine and ARVs has the potential for harmful interaction.
- Provide private consultation areas, for the purpose of maintaining confidentiality. It was observed by the researcher that there were only four rooms at the study clinic that were designed for consultation purposes. As a result, the nurse's duty room was also used for consultations and, as such, confidentiality and privacy were not assured.

**6.3.2.11 Guideline: Discourage the negative influence of culture on HIV and AIDS and ART**

The findings of the study indicated that some Swazi cultural practices have a negative influence on the way PLWHA view HIV and AIDS and ARVs. Harmful cultural norms that were identified include male dominance, multiple sex partners, polygamy, and extramarital relationships. It is very difficult to deal with issues of culture, since it is the life of the people. The researcher is of the opinion that the following strategies can be used by nurses to empower PLWHA to deal with such negative cultural influences:

- Render culturally sensitive nursing care, which means that the care is planned and implemented in such a way that it is sensitive to the needs of the individual, the family, and the community.
- Provide intensive education about HIV and AIDS and ART (as explained in Guideline 6.3.2.7).
- Enlighten PLWHA to practise those cultural practices that contribute positively to their health, and to avoid those cultural practices that are detrimental to their health.

**6.3.2.12 Guideline: Advocate for the protection of the rights of PLWHA**

The study revealed that the rights of PLWHA in Swaziland are violated. Their rights are violated in terms of privacy, confidentiality, judgemental attitudes, and bad labels given to PLWHA. Every individual, despite his or her HIV status, has the right to privacy, confidentiality, health, and health care. Upholding the rights of PLWHA is a fundamental principle in the prevention of stigma and discrimination. This means that there should be respect, protection, and fulfilment of the rights of PLWHA.

The following strategies can be used by nurses to protect the rights of PLWHA:

- Provide legal information, so that PLWHA can protect their rights and the rights of their families.
- Promote and preserve the trust that is inherent in the privileged relationship between a nurse and a patient.
- Ensure privacy and confidentiality, have a non-judgemental attitude, and avoid the many bad labels used for HIV and AIDS and ARVs. PLWHA should be treated with the same respect with which people with any other condition, such as cancer, would be treated.
- Advocate and campaign for the protection of patients' rights.
- Practise nursing in accordance with the legal and ethical codes of the profession.
- Build and strengthen the networks of PLWHA. PLWHA organisations and networks need to be empowered and structured in a way that allows them to fight for their own rights, instead of having people and organisations advocate on their behalf.

## **6.4 EVALUATION OF THE GUIDELINES**

The subject of the evaluation of the guidelines was introduced in Chapter 2, where the research methods were discussed. The effectiveness of the guidelines depends on the quality of the guidelines. Consequently, the guidelines were evaluated by external reviewers for their clarity, simplicity, generalisability, importance, and consistency (Chinn & Kramer 1999:111; Walker & Avant 2005:160-179).

Nine experts (three ART experts, three guideline development experts, and three potential users) were chosen by purposive sampling to review the guidelines. The external reviewers, which included experts in ART care, reviewed the guidelines to ensure clinical sensibility. Experts in guideline development reviewed the methodology by which the guidelines were developed, and potential users reviewed the guidelines for their usefulness in ART care. The experts were given a hard copy and an electronic copy of the guidelines. After careful reviewing the guidelines, they gave feedback in writing. Their concerns were attended to by the researcher and she developed guidelines that are feasible and specific to PLWHA who are on ART and their families.

## **6.5 UPDATING OF THE GUIDELINES**

The guidelines can be reviewed and updated as soon as new relevant evidence-based information becomes available, or after five years of being implemented. This period is considered appropriate, as it is in line with the 2007 Swaziland National Health Policy.

## **6.6 CONCLUSION**

This chapter contains guidelines that can be used to empower PLWHA who are on ART, so as to promote their adherence to ART, and thereby improve their QOL. The empowerment guidelines are based on the findings of the study and the literature review. The study revealed that there are many challenges that are faced by PLWHA in Swaziland who are on ART. PLWHA in Swaziland are powerless to deal with some of these challenges. These guidelines were developed as a means to empower PLWHA to be in control of their lives and have an improved QOL. These guidelines were formulated based on empowerment assumptions in the field of social work and the principles of the holistic approach, the human rights-based approach, and the Greater Involvement of People Living with HIV and AIDS approach. The chapter concludes with a discussion of the evaluation of the guidelines and considerations pertaining to the updating of the guidelines.

The following chapter deals with conclusions made on the basis of the study, as well as limitations of the study, and recommendations for nursing practice, education and research.

## **CHAPTER 7**

### **CONCLUSIONS, LIMITATIONS, AND RECOMMENDATIONS**

#### **7.1 INTRODUCTION**

The previous chapter dealt with the development and description of empowerment guidelines that can be used by nurses to support PLWHA. The purpose of the guidelines is to promote adherence to ART and to improve the QOL of PLWHA who are on ART. This chapter concludes the study, discusses its conclusions, and makes recommendations for nursing practice, education and research.

#### **7.2 CONCLUSIONS**

This study used qualitative, exploratory, descriptive, and contextual design to assess QOL of PLWHA in Swaziland who are on ART. The main purpose was to develop and describe guidelines to empower PLWHA in Swaziland who are on ART. Qualitative design was the most suitable approach for the study, since “QOL is a phenomenon that is subjective and unique to each individual” (Ventegodt et al. 2003:1032), and the qualitative approach has the advantage of eliciting the subjective experiences of participants.

This study began with a concept analysis of QOL. The method of concept analysis was beneficial to the researcher, since it gave a concise operational definition of the concepts of quality, life, and quality of life (QOL). Although this exercise was tedious, it helped the researcher identify definitions and common domains of QOL. From the analysis, four domains of QOL were identified and considered by the researcher as being relevant in the exploration of QOL of people living with HIV and AIDS (PLWHA)

who are on ART. As indicated in Chapter 3, these domains were the physiological, the psychological, the spiritual, and the social domain.

After concept analysis, the researcher's main concern was the issue of relevance of these domains to PLWHA in Swaziland who are on ART. This required the researcher to conduct a workshop with nurses who are experts in the care of PLWHA who are on ART, in order to validate the domains. Although the workshop strategy was costly in terms of money and time, it proved to be effective, as it brought a number of experts together in one venue at the same time, and the researcher was able to obtain the viewpoints of these experts in a timely manner. The workshop strategy also enabled the researcher to acquire rich information from the nurse experts, and she was thus able to validate the domains of QOL that were obtained through the literature review. Due to financial and time constraints, only nurses from two urban ART health care institutions were invited to attend the workshop. This means that the domains were validated by ART experts from urban settings only. Perhaps nurses from rural settings would have validated the domains differently.

The majority of studies reviewed by the researcher in the field of QOL have used pre-existing QOL questionnaires as a method of data gathering. The researcher felt that these instruments had limited usefulness, in that they were developed in contexts which were different from the context of this study. The researcher, therefore, contextualised her domains of QOL and used them to guide her interviews. The researcher used a semi-structured interview guide to assess the QOL of PLWHA in Swaziland who are on ART.

One of the challenges faced by the researcher was having to combine different methods of data collection, so as to obtain credible findings. The data collection methods employed by the researcher were observations, in-depth individual interviews, and focus group discussions (FGDs). Although observations, in-depth individual interviews, and FGDs are excellent qualitative methods of data collection, the researcher found it

difficult synthesising information in order to obtain credible findings from the study. However, with repeated reviews of transcripts, and comparing field notes, the researcher managed to get a coherent picture of the QOL of PLWHA in Swaziland who are on ART.

The findings of the study support other findings pertaining to the QOL of PLWHA who are on ART. The findings of the study assisted the researcher to formulate appropriate guidelines to empower PLWHA in Swaziland who are on ART. The guidelines received an external review of their usefulness in practice.

The study was unique in that it is the first of its kind to be done in Swaziland. The entire study was time-consuming and mentally taxing, because of its complexity. QOL, HIV, AIDS, and ARVs are complex phenomena, and combining the four concepts gave a complex understanding to nurses. This study offers an understanding that though ARVs were introduced to prolong the lives of PLWHA, their QOL remains a concern since it does not show improvement.

### **7.3 LIMITATIONS OF THE STUDY**

According to Polit and Beck (2008:74), a presentation of limitations demonstrates to readers that the author was aware of the limitations of his or her study, and there is a significant probability that the author took them into account in interpreting the findings of his or her study. The findings of this study should therefore be considered against the following list of limitations (some of these limitations were discussed in section 7.2):

- Because the study was qualitative and exploratory in nature, the sample of PLWHA who were on ART was small (24 PLWHA). Hence the findings of the study can only be generalised to PLWHA in Swaziland.

- The researcher used purposive sampling, which, although it provides credible data of the participants' experiences of the phenomena under study, restricts the generalisability of the findings.
- Due to financial and time constraints, only one VCT site (an urban VCT centre) was used for data collection. It is possible that similar research at a rural centre could yield different results.
- The researcher is employed as a nurse at the study site. The researcher is a lecturer at the institution where data was collected. She could have been known to some of the study participants, and this could have influenced their responses.

The researcher is of the view that, despite the above limitations, the study offers insight of the QOL of PLWHA who are on ART in Swaziland.

## **7.4 RECOMMENDATIONS**

These recommendations were drawn from the findings of the study and are in line with the principles of QOL. The researcher discusses the recommendations with regard to (1) nursing practice, (2) nursing education, and (3) further research. The recommendations are described in the subsections below.

### **7.4.1 Recommendations with regard to nursing practice**

Nursing practice responds to a patient's or client's actual, emerging, and potential health or nursing care needs and demands throughout the developmental stages of the patient's or client's life cycle and along the health-illness continuum (Swaziland Nursing Council 2010:32). It is important, therefore, that nurses offer quality holistic nursing care to PLWHA who are on ART, so as to improve their QOL.

In view of the above, the researcher recommends that:

- ART services be decentralised to ART-accredited facilities. The shortage of doctors, coupled with the need to scale up ART services, calls for a need for a task-shifting strategy, as was recommended by the WHO in 2008. This will necessitate the implementation of a task-shifting initiative, where nurses will be given the necessary training and support to prescribe ARVs, without compromising the quality of care provided. With a broadened scope of practice, nurses will be able to prescribe ARVs for manageable patients and refer complex patients to doctors. The task-shifting strategy has worked well in countries such as Uganda, Lesotho, and Botswana.
- An organisation be established in Swaziland to improve the health of the people, by promoting collaboration between traditional healers and the biomedical health system, to build a mutually respectful relationship between the two health care systems, so as to improve health services. Traditional healers should be taken as allies in the fight against AIDS. Cooperation should be on equal terms, regardless of the level of education of the health practitioners involved. Traditional healers are respected within their communities and know how to convey health information in a culturally acceptable manner. They are ideally suited to educate people about HIV prevention, distribute condoms, conduct counselling, encourage HIV testing, and set up support groups for affected people. The training of traditional healers can assist in the identification of illnesses that they are unable to treat, and such identification of illnesses can hasten referral of patients to the clinic where necessary.
- For evidence-based practice, the researcher be consulted or used in promoting ART adherence and the improvement of QOL of PLWHA who are on ART.
- Cultural care and spiritual care be considered as vital in the care of PLWHA. Nurses must render culturally and spiritually competent interventions.
- The churches be encouraged to play a major role in disseminating HIV and AIDS information and promoting ART.
- Continual in-service education be provided to nurses on HIV and AIDS, ART, and adherence management.

- These guidelines be disseminated, implemented, and tested in real life for usefulness and generalisability. Possible methods of disseminating these guidelines include the following: (1) publishing articles in appropriate accredited journals, (2) participating in in-service training at health care facilities, (3) implementing the guidelines in pre-service nursing education, and (4) presenting the guidelines at international conferences.

#### **7.4.2 Recommendations concerning nursing education**

Nursing education aims to prepare nurses to provide quality holistic nursing care and services, in order to meet the needs of society. Nurses are empowered through education to be competent in meeting the ever-changing demands of society. The researcher therefore recommends that nursing education be structured in a way that:

- HIV and AIDS, ART, transcultural nursing, nutrition for HIV and AIDS, and counselling courses are offered in pre-service nursing education. These courses should be integrated into other courses and, as a means of emphasising the importance of these courses, they should be presented as stand-alone courses, given just before students exit the nursing course.
- For those in service, short courses for the above are offered.

#### **7.4.3 Recommendations with regard to nursing research**

Nursing research is essential for the development of scientific knowledge that enables nurses to provide evidence-based health care (Brown 1999, and Omery & Williams 1999, in Burns & Grove 2005:4). Providing evidence-based ART nursing care requires conducting constant research to address emerging issues of HIV and AIDS and ART.

Given the scope and limitations of the study, the researcher recommends that further studies be done that will explore the following:

- The interaction of complementary and alternative medicine (CAM) and traditional medicine with ARVs.
- Comparative research on the QOL of PLWHA in rural areas and the QOL of PLWHA in urban areas. Is it possible that there could be a difference between the QOL of PLWHA in rural areas and the QOL of PLWHA in urban areas?
- The benefits of starting ART earlier. Do patients that start ART earlier, with a CD4 count of over 350, have a better QOL than patients that start ART with a CD4 count of below 350?
- The patient ART retention rate. The percentage of retention, and reasons for such a retention rate in Swaziland.
- Adherence patterns. At what point during ART do patients show the best adherence, on the one hand, and the poorest adherence, on the other hand? Is it during the first year of ART, or during subsequent years, and what are the reasons for such a pattern?
- This study has identified that PLWHA on ART improve physically during the first nine years of treatment. A study is needed to assess the long-term effects of ART.
- As this study was the first study to be done on the QOL of PLWHA in Swaziland who are on ART and suggests the first guidelines for empowerment, research is required to assess the impact of these guidelines on the QOL of PLWHA in Swaziland.

## **7.5 SUMMARY**

This chapter dealt with the conclusions of the study. It is concluded that the objectives of the study were met. Limitations of the study were also highlighted, and recommendations were made with regard to nursing practice, nursing education, and nursing research. It is also concluded that this is the first study addressing QOL of PLWHA in Swaziland who are on ART. The study revealed that although ART improves

some aspects of the lives of PLWHA, there are challenges that interfere with adherence to ART. These challenges include food shortages, stigma and discrimination, inconsistent condom use, a desire to have children, disfiguring side effects of ARVs, low socio-economic status, unsatisfactory health care delivery systems, and violation of the rights of PLWHA. The above challenges negatively influenced the QOL of PLWHA and hence their QOL was found to be lowered. These findings were discussed with reference to the relevant literature. The researcher developed guidelines as a means to empower PLWHA to effectively deal with these challenges. It is only when PLWHA are empowered that the vision of the Ministry of Health will be achieved, namely that by the year 2015 the people of the Kingdom of Swaziland will have reversed the trend of the AIDS epidemic, resulting in improved QOL, which will be characterised by reduced HIV and AIDS-related morbidity and mortality.

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