

# Enhancing Adherence to Antiretroviral Treatment: The potential role of church leaders in Vulindlela, KwaZulu-Natal.

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A Dissertation Submitted in Partial Fulfillment of the Requirement for  
Masters of Theology (Theology and Development) in the  
School of Religion, Philosophy and Classics  
University of KwaZulu-Natal

Pietermaritzburg, 2015

## **Abstract**

South Africa is currently managing the world's biggest antiretroviral treatment (ART) programme since a large section of its population is using ART daily. ART requires a meticulous adherence plan as this medication is a lifelong treatment. Currently there is an ongoing outcry about poor adherence to ART which leads to drug resistance. There are many factors that predict poor adherence to ART. These include the social structural system of socioeconomic formation, individual behaviours and medical conditions. Investigating the role of the church in enhancing adherence to ART is, therefore, important.

Parry's (2008) framework of an "HIV competent church" guided this study to analyze the engagement of Vulindlela church leaders in programmes that are meant to improve ART adherence. The findings of this analysis revealed that some Vulindlela church leaders had adequate competence to initiate church-based ART adherence programmes. This included a willingness to act against structural factors that facilitate treatment resistance. However, there were others who were unable to get involved due to particular theological traditions. Findings also revealed that these Vulindlela church leaders had little medical knowledge about ART and the importance of adherence. The field work process also revealed that, generally, the Vulindlela church leaders were uncomfortable to talk about sex and sexuality in the public realm. These findings suggest that more systematic theological training needs to be introduced that will assist church leaders in dealing with the HIV epidemic in a more positive theological way. This includes the need to tackle the subject of sexuality in a sensitive way taking into account cultural taboos and providing helpful theological insights. Through this investigation, lessons have been learnt which can assist in the future engagement of church leaders in enhancing ART adherence.

## Declaration

I, Thulani Ocret Ngubane, declare that

1. The research reported in this thesis, except where otherwise indicated, is my original research.
2. This thesis has not been submitted for any degree or examination at any other university.
3. This thesis does not contain other persons' data, pictures, graphs or other information, unless specifically acknowledged as being sourced from other persons.
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  - a. Their words have been re-written but the general information attributed to them has been referenced
  - b. Where their exact words have been used, then their writing has been placed in italics and inside quotation marks, and referenced.
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Name of Student: Thulani Ocret Ngubane

Signature:

Date: 06 March 2015

## **Dedication**

This dissertation is dedicated to my wife, Phindile Ngubane, and our boys Kwanele, Sibongakonke and Avela. They have supported me through the journey of completing this work and I will always appreciate all their sacrifices.

I also dedicate this dissertation to my church friends for prayers and words of encouragement. Glory be to God, the Creator who has been my source of strength in times of hardships and tribulations.

## **Acknowledgements**

This dissertation would not have been possible without the support of many people. I wish to thank my Supervisor, Professor Beverley Haddad, who has been more than generous with her expertise and precious time. She has read my numerous versions and helped make some sense of the confusion.

Also thanks to Reverend Joseph Naika, who offered technical guidance and academic writing support.

I would like to acknowledge and thank Dr Heidi van Rooyen, my director at HSRC for continuous encouragement, motivation and support.

And finally, thanks to Vulindlela church leaders for making time to participate in this study.

*Kuninanonke, ngithi ukwanda kwaliwa umthakathi. Ningadinwa nango muso!*

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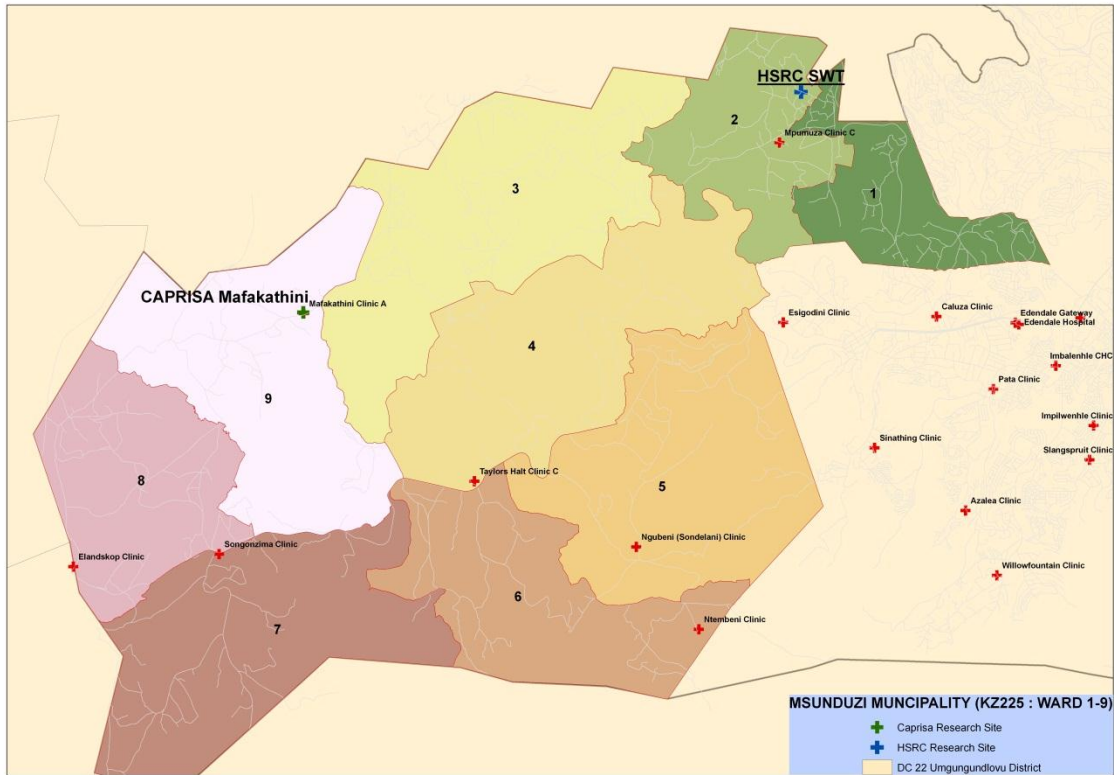
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# Map of the Vulindlela Region



Map 1: Map of the Vulindlela region in KwaZulu-Natal

## Acronyms

AICs	: African Initiated Churches
AIDS	: Acquired Immune Deficiency Syndrome
ART	: Antiretroviral Treatment/ Therapy
ARV	: Antiretroviral drug
CAP	: Community AIDS Project
COSATU	: Congress of South African Unions
DOH	: Department of Health
ECAP	: Evangelical Community AIDS Project
EPHP	: Enhanced Peoples Housing Process
EPN	: Ecumenical Pharmaceuticals Network
FDA	: Food and Drugs Administration
FDC	: Fixed Dose Combination
HIV	: Human Immunodeficiency Virus
IDP	: Integrated Development Plan
MCCSA	: Medicines Control Council of South Africa
MICs	: Mission Initiated Churches
PACSA	: Pietermaritzburg Agency for Community Social Action
PHC	: Primary Health Care
SACC	: South African Council of Churches
STIs	: Sexually Transmitted Infections
TAC	: Treatment Action Campaign
TB	: Tuberculosis
UNAIDS	: Joint United Nations Programme on HIV/AIDS
VDA	: Vulindlela Development Association
WCC	: World Council of Churches
WHO	: World Health Organization

# Chapter One

## Introducing the study

### 1.1 Introduction

Scott (2002:2) indicates that the devastating consequences of the Human Immunodeficiency Virus (HIV) negatively impact on health and human developmental livelihood. April et al. (2014:1) argue that the introduction of Antiretroviral Treatment (ART) since 2004 in South Africa has been interpreted as a positive stride to reverse HIV related deaths. Mills et al. (2006a: 285) assert that there is sufficient consensus within the medical fraternity about the efficacy of ART and there is a belief that ART users can only attain full physical well-being if they follow their treatment instructions meticulously. However, Livingston et al. (2009:7) argue that HIV is not just a medical problem but a socio-economic problem as well and a comprehensive and multifaceted approach is required.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) (2013:48) reported that the number of South Africans who are receiving ART has increased and this increase has contributed to a higher life expectancy compared with previous years. The UNAIDS Global Report of 2013 further indicates that two million people are receiving antiretroviral therapy in South Africa from government facilities (UNAIDS 2013:48).

Van Dyk (2011:1) indicates that South Africa has currently received praise for the commitment it has shown to providing ART, becoming the first country with the largest ART programme in the world. However, van Dyk (2011:1) further notes that there is a growing concern about the sustainability of the ART programme in the world. Van Dyk (2011:1) argues that this concern emanates from inadequate availability of treatment adherence programmes that are meant to enhance treatment efficacy.

The World Health Organization (WHO) (2011a:1) gave a clear warning on World Health Day 2011 that the emergence and spread of drug-resistant pathogens has accelerated and

that essential medicines are failing. Van Dyk (2011:2) asserts that HIV drugs are also failing to sustain virological resistance. The WHO suggests that “protective and corrective interventions should be conducted as a matter of urgency to prevent the world from losing the success of ARV treatment” (2011a:1).

Watt et al. (2009:387) argue that churches and religious organizations are influential social formations with a pivotal role in the manifestation of beliefs and behavioural tendencies among people. Watt et al. (2009: 389) further note that churches and religious organizations have accumulated relevant experience and capacity to provide support and care to ART users. The involvement of the church in debates and struggles against HIV and AIDS can be characterized by three evolutionary phases.

First, when the awareness of the HIV and AIDS as a pandemic emerged, “churches displayed severe skepticism and launched judgmental criticism against anyone who had been diagnosed with HIV” (Khathide 2003:1). This led the church to miss the opportunity to get involved in the debate. Khathide (2003:1) indicates that religious groupings/communities upheld different views and principles about HIV and AIDS, based on different theological hermeneutics and convictions. This reluctance and ill-informed response on the side of the church can be interpreted as the first phase of a huge evolutionary learning curve marked by its denial.

The second phase was an “awakening about the severity of the onslaught of HIV and its manifestation as a dreadful and destructive illness causing unprecedented human suffering and displaying its capability of wiping out large parts of humanity” (Dube 2003a: vii). Acknowledging the devastation of the HIV pandemic was a crucial turning point for the church.

Phase three constitutes the responses of the church that have emerged subsequent to this awakening which compelled the church to “reconsider its theological position” (Maluleke 2003:63). Maluleke (2003:63) notes a large outcry from the church to its members to get involved in HIV and AIDS curbing interventions and a mass mobilization towards integrating HIV and AIDS within theological education has emerged.

Parry (2008:9) uses the concept of an “HIV competent church” to refer to those churches and church leaders who are well acquainted with the facts and implications of the HIV and AIDS pandemic. Parry (2008:9) further argues that an HIV competent church is has the potential to impart meaningful interventions as a direct response to the HIV epidemic. This includes formulations of preventative messages, with the aim to eradicate the scourge of HIV.

Furthermore, Parry (2008:9) argues that calling church leaders to be “HIV competent” is an attempt to deepen the engagement and the involvement of the church in an effort to formulate strategies to fight against the HIV epidemic. While the Ecumenical Pharmaceutical Network (EPN) (2009:75) argues for new church policies on HIV and AIDS, Dube (2003b:153) makes a plea for a new HIV and AIDS curriculum to be integrated into theological institutions. Both the EPN and Dube agree that these contributions will accelerate the process of transformation and the development of a new mindset among ordinary Christians with regard to HIV and AIDS. According to Maluleke (2003:63), the involvement of church leadership in the HIV and AIDS struggle will bring hope and new knowledge and better use of church resources to mitigate the pandemic.

ART has presented a new phase of HIV and a new phase as to the role of the church. EPN (2009:xii) indicates that ART is a wonderful gift that is ensuring a new beginning for people who are living with HIV. This gift ensures that HIV is no longer a death sentence but rather can be managed as a chronic illness. Parry (2008:8) asserts that the involvement of the church in starting HIV treatment enhancing programmes and instilling a willingness to participate will guarantee the desired church response to HIV challenges.

In light of the phases that the church has gone through during the pandemic, there are four factors that have motivated me to conduct this study. First, there have been a number of studies conducted relating to the church in the Vulindlela region (see Chapter Two), but there has been no study that has investigated the role of church leaders in enhancing adherence to ART in the Vulindlela region.

Secondly, my professional involvement in conducting community-based mobilization programmes and HIV and AIDS interventions in the Vulindlela region has made me realize that churches and church leaders have a potential role to enhance adherence to ART programmes. Given my professional involvement in the Vulindlela region I decided to locate the study in this geographic locality.

Thirdly, it is essential to determine current strategies that the church is using as supportive means for ART users in the community, such as in Vulindlela, and to understand the social and medical barriers that decrease ART adherence and to check involvement therein.

Lastly, I am convinced that an academic study of this nature will contribute to building new knowledge on church-based ART adherence strategies.

## **1.2 Research questions and objectives**

Activities of the church and those of the church leaders should transcend the normal and traditional liturgy through “mainstreaming of HIV and AIDS into theological programmes” and subsequently into the life of the church (Chitando 2008:108). Emerging social issues such as HIV treatment resistance and adherence should be included in the programmes of the church. Nachega et al. claim that “informal care giving and social influence theories suggest that taking advantage of existing supportive relationships may lead to sustained positive changes in adherence behavior” (2006:128). However, this is impossible if there is not adequate knowledge and necessary competencies in the church. Hence, this study provides a critical assessment of the role of church leaders in the Vulindlela region.

On the basis of the above argument, this study is an attempt to answer the research question: *What knowledge of ART do Vulindlela church leaders have and what is their potential role in adherence programmes?*

In order to answer this research question, there are four research sub-questions that have emerged. First, what knowledge do Vulindlela church leaders have of ART? Secondly,

what knowledge do Vulindlela church leaders have about adherence to ART? Thirdly, are any of these church leaders involved in ART adherence programmes? Lastly, what potential future role can they play?

Furthermore, there are three objectives that guide the process of conducting this study. The first is to investigate the knowledge of adherence to ART of Vulindlela church leaders; the second is to ascertain any involvement of these church leaders in ART adherence programmes; the last is to explore the potential future role they might play in enhancing ART adherence.

### **1.3 Research methodology**

In 2005 and 2006 Haddad conducted a baseline study in Vulindlela outside Pietermaritzburg (Haddad 2006a:4). The objectives of this study included the auditing of existing Faith-Based Organizations (FBOs) in the Vulindlela region, to map the FBO's located in the study area, and to understand the positive and/or negative role that the leadership of these FBOs played in responding to the HIV epidemic (Haddad 2006a:4) (see section 5.4). This study is a follow-up study built on the Haddad study in order to ascertain if there are any church-based HIV and ART adherence programmes that the church leaders have initiated since then.

Subsequently, this study is based on two sources of information. The primary source of information is field work findings that were gathered through in-depth interviews with study participants. The location of this study is the Vulindlela region (see Map 1). Ten male church leaders who participated in the baseline study that was conducted in 2005/6 by Beverley Haddad were recruited to participate in this study (see Chapter Five). Documented material gathered from different sources of knowledge management has been used in this study as the secondary source of information. This includes a substantial literature review.

As highlighted in the above section, this study intends to explore the possibilities of enhancing adherence to HIV treatment and the potential role of Vulindlela church leaders. The research methodology for this study is qualitative: “qualitative methods allow the researcher to study selected issues in depth, openness, and detail as they

identify and attempt to understand the categories of information that emerge from data” (Durrheim 2006:47).

Given that this study investigates human subjects, the researcher managed to “avoid exposing research participants to any physical or mental harm as it is one of the ethical requirements to observe” (Reaves 1992:41). Essentially, all participants in this study participated voluntarily and written informed consent was obtained (see Appendix A).

A semi-structured interview guide was constructed, based on existing literature, and sought to obtain information relating to enhancing ART adherence and the potential role of church leaders in the Vulindlela region (see Appendix B). Frank and Duncan argue that “this type of interview schedule technique allows the researcher to explore emotions and convictions, thus adding to the richness of the experiences being explored” (2009: 3). A tape recorder was used to record all interviews and field notes were taken by the researcher. Permission was solicited to record the interviews (see Appendix A). All interviews were conducted in isiZulu.

The interview tape recordings were transcribed and translated into English. Thematic content analysis was chosen as the method by which to analyze the interviews. Ibrahim (2012:43) describes thematic content analysis as the process of analyzing data word-by-word, using tables to show any significant patterns or themes. In addition, Namely et al. conclude that:

Thematic moves beyond counting explicit words or phrases and focuses on identifying and describing both implicit and explicit ideas. Codes developed for ideas or themes are then applied or linked to raw data as summary markers for later analysis, which may include comparing the relative frequencies of themes or topics within a data set, looking for code co-occurrence, or graphically displaying code relationships (cited in Ibrahim 2012:40).

Therefore, thematic content analysis is useful in providing the researcher with an opportunity to link the different ideas and thoughts of participants. In using this technique, the researcher carefully selected themes that would provide relevant answers



to the research question. To ensure confidentiality and anonymity of the participants, fictitious names of the study participants have been used in this study.

#### **1.4 Theoretical framework**

This study uses the conceptual framework developed by Sue Parry (2008:8). Parry (2008:8) indicates that her framework of an “HIV competent church” is intended to be used by church leaders and Faith Based Organizations (FBOs) to structure their responses to HIV challenges. This framework is divided into three major interconnected parts. The first is called “inner competency”, the second is “outer competency”, and the third is the “bridge” that provides the link between these two competencies (Parry 2008:9). This frame will be discussed in more detail in Chapter Four.

Inner competence includes “abilities to personalize or internalize the risk of HIV, to recognize the impact and consider long term consequences, to assess the risk factors that increase vulnerability and to confront stigma, discrimination and denial associated with HIV” (Parry 2008:9). A change of attitude and the ability to personalize HIV risk are integral to HIV inner competence. Outer competence includes “theological competence, technical competence, social relevance, inclusiveness, networking, advocacy and compassion and the restoration of dignity and hope” (Parry 2008:45-79). This competence describes skills, activities and knowledge that is crucial in formulating adequate church responses to HIV challenges. However, Parry (2008:9) argues that to move from inner competence to outer competence there must be a bridge that links both competencies. This bridge requires strong leadership, vast knowledge and availability of resources (Parry 2008:9). Parry has described the linking competence as pivotal in the process of moving towards an HIV competent church (Parry 2008:9).

In order for the church to move beyond the challenges of HIV, it requires HIV competent and committed leaders (Parry 2008:8). Parry argues that:

Knowledge alone does not bring about behaviour change. Sound technical know-how, improved infrastructure and human capacity and sufficient resources will still be deficient without committed leadership, recognition of the social drivers of the epidemic and appropriate engagement (2008:8).

This theoretical framework assists in analyzing the appropriate engagement of church leaders in the challenges of ART adherence.

### **1.5 Outline of the study**

The next chapter, Chapter Two, describes the context of the study which is the Vulindlela region. The socioeconomic and developmental issues, the political structural formation, as well as churches and health services available in the area, are outlined in this chapter.

Chapter Three discusses the notion of ART adherence, the historical background of ART worldwide, the history of ART provision in South Africa, and different strategies of ART adherence. Prominent role players and historical events that have culminated in the provision of ART in South Africa are discussed in this chapter.

In Chapter Four Parry's (2008) theoretical framework that underpins this study will be discussed. This framework describes three essential components that lead to an HIV competent church which are discussed in detail in this chapter.

Chapter Five presents the field work research findings, using thematic analysis. The role of Vulindlela church leaders in initiating and supporting ART adherence programmes is discussed.

Chapter Six analyses the study findings as they relate to the theoretical framework.

Chapter Seven concludes the study through provision of a full summary of the key arguments of the study. Possible future research is suggested in this chapter as a way forward.

## **Chapter Two**

### **Context of the study**

#### **2.1 Introduction**

This Chapter discusses the context of the study which is the Vulindlela region. This will include HIV and AIDS prevalence in the area, together with social aspects concerning the HIV epidemic. The involvement of the Vulindlela churches in the struggle against the HIV and AIDS will also be discussed. Furthermore, I will deal with the socio-economic conditions which have an influence on the livelihood of the Vulindlela population.

In addition, this chapter will provide an account of some studies that have been conducted on different issues around HIV and AIDS in the area. This includes a faith-based audit that was conducted in Vulindlela, food security investigations that were conducted in one portion of the Vulindlela region, and an investigative study into the involvement of one particular church denomination.

#### **2.2 The Vulindlela Region**

This study was conducted in the Vulindlela region, a rural area situated approximately 25 km to the South West of the city of Pietermaritzburg (Burgess 1998:313). Pietermaritzburg is the provincial capital of KwaZulu-Natal (Chirowodza et al. 2008:44). According to the Msunduzi Municipality Integrated Development Plan (IDP) (Msunduzi Municipality 2014:56) the region of Vulindlela covers an estimated of 28 000 hectares. Chirowodza et al. (2008:44) report that the population of Vulindlela region was estimated to be 400, 000 in 2004. Recent census data is not immediately available but it can be concluded that the population has grown significantly in the past ten years.

The IDP (Msunduzi Municipality 2013:87) reports that the Vulindlela region is the largest rural settlement in Pietermaritzburg, previously known as Zwartkop Native Location. This was the first area in Natal to be set aside for black residents by the British colonial authorities. The IDP (Msunduzi Municipality 2014:56) reports that, currently,

the Vulindlela region has nine municipal wards with nine politically elected ward councilors and five traditional leaders known as *Amakhosi*.

*Amakhosi* are traditional leaders who are not voted into power but acquire chieftom (*Ubukhosi*) through “customary law in accordance with the Act” (KwaZulu-Natal Traditional Leadership Act No. 5 of 2005) (KwaZulu-Natal Provincial Government 2005:19). According to this Act, *Amakhosi* are highly respected as they possess authority and are regarded as the rightful owners or overseers of the *Ingonyama* Trust land.<sup>1</sup> In addition, they are seen to be custodians of Zulu culture (KwaZulu-Natal Provincial Government 2005:19).

The majority of the land in Vulindlela belongs to the *Ingonyama* Trust (Msunduzi Municipality 2013:88). Uddi environmental planning and development consultants (2011:20) report that it is difficult to differentiate between political and traditional demarcations. Political demarcations are reviewed every five years by the Provincial Demarcation Board (South African Municipal Demarcation Board Act No 27 of 1998:7). Burgess (1998:313) asserts that since there are five *Amakhosi* that share the Vulindlela region, there are also five traditional authorities that are led by the *Amakhosi*. The IDP (Msunduzi Municipality 2013:56) reports that Vulindlela traditional leadership consists of *Amakhosi* for *Mpumuzu* Traditional Authority, *Inadi* Traditional Authority, *Mafunze* Traditional Authority, *Nxamalala* Traditional Authority and *Ximba* Traditional Authority.

The Vulindlela region has seven Primary Health Care (PHC) clinics with nurses providing minor ailment treatment, family planning services, sexually transmitted infection management, voluntary counselling, testing and antenatal care (Kharsany et al. 2012:2).

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<sup>1</sup> The Ingonyama Trust was established in 1994 by the KwaZulu-Natal Ingonyama Trust Act (Act No 3 of 1994) to hold the land in title for the benefit, material welfare and social well-being of the members of the tribes and communities living on the land (see <http://www.ingonyamatrust.org.za/> \_Accessed on 31 October 2014).

### **2.3 Socio-economic and infrastructural development in Vulindlela**

The Vulindlela region is reported to be attracting development projects. Burgess (1998:313) notes that the Vulindlela Water Scheme that was introduced in 1995 was the first developmental project that was initiated in the area by the new democratic government under the Reconstruction and Development Programme (RDP). According to Udidi (2011:20), 45% of the households in the Vulindlela region get their water from a communal water tap. Udidi further indicates that “19% of the households have access to piped water within their dwelling structures and 16% have access to piped water within their yards” (2011:20). However, the Vulindlela region does not have a proper sanitation system. It is argued that “85% of households are still depending on the pit latrine system” (Udidi 2011:20).

Currently in the Vulindlela region there is an ongoing housing project that was first announced on 10<sup>th</sup> March 2011 by the KZN Department of Human Settlements (DOHS).<sup>2</sup> This housing project has been reported as one of the largest single projects in the history of the national housing subsidy scheme – R2.1 billion for 25,000 houses and related work in the rural Vulindlela area of the Msunduzi municipality.<sup>3</sup>

The DOHS has entered into an exclusive contract with a non-profit making company, known as the “Vulindlela Development Association” (VDA)<sup>4</sup>, whose directors are mostly *Amakhosi* from the Vulindlela region. The DOHS’s (2009:1) Enhanced People’s Housing Policy (EHP) is a bottom-up approach that has been recently adopted as a new policy, with the aim of supporting community initiated development through low-cost houses. According to the DOHS (2009:2), EHP is meant to facilitate the process where the

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<sup>2</sup> <http://www.besg.co.za/human-settlements/case-study-in-housing-intervention-vulindlela-rural-housing-project.html>. Accessed on 16 October 2013.

<sup>3</sup> <http://www.besg.co.za/human-settlements/case-study-in-housing-intervention-vulindlela-rural-housing-project.html>. Accessed on 16 October 2013.  
<http://www.besg.co.za/human-settlements/case-study-in-housing-intervention-vulindlela-rural-housing-project.html>. Accessed on 16 October 2013.

DOHS enters into negotiated contracts with accredited non-profit organisations acting as “Community Resource Organisations” (CROs) to support the community and households involved.

Udidi (2011:22) reports that the Vulindlela Housing Project has afforded some community members with well-constructed houses and furnished some with job opportunities. Udidi (2011:22) further argues that the Vulindlela Housing Project has been the main source of employment in the region since the inception of the project.

On the provision of electricity, Udidi says that the “majority of the households within the Vulindlela region have electricity for lighting, heating and cooking” (2011:21). However, it has been reported that there are still some households that rely on “fire wood, candles and paraffin” for household consumption (Udidi 2011:21). An electricity usage survey that was conducted in one of the Vulindlela wards revealed that “electricity is generally expensive; however, 88% of households use electricity for lighting due to the perception that electricity is clean and safe if compared with candles, paraffin and wood” (Udidi 2011:19).

Regarding the transport infrastructure, there are three hierarchies of roads identified in the Vulindlela area, i.e., “Provincial roads, District roads and Local roads” (Msunduzi Municipality IDP 2013: 91). Naidoo (2010: 10) indicates that most of the provincial roads have black tar and are in good condition. In addition to existing provincial roads, Udidi (2011:14) reports that there is a newly constructed road that connects Hilton, Sweetwaters and Taylor’s Halt. However, Naidoo (2010:12) notes that most of the district or local roads are predominantly without tar and most of the local roads are maintained by the local women’s programme called *Zibambele*. Naidoo (2010:13) further asserts that the ongoing construction of roads has created job opportunities in the Vulindlela area.

The IDP (Msunduzi Municipality 2013: 93) reports that the remaining section of the population in the Vulindlela region is employed as casual workers and domestic workers in the nearest affluent towns and suburbs. The IDP (Msunduzi Municipality 2013:93)

further reports that small scale farming for individual subsistence is a main source of food security in the Vulindlela region.

However, a study that was conducted in the Vulindlela region by Vusumuzi Lushaba in 2005 indicated that socioeconomic factors had a negative impact in the Vulindlela region, resulting in food insecurity (2005:80). Lushaba examined various dimensions and characteristics of low income households affected by HIV and AIDS, with a special focus on food security. The main objective of Lushaba's study was to investigate "how households cope with ensuring food security when dealing with HIV and AIDS" (Lushaba 2005:82). Among the findings was the fact that "some families were becoming poorer due to illness and death of their household breadwinners" (2005:82). In his conclusion, Lushaba (2005:84) purports that there is a close relationship between access to food and HIV treatment. Lushaba's study has shown the importance of the link between food security and ART adherence.

## **2.4 HIV and AIDS in Vulindlela**

According to Shisana et al. (2014:36), KwaZulu-Natal has the highest number of HIV positive people in South Africa. While HIV prevalence has increased in all South African provinces, KwaZulu-Natal still records the highest number at 16.9% (Shisana et al. 2014:36). The reported increase of HIV prevalence in KwaZulu-Natal is higher when compared with the 2008 survey which indicated an HIV prevalence rate of 15.8%. Shisana et al. (2014: 108) further show that the provision of ART has delayed the rate of mortality, hence the number of people who are living with HIV has increased.

In the Vulindlela region, Abdool-Karim et al. (cited in Nel et al. 2012: 1) reports that the HIV prevalence rate is high. The survey that was undertaken among different age groups in Vulindlela indicates that women between the ages 30-34 show an HIV prevalence rate of 46.8% (cited in Nel et al. 2012:1). Nel et al in their report assert that "women in Vulindlela are more likely to be infected with HIV than their counterparts in Durban" (Nel et al. 2012:1). Chirowodza et al. (2008:44) argue that in the late 1990s and early 2000s people were dying in the Vulindlela region of AIDS related diseases.

The report of the Umgungundlovu Health District Department of Health also indicates that, in the Vulindlela region, there are currently 6182 people who are enrolled in the ART programme (Umgungundlovu Health District: April – June 2014 report). As stated above, with the introduction of ART the mortality rate has decreased and ART has afforded ART users a long life expectancy (Shisana et al. 2014:108).

Welz et al. (2007:1472) note that an area like the Vulindlela region with a high HIV prevalence suggests an urgent need to allocate adequate resources for HIV prevention and treatment. Some of the resources that might be required include an increased number of primary health care services with the necessary capacity to provide ART services. In addition, Maqutu et al. (2011:01) argue that provision of ART requires strict compliance with the programme to attain best clinical and survival benefits.

However, Mtembu (2008:88) notes that in the Vulindlela region the provision of ART has imposed an increased demand on health care services. Fleischman (2011:2) adds that it is particularly the clinics that are under pressure, with higher workloads, as a result of the fact that NGOs are no longer funded by the President's Emergency Plan for AIDS Relief (PEPFAR) and have had to cut-down their services, while patients are down-referred rather to primary health care facilities that are already overstretched.

## **2.5 Response of the Vulindlela churches to HIV and AIDS**

The high number of visible church buildings in the Vulindlela community suggests that Vulindlela is a religious community. Haddad (2006b: 81) notes that religion “plays an important role in community” life in Vulindlela. Haddad (2006a:2) further indicates that African Initiated Churches (AICs) in the area are greater in number than Mission Initiated Church (MICs). According to an audit of existing faith based organizations concluded in 2005, the Mpumuza community, which is one ward out of nine in the Vulindlela region, “has 34 faith based organizations” (Haddad 2006a:4). There is a lack of statistical evidence pertaining to the number of churches in the greater Vulindlela area. However, participants in this study indicate that Christianity is the dominant religion in the Vulindlela area. These assumptions are based on individual experience and on



socialization in the community. During my fieldwork visits in the Vulindlela region there were many visible church buildings in almost all sub-areas that were visited.

Studies that have been conducted in the Vulindlela region have indicated different responses to HIV and AIDS by the Vulindlela churches. In 2005, Rosemary Mboya conducted a study that investigated the responses of the Holy Trinity Church (Church of England) in Vulindlela. This study, while limited to one denomination, revealed a disagreement between church leaders and those living with HIV as to “what was the preferred church response to HIV and AIDS” (Mboya 2005:51). Mboya (2005:51) argues that the church leaders’ focus was on social and medical factors of the epidemic, while those who were HIV positive paid more attention to how one could live positively with the virus. Mboya’s study further shows that there is a need for “HIV competent church leaders” if the church is to respond constructively to HIV and AIDS (Parry 2008:9).

Another study that was conducted in the Vulindlela region in 2005, found that there was “theological confusion within the ranks of the church leadership” (Haddad 2006b:83). The recommendations made by Haddad (2006b:88) highlighted the urgent need for Vulindlela church leaders to be furnished with the correct information and advice if they were to make a meaningful response to HIV and AIDS. Haddad (2006b:84) indicated that the theological confusion within the leadership of the church was created by personal convictions, cultural beliefs and a lack of theological reflection. There are two examples indicating this theological confusion that I want to highlight. First, there were utterances like “AIDS is a punishment from God” (Haddad 2006b:82). This statement implies that people living with HIV are condemned due to their wrong doing. Chitando (2007b:64) notes that lack of critical reading of the Bible in the context of HIV and underprivileged church leadership have deprived the church and its leadership of the opportunity to respond positively to HIV challenges. Munyika and Jarvinen interpret such utterances as a sign of a “low level of HIV and AIDS competence” (n.d.:39). Secondly, the statement that says “we do not have AIDS in our church” indicates denial and lack of knowledge about HIV transmission (Haddad 2006b:82). These two statements are major contributing factors that fuel stigmatization and discrimination.

Haddad (2006b:83) argues that this theological confusion has paralyzed the response of Vulindlela church leaders to HIV. West (cited in Haddad 2006b:112) notes that people who are living with HIV have lost trust in the church and this has resulted in a situation where HIV positive people prefer to attend Bible studies rather than attend church. This indicates a clear lack of compassion and discrimination in some churches.

Haddad (2006b:88) furthermore indicated that there were many challenges that church leaders in the Vulindlela region were facing when they tried to respond to HIV and AIDS-related issues. In her recommendations, Haddad argued that it was important for the church in Vulindlela to become a redemptive community, a place of hope, healing and redemption (Haddad 2006b:90). The availability of ART brings “hope, healing and redemption” (Haddad 2006b:90). I, therefore, argue that the church and ART have, in some cases, a common mandate. Since ART requires a comprehensive adherence programme, churches in the Vulindlela region have to be in partnership with the work that is being done by ART dispensing agencies.

## **2.6 Conclusion**

The Vulindlela region is predominantly semi-rural but is slowly developing economically. In the past few years different socio-economic projects have been initiated. The Vulindlela region residents have benefited from these developmental projects, some of which have created short-term employment opportunities. In the past twenty years people have benefited by having access to government services, better roads, piped water and increased housing.

Available statistics of HIV prevalence have shown that HIV remains a huge concern in Vulindlela. The large number of people who are currently on ART in Vulindlela suggests that there is a need for sustainable community-based programmes that should be initiated to assist people living with HIV to maintain adherence to treatment. The church has a role to play in these programmes.

The following Chapter will discuss the history of ART in South Africa and adherence to HIV treatment. It will also discuss the contribution made by civil society in lobbying and mobilizing the South African government to scale-up free ART.

## **Chapter Three**

### **Antiretroviral treatment (ART) in South Africa and adherence to ART**

#### **3.1 Introduction**

The previous Chapter has dealt with the context of the study. In order to facilitate an understanding of ART, this Chapter will begin by discussing the history of ART and different clusters of ART that have been approved by the Food and Drugs Administration (FDA) of the United States of America and have been registered in South Africa with the Medicines Control Council of South Africa (MCCSA). Scientists in the medical fraternity have raised different factors that influence adherence and non-adherence to ART which will also be discussed in this chapter.

#### **3.2 The development of ART**

There are three reasons why it is important to discuss the historical development of ART. First, this historical account recognizes the effort that has been made by medical scientists to curb the spread of HIV and to recognize their role as medical scientists. Secondly, it is important to know when ART was started and why there is a variation of ARTs. Lastly, it is important to understand how these different types of ART contribute to treatment adherence or to treatment non-adherence.

In the history of HIV treatment there are four clusters of ARTs. These clusters are made up of different groups of tablets or drugs; each cluster has its own significance in the process of viral suppression. The first drug that was developed is zidovudine (AZT) “for use in patients with advanced HIV” and it was first registered in the United States of America in 1987 by the US Food and Drug Administration (FDA) (Vella et al 2012:1). Maenza and Flexner (1998:2789) report that AZT remained as a mono-therapy up until 1992 when Zalcitabine or Hivid (DDC) was introduced and approved as the second drug. Vella et al (2012:1231) report that in 1994 and 1995 Zertiv or Stavudine (D4T) and Efavirenz

or Lamivudine (3TC) were approved as the third and fourth generations of HIV drugs respectively.

The process of developing HIV drugs as stated above indicates that the development of HIV treatment took almost ten years from 1987 to 1995. Vella et al (2012:1231) note that the first ten years of HIV drugs were overwhelmed by treatment failure and disappointment. The availability of a cluster of drugs that had the capacity to inhibit viral replication was indeed a major breakthrough. These four different pills are classified under the “first cluster that is called Nucleoside Reverse Transcriptase Inhibitors” (NRTIs) (Vella et al 2012: 1231). It is said that “NRTIs have a chemical twist, which ensures that, once taken up by enzyme, the NRTI molecules terminate the building of the viral DNA chain, stalling HIV production” (Vella et al 2012:1232).

Between 1996 and 1998 the second advance in HIV treatment is noted with another cluster of HIV drugs developed and this new group is called “Non-Nucleoside Reverse Transcriptase inhibitors (NNRTIs)” (Vella et al 2012:1232). These ARTs are reported to have worked against viruses that had become resistant to the first cluster (Vella et al 2012:1232). As is stated, “NNRTIs stop the duplication of viral DNA by directly disabling the reverse transcriptase enzyme itself” (Vella et al 2012:1232). This cluster includes “Nevirapine or Viramune (NVP), Delivudine or Rescriptor (DLV) and Efavirenz or Sustiva or Stocrin (EFV)” (Vella et al 2012:1232).

The third cluster is called “protease inhibitors” and this cluster of ART works at the later stage of the HIV life cycle as a “salvage phase” by interfering with the protease enzyme (Vella et al 2012:1233).

In March 2003 a new generation of ART, which is called “fusion inhibitors” (FIs), was registered and there are currently two drugs in this group called “Enfuvirtide or Fuzeon (T-20) and Maraviroc” (Vella et al 2012:1233). Vella et al say “these drugs have to be administered by injection to prevent the HIV from infecting human cells by blocking the viral proteins used to dock into cell membranes” (2012:1233).

The recent revolution in the struggle against HIV was the introduction in 2011 of a single tablet called a “fixed-dose combination” (Vella et al 2012:1233). This tablet is taken once a day and it has been reported to be “associated with even higher treatment success rates, mainly because of improved adherence” (Vella et al 2012:1233).

The effort and contribution of the scientific community in the struggle to transform HIV from being a deadly illness to a chronic and manageable condition has been very significant. Although HIV is still not curable, this effort and contribution has saved thousands of lives.

### **3.3 History of Antiretroviral Treatment roll-out in South Africa**

The history of the roll-out of ART in South Africa is mainly characterized by inaction, moralizing, blaming and denial (van Dyk 2011:1). These four characteristics were rife in political circles, the church and in society at large. The consequences emanating from the recalcitrance of the South African government were disastrous: many people lost their lives unnecessarily (van Dyk 2011:1). When the South African government eventually took the positive decision in 2003 to start the programme to provide people living with HIV with ART, van Dyk asserts that it was “too little too late” (van Dyk 2011:1).

The process of dispensing ART has been very challenging and has been “marked by more than two court litigations” (Heywood 2009: 20). ART provision in South Africa made headlines in 1998 when the South African government refused to provide pregnant women with ART that would prevent mother-to-child transmission of HIV (van Dyk 2011:2). This government action was condemned by civil society at large, including civil society organizations such as the church, and this led to the birth of the Treatment Action Campaign (TAC) (Heywood 2009: 1).

Heywood (2009:1) argues that the formation of the TAC was a joint response of civil society organizations, calling for the right of access to treatment. The campaign was underpinned by a human rights framework and was designed to use a combination of protest, mobilization and legal action (Heywood 2009:2). Heywood (2009:18) furthermore asserts that the TAC was highly supported by two mass-based organizations,

i.e., the Congress of South Africa Trade Unions (COSATU) and the South African Council of Churches (SACC). The TAC was launched as an organization on International Human Rights Day in Cape Town at St George's Cathedral on 10 December 1998 (Heywood 2009:17). This marked the beginning of a lengthy and serious engagement with the South African government and the pharmaceutical companies.

Campaigns organized by the TAC were aimed at forcing the hand of the South African government to expedite the provision of ART and to acknowledge the principle of "right of access to treatment" (Heywood 2009: 16). Heywood (2009:20) asserts that these protest actions resulted in at least five constitutional court battles. First, in 2001 the TAC filed court papers to force the South African government to make Nevirapine available to pregnant women. By then, the HIV levels in pregnant women had already increased to 24.5% (van Dyk 2011:2). (Heywood 2009:9) argues that other legal actions included forcing the South African department of Health to implement plan for the ART roll-out, access to ART for prisoners at Westville prison in KwaZulu-Natal Province, the high price of ART, profit-making by multi-national pharmaceutical companies and, finally, the defense of the Medicines Act against an individual who denounced ART and instead marketed his vitamin pills as therapy for HIV.

Heywood (2009:18) contends that these court cases were marked by mass community mobilization and robust protest and the TAC was victorious in all these cases, which made their campaign a victory for people that were living with HIV:

At its best the TAC model did two things: it created a national social mobilization capable of unifying people to demand the right to health from government and pharmaceutical companies and it created an empowered citizenry at a local level who assisted and demanded the delivery of healthcare services within poor communities as a matter of right and law. TAC's 'narrow' demands for access to ARVs was grounded in the reality of the AIDS epidemic, rather than public health or social justice theory. Pregnant women infected with HIV needed ARV drugs to reduce the risk of HIV transmission to their babies (known as 'vertical transmission'). People living with AIDS needed medicines in order to stay alive (Heywood 2009: 19).

Currently, in South Africa, a large section of the community is living with HIV and is taking medication on a daily basis (Park and Nachman 2010:01). The South African ART programme is growing rapidly, with a large number of people benefiting from the programme (see Chapter One). The 2013 UNAIDS (2013:48) report on the global AIDS epidemic commends the effort and gains made by South Africa. However, the UNAIDS (2013:57) report also suggests that South Africa will need to accelerate the pace at which treatment is provided and also increase the number of recipients of ART in order to eradicate the backlog of people who are still not on HIV treatment.

### **3.4 Evolutionary process of change to guidelines, regimens and protocols**

Since 2004, South Africa has made three significant amendments to the ART guidelines. The first version of ART guidelines was published in 2004, the second version was published in 2010 and the current version was published in 2013. These versions were amended and republished with the objective of improving the effectiveness of the ART programme and to ensure “timeous supply of ART for treatment and prevention according to the Presidential mandates” (DoH 2013:3).

The South African ART guidelines for 2013 (DoH 2013) provided an exposition comprising ten goals to be achieved. These goals include the following:

- (i) Saving lives, improving the quality of life of people living with HIV;
- (ii) Achieving the best health outcomes in the most cost-efficient manner;
- (iii) Implementing nurse-initiated treatment;
- (iv) Decentralizing service delivery to primary health care facilities;
- (v) Integrating services for HIV and other related illnesses;
- (vi) Diagnosing HIV earlier;
- (vii) Preventing HIV disease progression, averting AIDS-related deaths;
- (viii) Retaining patients on lifelong therapy;
- (ix) Preventing new infections among children, adolescents, and adults;
- (x) Mitigating the impact of HIV and AIDS.<sup>5</sup>

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<sup>5</sup> The South African Antiretroviral Treatment Guidelines 2013



Further, the 2013 ART guidelines have introduced a new protocol for ART roll-out and clinical procedures to be observed by health professionals when introducing ART (DoH 2013:4). The new guidelines highlight that treatment can start in patients with CD4 counts lower than 350 cells/mm,<sup>6</sup> those with severe HIV disease (WHO Stage 3 or Stage 4), irrespective of their CD4 count and patients co-infected with drug sensitive or resistant TB, irrespective of their CD4 count. Fixed dose combination (FDC)<sup>7</sup> ART should be given to all patients that are initiated with ART for the first time, to all HIV positive pregnant women irrespective of their CD4 count during pregnancy and during the breastfeeding period, to all patients with other co-morbidities (diabetes, hypertension and respiratory diseases, including TB), to all patients who require switching due to drug toxicity and to patients who are stable on ART and whose viral loads are suppressed.

These guidelines have, thus, introduced a radical change in terms of the clinical benefits of early treatment. Wanjohi argues that early treatment hugely “contributes to total control of viral replication, contributes to prevention of immune system compromise, and lowers the risk of resistance with complete viral suppression and possible decreased risk of HIV transmission” (2009:14). Concordant with Wanjohi, research findings of a study conducted in ten African countries revealed that “HIV patients live longer with early start strategies in low income” (Johansson et al. 2010).

### **3.5 Adherence to ART**

Scholars define adherence to ART differently. The WHO has defined adherence as “the extent to which a patient follows medical instructions” (Sabate 2001:7). Shah defines adherence as “the extent to which time history corresponds to a drug regimen” (2007:55). Paterson et al. define adherence as “taking 95% or more of prescribed medication” (1999:22). Adherence to medication is also known as “compliance with medication” (Kogos 2004:281). I, therefore, draw the inference that, within the context of ART,

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<sup>6</sup> CD4 cells or T-helper cells are a type of white blood cell that fights infection and their count indicates the stage of HIV or AIDS in a patient. Medical professionals refer to the CD4 count to decide when to begin treatment during HIV infection.

<sup>7</sup> Fixed-dose combinations or FDC of antiretrovirals are multiple antiretroviral drugs combined into a single pill, which helps reduce pill burden. They may combine different classes of antiretroviral or contain only a single class

adherence implies how a patient complies with basic instructions, as given by the medical practitioner, and subsequent prescriptions, as per label on the ART container.

Like any other treatment, doctors always remind their patients to complete their medication. HIV treatment or ART is not just any treatment: these drugs the patient has to use for the rest of his or her life. Poor adherence to ART can cost him or her, his or her life. ART adherence is a strong predictor of viral load suppression and improved survival rates among HIV infected individuals (Gazzola et al. 2009:328). As is stated, “high levels of adherence are consistently necessary for reliable viral suppression and prevention of resistance, disease progression, and death” (Mills et al. 2006a:679). Bangsberg et al. (2000:362) note that some studies that have been conducted on adherence have reported that there is a strong relationship between adherence and viral suppression. Current thinking is that “non-adherence will lead to rapid ART resistance as a result of viral replication in the presence of drug pressure” (Bangsberg et al., 2000:364). When a patient develops drug resistance, continuation with the drug will impose another problem because that particular combination of treatment will no longer be effective and will become a strain on the relevant physiological functions of the body.

Based on the professional assertions as expressed above, I conclude that adherence to ART is well recognized to be an essential component of treatment success. Paterson et al. say, “higher levels of adherence are associated with improved virological and clinical outcomes” (1999:1). This means that if the patient complies meticulously with the medical prescription, the ART will impose a high level of resistance to the virus and this will lead to a better quality of life for the patient with proven positive clinical results. Meticulous adherence to the prescribed treatment (value exceeding 95%) is desirable in order to maximize the benefits of ART (Paterson et al. 1999:2). This means taking the correct dose of drugs at the right times and observing any dietary restrictions (Paterson et al., 1999: 2). Anything less than 95% leads to the rapid development of viral resistance and, hence, to much earlier treatment failure (Paterson et al. 1999:2). Thus, if a patient lowers the standardized intake of the medication, the body becomes less resistant to the virus, which leads to its relentless attack and the destruction of white blood cells.

Maqutu et al. (2011:1) argue that ART has dramatically reduced morbidity and mortality among HIV infected individuals. However, Park and Nachman (2010:556) argue that HIV treatment demands high adherence in order to maximize the effects of ART. In simple terms, for effective treatment it is important for HIV positive patients to remember which medication to take at what time, and with what dietary restrictions (Frank and Duncan 2009:1). While it seems as if Maqutu, Park and Nachman and Frank and Duncan are in agreement, it becomes clear from the three respective observations made above that the success of ART is not automatic but is dependent upon high level of adherence and sensitivity to time and dietary parameters.

For any country to have such an unprecedentedly high population of HIV and AIDS infected people is counterproductive towards its Gross Domestic Product (GDP) and, thus, its economy. It is, therefore, important that the high number of South Africans who are recipients of ART should be meticulously self-disciplined in their adherence to the requirements prescribed for antiretroviral medication in order to prevent any failure in ART.

The South African National Health Department continuously strives to stress the importance of achieving optimum adherence to ART. This is evident in its policy document entitled “South African Department of Health Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa” (Nachega et al. 2006:127). Herein it emphasizes strict treatment readiness recommendations for patients who are about to start ART. This document distinguishes five mandatory steps for all HIV positive patients who are recommended and who meet the prescribed criteria to start ART. These steps are as follows:

1. Attend at least three preparation visits at an ART clinic;
2. Demonstrate no active alcohol or other substance abuse;
3. Have no untreated active depression;
4. Have already disclosed their HIV status to at least one friend or family member or have joined a HIV support group;

5. Have accepted their HIV positive status and have insight into the consequences of the HIV infection and the role of ART before starting the HIV treatment (Nachega et al. 2006:127).

It is clear that all these steps are compulsory because HIV treatment is very complicated. It is imperative for each patient who is ready for ART to understand all the complications and have a strong support structure with different strategies to deal with ART complications.

### **3.6 Barriers to ART adherence**

This sub-section outlines the four common barriers to adherence which are reported to be the major contributors to non-adherence (Osterberg and Blaschke 2005:490). These barriers include medical factors, personal factors, social factors and family and community factors (Chesney 2004:172-173). Osterberg and Blaschke (2005:490) warn that these factors have the potential to destroy all the gains that have been achieved over the years in terms of treatment adherence.

#### **3.6.1 Medical factors**

Diagnosis and treatment of any disease is conducted at a health facility. Health facilities are equipped with health care and medication or treatment tools. The process that leads to actual treatment at the facility level is in the form of a triangle (health care worker, patient and medication). If this triangle is broken, or if there is no synergy, the entire process breaks down.

In the case of ART adherence, van Dyk (2011:7) notes that the nature of medication (pill size), including treatment regime, can be the first major factor of non-adherence. Van Dyk (2011:9) argues that ART users who have to take a cocktail of different and a large number of pills at different intervals in a day, struggle to maintain optimum adherence to ART. Van Dyk (2011:9) substantiates this assertion by showing psychologically how each ART pill looks unpleasant and bigger, with the result that it becomes difficult for a patient to keep to a regimen. In addition, there may be side effects that are adding strain to ART users who, in some cases, end up quitting ART intermittently.

Lack of or “poor support by health care workers” has been identified as the second major problem (van Dyk 2011:10). These include medical doctors, nurses, lay counsellors and stock control officers. All these professionals have an important role to play in the whole “treatment triangle” (van Dyk 2011:12). Nozaki et al. (2011:846) emphasize that counsellors are required to ensure maximum preparation of patients before ART can be started and issues of side effects and pill size should be dealt with in a lay counselling environment. Osterberg and Blaschke (2005:490) note that the attitudes of nursing staff and medical doctors failing to discuss the treatment regimen with patients have a predictable non-adherence capacity. Regular out-of-stock encounters are counterproductive for successful ART, because they culminate in an interruption in the continuity of the treatment and ultimately lead to failing the patient (van Dyk 2011:10).

### **3.6.2 Personal factors**

The social enrolment and personal ability to be in control of personal health have a negative impact on ART adherence. ART adherence studies that have been conducted by different scientists have indicated that excessive drinking of alcohol, as well as clinical depression, is of great concern. Van Dyk (2011:10) has discovered that 21% of alcohol users forget to take their medication when intoxicated. Bottonari et al. (2005:723) concur with van Dyk, stating that ART users that report that they forget to take their medication when they use alcohol or when they feel depressed, ranges in the region of 24%.

Perceived lack of control over personal health is yet another barrier to ART adherence. Van Dyk (2011:13) argues that 44% of participants who participated in his adherence study had a strong belief that what had happened to them was determined by factors beyond their control. Those factors included cultural beliefs, gender imbalance and the unpredictable nature of HIV.

### **3.6.3 Family and Community factors**

The lack of a family support system is one of the major contributors to non-adherence. Mills et al. (2006b:2025) argue that those patients who are not living alone, or have a partner, or social and family support, or peer interaction, achieve optimal adherence. Nachega et al. (2006:127) indicate that poor social networks predict poor adherence to ART and these factors have a direct correlation with HIV disclosure. If the ART user does not disclose that he or she is using ART, out of fear of discrimination, this might also lead to non-adherence.

Nachega et al. (2006:132) further assert that stigmatization and discrimination are major indicators of a lack of family and community support, with HIV still associated with individual moral behaviour and death. Nachega et al. (2006:132) claim that people who are using ART sometimes hide that they are HIV infected, because they are afraid of family and community members who will be judgmental and prejudiced towards them. Consequently, people who are using ART live in fear of rejection and their HIV status is usually not discussed. Mills et al. (2006a:687) note that people with this problem often fail to take their medication if they are surrounded by family or community members.

Mills et al. (2006a:687) argue that it is common practice for people who have not disclosed their status to avoid taking the medication in public places or in full view of other people. Mills et al. (2006a:687) note that avoiding people leads to forgetting to take medication at the specified times. Van Dyk (2011:14) argues that 60% of ART users hide the fact that they are using ART because their communities discourage the idea of being “open” about discussing HIV and ART.

It is my experience that if a community is less educated about the need for accepting people who are using ART, it leads to discrimination. A favorable disclosure environment should be created in such a way that people who are using ART should feel free to disclose this to a family member and or a church member. This will require advanced family and community education.

### **3.6.4 Socio-economic factors**

Nokazi et al. note that socio-economic factors include, inter alia, “poverty, long distance to health care facilities, lack of education and ART adherence knowledge, etc” (2011:831). According to Nokazi et al. (2011:831), “the situation for ART users in rural areas differs substantially from those in urban areas or in developed countries”.

These conditions that Nozaki et al. (2011:831) highlight have, directly or indirectly, a negative effect on the process of compliance. Unavailability of healthy diets and clean drinking water are some of the examples that negatively impact on meticulous ART adherence. Thus, for effective adherence to ART, socio-economic factors must be considered by all stakeholders.

Ford et al. (2009:2068) note that access to health facilities is another obstacle that hinders adherence to ART. Both Ford et al. (2009:2068) and Nozaki et al. (2011:834) argue that the proximity of health care providers to the patient’s home or place of work, the expense of reaching the facility, intervals between appointments, clinic opening and closing hours, long waiting hours in queues, lack of services such as child care, privacy and confidentiality are critical social issues that also contribute to non-adherence.

This lack of access to health facilities provides an ideal opportunity for church leaders to make available their facilities, such as church buildings and halls, which would otherwise be unutilized during the week. These facilities can be placed at the disposal of the Department of Health in the different provinces to the advantage of rural people.

Furthermore, Mills et al. (2006a: 680) and Nozaki et al. (2011:834) are in agreement that the lack of education and ART adherence knowledge is yet another social factor identified as a contributing factor to non-adherence to treatment. These scholars argue that low levels of education may impact on a patient’s ability to adhere, while high levels of education have a positive impact on ART adherence.

Van Dyk (2011:13) says that treatment literacy has a major role to play to ensure a clear understanding of the treatment and the importance of adherence. He argues that under

normal circumstances, ART users generally receive training through treatment literacy classes, but some fail to understand the relationship between non-adherence, drug resistance and drug failure (van Dyk 2011:13). “The common perception amongst ART users is that if drug resistance develops, health care workers will simple prescribe another regiment of drug” (van Dyk 2011:13).

It is precisely in the area of treatment literacy classes that church leaders can be innovative, through partnership with relevant stakeholders. Together these partners can devise strategic plans to incorporate the skills and the expertise of trained teachers and facilitators. These professionals will be assigned to equip and empower ART users with knowledge of the implications of non-adherence, the process involved in the development of drug resistance, and when drug failure will occur.

### **3.7 Monitoring of ART adherence**

According to Nunes et al. (2009:178) there are many different strategies which have been researched with the aim of ensuring optimum adherence to medication and to minimize non-adherence trends. As a result, a number of strategies with regard to measuring adherence have been developed. Nunes et al. (2009:178) argue that these strategies are divided into direct and indirect strategies. Direct strategies include the “examination of blood, urine or other bodily fluids in a search for medicine or a metabolite” (Nunes et al. 2009:178). Some of the strategies which are described as indirect strategies involve “pill count, smart box, directly observed treatment, self-reporting, prescription reordering, pharmacy refill records and electronic medicine monitoring” (Nunes et al. 2009:178). I will explore five of these that have emerged as strategies that are in line with the objectives of this study, as discussed in Chapter One. The strategies are as follows: pill count, medication event monitoring system, self-reporting, directly observed therapy and community support programmes.

#### **3.7.1 Pill Count**

Cinti et al. (2000:4) explain that pill count refers to the measuring of compliance by comparing the number of doses remaining in a container with the number of doses that



should remain if the patient's compliance were perfect. Van Dyk (2011:7) indicates that pill count is a popular adherence measurement strategy that is commonly used in public health facilities in South Africa.

According to Maqutu et al. (2011:1466), the pill count strategy works well when “patients are provided with more medication than required, i.e., tablets are dispensed in multiples of 30, whereas visits are scheduled in multiples of 28 days”. Maqutu continues to say “patients are asked to bring all medication bottles or containers and unused pills to each clinic visit, but are not told that the remaining pills are to be counted” (2011:1466).

The advantages of using pill count as an adherence measurement is the “simplicity and empiric nature of this strategy” (Osterberg and Blaschke 2005:488). However, Kogos (2004:281) draws our attention to the fact that the pill count can provide an overestimation of compliance if the patient is aware that a pill count is going to be conducted: patients may remove the excess doses and discard them. Kogos (2004:281) also draws our attention to another drawback to this method: it cannot be verified that a dose removed from a container was actually consumed, or that it was consumed at the correct time.

### **3.7.2 Self-reporting**

The Self-reporting strategy falls under the shared “decision-making (SMD) model” (Elwyn et al. 2012:1361). Elwyn et al. indicate that in this model the information exchange is a two-way process that involves “consultation, deliberation and decision-making” (2012: 1361). Decisions are made by both the healthcare professional and the patient. Elwyn et al. (2012:1361) further note that the patient receives all the information about his or her illness and all relevant information about treatment and then the patient engages medical professionals about his or her preferences. Elwyn et al. (2012:1361) assert that preferences will include the preferred regimen of drugs and times of taking medications. In this case, the patient is actively involved in making decisions and the communication is a two-way process.

The shared decision-making model can easily be understood as a treatment triangle process where there is “(i) a sufficient consensus about type of treatment, (ii) when the treatment is to be taken and (iii) how the treatment is used “(Nunes et al. 2009: 55).

Garfield et al. (2011:2) state that the process of self-reporting requires the patient first to keep a strict logbook of how medication was taken and secondly, it requires the medical professional to conduct regular interviews on pre-set dates. “On the relevant dates the patient will submit his or her logbook to the medical professional” (Garfield et al. 2011:2). Garfield asserts that self-reporting may be considered the most “appropriate method for monitoring adherence as part of the continuous quality improvement in clinical practice” (2011:2). The adherence strategy largely measures the patient’s record of all the medication he or she has absorbed.

The self-reporting adherence strategy has been under scrutiny by various researchers. Some of those researchers have discovered that it has certain advantages and disadvantages.

Nunes et al. (2009:179) report that a study that was conducted by the National Collaborating Centre for Primary Care (NCCPC) discovered that self-reporting is the most simple and inexpensive method of measuring adherence. Osterberg and Blaschke (2005:488) concur with this view and argue that patient diaries and assessment of clinical responses are relatively easy to use.

As much as the self-reporting strategy has received endorsement by many researchers, there are other competing views which point to the disadvantages of self-reporting. The strategy of “self-reporting has the problem of overestimating adherence and this inaccuracy can be caused by a particular bias when patients are trying to recall the number of pills they have swallowed” (Garfield et al. 2011:2; Nunes et al. 2009:180; and Osterberg and Blaschke. 2005:488). In addition to the argument raised against self-reporting, Garfield et al. (2011:2) have noted that people from rural communities, where illiteracy is rife, will find it difficult to keep an accurate record of the statistics that refer to the quantities of the medication that they have consumed.

### **3.7.3 Medication Event Monitoring System (MEMS)**

The Medication Event Monitoring System (MEMS) is an adherence strategy that uses a “microchip housed in a plastic cap that fits on standard medication bottles” (Cinti et al. 2000:2). Cinti et al. say “the chip records the date and time when the medication bottle was opened and closed” (2000:2). As stated, the purpose will “invariably correspond with the times that the patient has taken his or her medication and when the patient returns to the health facility for his or her next appointment, the MEMS cap is placed on a communicator that reads the data on a microchip” (Cinti et al. 2000:2).

MEMS have been available since 1990 and have been used recently to monitor HIV positive patients receiving ART regimens. Osterberg and Blaschke (2005:489) argue that electronic medication monitoring devices have provided very detailed information about the patterns of medication-taking behaviour. MEMS provides three indicators of adherence that reflect various aspects of medication-taking behaviour: 1) dose-count, the percentage of prescribed doses taken; 2) dose-days, the percentage of days the correct number of doses taken; and 3) dose-time, the percentage of doses taken on schedule (Wu et al 2008:2).

MEMS have advantages and disadvantages like other adherence strategies. Cinti et al. argue that the advantage of MEMS is that “when used properly, it is an excellent day-to-day monitor of medication dosing patterns” (2000:2). Burnier asserts that the “most deviations in medication taking occur as omission of doses rather than additions or delays in the timing of doses” (cited in Beena and Jose 2011:156).

While MEMS may be a reliable treatment adherence intervention, it is a very expensive undertaking when compared with other medications used in primary health care facilities. Wu et al. (2008:7) is of the opinion that even though a patient may open the bottle or record that the correct dosage was taken, there is no guarantee that the patient has indeed actually taken the correct dose as indicated. Cinti et al. (2000:2) furthermore argue that

MEMS is a cumbersome device for patients and has proven to be unreliable when a patient removes multiple doses from the MEMS container at one time.

The MEMS invention is a highly sophisticated electronic intervention with the capacity to reflect the exact data needed to monitor a patient's self-discipline in the taking of medication and, subsequently, the success or failure of the medication to improve the health and quality of life of the patient. It is, however, an expensive invention and given the HIV infected population in South Africa, one can draw the inference that this device will not only place a strain on the budget of the National Health Department, but also on the economy of South Africa. This argument is exacerbated when patients deliberately try to beat the system through ill-discipline and engage in behaviour that prevents this device, acquired at an exorbitant cost, to lend itself to accuracy and to the improved health of the patient.

### **3.7.4 Directly Observed Therapy**

Directly Observed Therapy (DOT) refers to a medical strategy whereby the prescribed medication is taken by the patient in the presence of an observing health care worker or a designated individual (Ford et al. 2009:14). Ford et al. (2009:14) assert that this is a well-known and trustworthy strategy. According to Ford et al. (2009:14) DOT was invented as a support strategy to enhance treatment adherence in tuberculosis patients. Calder (2006:2064) says that the success of this intervention was so immense that it was eventually adopted as part of the global tuberculosis control strategy.

Researchers have expressed diverse opinions pertaining to the use of DOT as a treatment adherence strategy. Ford et al. (2009:2068) acknowledge the benefits involved in DOT which, according to them, "ensures optimum treatment adherence", but requires a strong support system. Osterberg and Blaschke (2005:488) rate DOT as the most accurate treatment adherence strategy.

DOT is acknowledged as a "feasible and effective medical intervention" (Mills et al. 2006a:688). Ford et al. (2009:2069) observe its performance in the quest to attain high

levels of ART adherence in areas where HIV status disclosures are high. They highlight its cost-effectiveness and the eradication of long travel distance to health care facilities as beneficial, especially to the contexts where resources are limited (Ford et al. 2009:2069).

Mills et al. (2006a:688), however, identify multiple disadvantages associated with DOT and their argument is that while DOT may be effective for those who have declared their HIV status, an alternative strategy is needed to assist those who have not declared their HIV status, fearing stigmatization, discrimination or even violence engendered by their culture.

DOT seems to have had a high level of success since its inception and in use against other diseases. Its adoption as a workable strategy in the quest to conquer the scourge of the HIV and AIDS pandemic proves its effectiveness both in terms of enhancing the quality of life of the patient, as well as overcoming other debilitating barriers such as travelling long distances. Continued research needs to find a strategy that creates a safe, confidential and secure environment for those who still fear to declare their HIV status. At the same time, more needs to be done to minimize the culture of stigmatization, discrimination and violence.

### **3.7.5 Community support programmes**

Community support programmes include a combination of different strategies that are based in the community. Wouters et al. (2012:1) describe community support programmes as a process where the community gets involved in supporting HIV related initiatives. Wouters et al. (2012:1) further indicate that community support programmes are an opportunity to be explored in the process of addressing ART adherence. Snow is in agreement with Wouters et al. and argues that “engaging individuals and communities effectively around ART can improve health outcomes, contribute to greater understanding of adherence benefits, lead to a stronger belief in the effectiveness of ART, and reduce stigma in the community” (2010:14).

Four strategies are incorporated into community support programmes. The first strategy is the family and friends support system. Hlophe (2010:20) notes that the role of family

members and friends in supporting an HIV positive family member is critical in order to provide physical, emotional and instrumental support. Li is of the opinion that “family support starts with the disclosure process, and may include financial assistance, help with daily activities, medical assistance, and psychological support” (2009:11). In addition, Hall says, “friends have also been found to be an important source of social support” (cited in Hlophe 2010:29). The presence and the role of family and friends in the life of the ART user is important to the process of treatment adherence, as family and friends should become a first line of support and protection.

The second strategy is the “treatment buddy support system” (Wouters et al. 2012:4). According to Zuyderduin et al. (2008:6) a treatment buddy is a friend or someone that is assigned to provide treatment support to ensure meticulous and optimum treatment adherence. In addition, Hlophe (2010:30) notes that treatment buddies are a credible source of information and they play a vital role in reminding ART users to take their relevant dosage timeously. Wouters et al. (2012:11) assert that treatment buddies have the capability to stimulate and facilitate the process of disclosure to family members and to the public through the emotional support they constantly provide to the ART user. These studies conducted by Wouters et al., Zuyderduin et al. and Hlophe indicate that the role of treatment buddies is of great significance to enhance optimum ART adherence. The treatment buddy system is a vital strategy providing companionship to the ART users and, thus, eliminating the element of loneliness, while enhancing virological suppression.

The third strategy is the “psychosocial support group” or “support group” (Wouters et al. 2012: 13; Hlophe 2010:29). It is argued that the “support group is a structure or meeting where people with common challenges, concerns and needs come together to support one another in various aspects of daily living and functioning” (Hlophe 2010:29). In addition, Luque-Fernandez et al. are of the opinion that “support groups are an essential mechanism of service delivery, including dispensing of ART and symptom screening, and a means of decongesting formal health services” (2013:2). The argument made by Hlophe and Luque-Fernandez et al. indicates that support groups are a safe space for ART users and are an effective strategy to enhance positive living and ART adherence

through community participation. The church could play an important role in initiating such support groups.

The final strategy is “treatment adherence clubs” (Wilkinson 2013:1). The design and the approach that is used to formulate ART adherence clubs are similar to that of psychosocial support groups. However, Wilkinson says that “treatment adherence clubs are specifically meant to provide patient-friendly access to antiretroviral treatment for clinically stable patients” (2013:1). Wilkinson (2013:1) indicates that these clubs are a vehicle to bridge the gap between the health care facility and ART users, since ARTs are delivered directly to the meeting venues. This innovation has been instrumental in reducing travelling costs to health care facilities and it has decreased the workload on health care workers. Wilkinson (2013:1) further asserts that participating members of the club become a strong support system that provides emotional support to other members as they share their ART stories and experiences. In agreement with ART adherence clubs, Wouters et al. (2012:2) assert that ART users should be empowered towards self-management of their chronic illness and this process should include peer counselling, ART literacy and chronic disease management skills.

Community support programmes can be conceptualized as a fundamental aspect of enhancing ART adherence. The research indicates that community support programmes are cost effective, culturally relevant and have practical benefits for ART users. Community support programmes have been found to promote quality of life through community participation. It is my considered opinion that community support programmes can play a vital role in assisting the church in its relevant response to HIV.

### **3.8 Conclusion**

In this chapter, I have discussed the history of ART including contributions made by different sectors in mobilizing the South African government to provide ART to eligible individuals. Furthermore, I have discussed the fundamental aspects of ART adherence including different factors that have the potential to thwart optimum adherence to ART.

Regardless of the severity of factors that diminish adherence to ART, there are strategies to enhance optimum adherence that have been found to be effective. Treatment adherence strategies are provided in many different forms including pill count, the self-reporting system, the medication event monitoring system, directly observed therapy and community support programmes. Some of these strategies are clinic-based and others are community-based strategies. All community-based strategies have the potential to be adopted by the church in order to maximize the response of the church to HIV.

The following Chapter will discuss the theoretical framework underpinning this study that focuses on an effective response of the church to the HIV epidemic.



## **Chapter Four**

### **Becoming an HIV Competent Church**

#### **4.1 Introduction**

The previous Chapter discussed the history of ART in South Africa, ART roll-out and ART adherence. In this Chapter, I seek to understand an appropriate response by the church to the HIV epidemic and, particularly, to the need for involvement in ART adherence. I outline the work of Sue Parry (2008) who builds on the idea of an “HIV Competent Church”. She has developed a framework for action which can lead to a more adequate and holistic response by churches to the HIV epidemic.

Parry (2008:8) asserts that her framework is relevant since HIV and AIDS remains a complex issue with all the effort and energy that has already been invested in HIV and AIDS programmes failing to yield the desired outcomes. Parry (2008:15) notes that the main shortfall of the church is a resistance to build on existing strengths that will assist it to respond effectively and efficiently to HIV. Thus, she has constructed a framework to assist the church in becoming more “HIV competent”.

#### **4.2 An HIV competent church**

Scholars such as Chitando (2007a), Parry (2008) and Happonen et al. (n.d.) and faith-based international organizations such as the World Council of Churches (2007) and Churches United Against HIV and AIDS in Eastern and Southern Africa (2009) have interdependently defined and discussed the concept of a “HIV competent church” with different emphases.

Chitando defines the HIV competent church as a church with “sharp minds” (2007b:1). This definition is broadly explained in three analogical themes. Chitando says that the competent church should have “friendly feet to journey with individuals and communities living with HIV”, should have “warm hearts to demonstrate compassion” and should have “anointed hands to effect healing”(2007b:1). The HIV competent church must, therefore, demonstrate solidarity and unconditional love through accepting the reality of

HIV, through lobbying on behalf of people living with HIV and being part of their everyday struggle.

Following the analogical definition of the HIV competent church as outlined by Chitando (2007b), Parry (2008:20) defines the HIV competent church as a church that is willing to acknowledge the extent of the damage caused by HIV and the likelihood of being exposed to HIV. Parry (2008:20) argues that to a great extent an HIV competent church should accept all its failures of the past, including denial, stigmatization and discrimination against people living with HIV. According to Parry (2008:20), a true reflection of the HIV competent church is a church with compassion, built on a profound theological response to HIV. Parry (2008:20) argues that this requires strong leadership, with adequate knowledge and a better use of available resources.

Happonen et al. (n.d.:79) also describe the HIV competent church as a church with compassion. This description is partly in agreement with the definition asserted by Chitando (2007b), as discussed above. Happonen et al. (n.d.:79) further equate an HIV competent church with a church that practices a theology of love. They say that since the “theology of loving and caring is found throughout the Bible”, compassion should be central to the Christian community (Happonen et al. n.d.:79). As is stated, “an HIV competent church should be able to provide compassionate HIV counselling and psycho-spiritual care to people living with HIV” (Happonen et al. n.d.:79). In essence, an HIV competent church should resonate with Christian values, with compassion being at the heart of the Christian community.

In addition to these definitions, the WCC characterises the HIV competent church as “a church that recognises and accepts the imperatives of HIV to itself and communities” (cited in Parry 2008:88). The WCC (cited in Parry 2008:88) further argues that the response of a HIV competent church should portray qualities of the prophetic church, through Christian values such as love, joy, peace, kindness, goodness, gentleness, faithfulness and self-control.

The Churches United Against HIV & AIDS in Eastern and Southern Africa (CUAHA) (Happonen et al. n.d.:5) is in agreement with the WCC and widely uses the concept of an HIV competent church in their programmes, to empower church leaders and faith-based organisations to develop a better response to HIV and AIDS.

In the context of ART the notion of compassion should be at the heart of the HIV competent church. The HIV competent church is, consequently, a church that is inclined towards a new HIV and AIDS attitude, a church that admits to the truth, particularly in the context of having been uncompassionate, and a church with a leadership that is committed to acquiring accurate and adequate HIV knowledge.

The notion of compassion is a common denominator across all definitions that I have discussed in this section. For the church to be HIV competent it should demonstrate sufficient understanding of the sufferings of people living with HIV and indicate a willingness to stand in solidarity.

Parry (2008:21) has developed and characterized three components that need to be addressed in order to become an HIV competent church. These components comprise of inner competence, outer competence, and a bridge between the two. These three components will strengthen the response of the church to HIV and AIDS.

### **4.3 Inner HIV competence**

Inner HIV competence is a new trajectory of reconstructing church theology, values and attitudes. The current theology, values and attitudes of the church have failed to contribute in formulating a positive response on HIV related issues. Inner HIV competence assists the church to rethink its stance on HIV. This process ensures deeper self-introspection by the church, which involves accepting the risk of HIV and accepting its failures in the past to respond adequately to HIV related issues.

Inner HIV competence involves two components. The first component is “acknowledging the scope and risk of contracting HIV” (Parry 2008:24). This component includes four principles: the first principle involves personalising and internalising the challenge of HIV (Parry 2008:24). This process emphasises the need to accept that we are not

immune to contracting HIV. The church needs to accept and acknowledge that some members are living with HIV and others are on ART: “if one of our members has HIV then we are infected” (Parry 2008:24). This personalization of the risk of HIV eliminates the element of denying that the church has HIV. This process allows the church to begin to ask critical questions about its existence, teachings, values and attitudes in the context of HIV. Internalization of the HIV challenge enables the church to recognise its failures in becoming a safe space for ART adherence programmes, as discussed in Chapter Three.

Chitando pronounces his disapproval of the past “tendencies of the church to reduce HIV and AIDS to the issue of personal morality” (2007a:20). He agrees with Parry about the failures of the church to personalize HIV challenges and he says that this “has in many ways prevented the church from being the welcoming and loving community it is meant to be” (2007a:20). If our personal awareness is accurate in terms of acceptance, attitudes and approaches to HIV, our response to HIV will be accurate as well.

The second principle of acknowledging the scope and risk of HIV is to recognize the impact and to consider the long-term consequences of HIV (Parry 2008:24). As is stated, “HIV is a major threat to human development” (Parry 2008:24). The church must be acquainted with the current damage that HIV is causing and should give careful consideration to future damage. Parry (2008:24) asserts that, as part of the process of recognising the impact of the epidemic, the church should seek to understand the HIV prevalence and incidence in families, communities, and within the ranks of the church. According to Parry, this process will assist the church to ascertain the destruction in all developmental spheres, including the “education sector, to the country’s economic growth, and to health service delivery” (2008:24). The recognition of the short and long term negative impact of the epidemic will strengthen the church’s positive response to HIV. The church will begin to recognise the vulnerability of its members and start to appreciate the role of HIV treatment. This will encourage the church’s support of ART programmes.

The third principle is a call for “assessing the risk factors that are increasing HIV vulnerability” (Parry 2008:25). There are six risk factors that are involved in this

principle. The first of these is “structural and social risks”, which includes individual behaviour being influenced by financial stability, social control, order and social cohesion (Parry 2008:25). Contextual factors determine risky sexual behaviour, including the economic dependence of women on men, women’s cultural subordination and, therefore, inability to negotiate safe sex (Parry 2008:25). She further argues that discrimination against women, inequalities, lower educational status and social norms are major contributing risk factors that accelerate the rate of HIV infection (2008:25). Unequal power relationships and socialisation have contributed to women’s vulnerability to contract HIV and, since HIV is transmitted primarily through sex, the church must address these issues (Parry 2008:25).

The second risk factor is “gender imbalance and norms” which include boy child and girl child upbringing and gender roles (Parry 2008:26). Cultural teachings such as girls being thought to be subservient and submissive to men have limited their control over sexual choices (Parry 2008:26). These have instilled a mentality of superiority and have encouraged boys to be dominant in relationships (Parry 2008: 26). Gender imbalance is one risk factor that exposes both girls and boys to the risk of contracting HIV (Parry 2008:26). The fundamental role of the church with this risk factor is to understand and acknowledge the vulnerability of both sexes (Parry 2008:26). Chitando is in agreement with Parry: he notes that “a cocktail of biological, cultural and socioeconomic factors contributes to women’s greater vulnerability to HIV” (cited in Chitando 2007b:7). The church should admit and acknowledge that gender imbalance and social norms are contributing factors that the escalate risk of HIV.

The third risk factor is “Gender-Based Violence (GBV)” which includes harmful customs and behaviour against girls, women and children (Parry 2008:26). This risk factor has a devastating impact on women and children, as it is facilitates the spread of HIV. Parry says “gender based violence must be acknowledged and addressed if prevention strategies are to have any meaningful effect” (2008:26). Concurring with Parry, Chitando argues that “AIDS competent churches must express outrage when women are subjected to any form of physical or psychological violence” (2007b:20). The church cannot ignore

the fact that women are subjected to HIV infection through rape and other forms of gender-based violence.

The fourth risk factor is “negative cultural practices” (Parry 2008: 26). This includes underage marriages, female genital mutilation, unhygienic male circumcision, wife inheritance and widow cleansing (Parry 2008:26). The church should acknowledge and discourage “negative cultural practices” as this is one of the risk factors that “scripts women’s and men’s sexual roles” (Parry 2008:26).

The fifth risk factor is “economic risks” (Parry 2008:27). This includes poverty and food insecurity, health access and services, housing and vital transport access (Parry 2008:27). The economic risk factor is a driver that “influences choices people make, particularly in the case of women resorting to survival transactional sex-work” (Parry 2008:27). Churches should not be afraid to confront the frontiers of “economic risks that have the potential to facilitate the spread of HIV” and ART non-adherence (Parry 2008:27). In Chapter Three I discussed the negative impact of the economic risk factor as a major facilitator of ART non-adherence. The economic risk factor not only facilitates the spread of HIV, but in the context of ART, it is a critical factor that predicts non-adherence to treatment. Poor people have difficulty in accessing health care facilities, as a result of inadequate transport money, and in meeting dietary requirements as prescribed by health workers and they resort to not taking their medication meticulously.

The sixth and final risk factor is “political challenges” (Parry 2008:27). This includes difficulty in accessing health-care “resources and services due to violence, restricted access to services based on political affiliations and a lack of an enabling environment in which to provide services and support” (Parry 2008:27). It is stated that “conflicts generate and entrench many of the conditions and human rights abuses in which the HIV epidemic flourishes” (Parry 2008:27).

The fourth principle of acknowledging the scope and risk of HIV focuses on the reality posed by stigmatization and discrimination. Parry describes stigma, discrimination and denial as a “reflection of human values, heart issues, and stems from fear, ignorance,

anxieties, prejudices and rigid attitudes” (2008:27). The church must accept that stigma has its roots in the traditional theology of the church. Those churches that are fuelling stigma through their selective usage of the Bible must realize that they are still caught up in a rigid theology and that that particular theology will obstruct the determination to combat HIV. In the era of HIV, traditional and rigid theology needs transformation and new truths (Chitando 2007a:20). This includes understanding and acknowledging the fact that stigma, discrimination and denial are critical facilitators of poor ART adherence. In Chapter Three I discussed stigma and discrimination as one of the factors that prohibits optimum ART adherence.

The second component of inner HIV competence is to “accept the imperative to respond appropriately and with compassion” (Parry 2008:29). This includes clear understanding and acceptance of inner issues, with determination to formulate “informed, evidence-based and compassionate” responses (Parry 2008:29). This process begins by acknowledging that HIV is not a stand-alone health issue but there are social aspects and economic aspects that are involved (Parry 2008:29). A God-given mandate to respond adequately to HIV should be a combination prevention strategy that includes care, support and HIV treatment (Parry 2008:29). But HIV treatment will fail if ART non-adherence factors, as discussed in Chapter Three, are not understood and acknowledged. Parry argues that the desired response should incorporate five aspects in order to be proactive and reactive (2008:29). These include preventing new HIV infections, strengthening quality of life, eradicating stigma, discrimination and denial, mitigating against the impact of HIV and compassionately restoring dignity and hope to our communities (Parry 2008:29). While inner HIV competence is a new trajectory of reconstructing church theology, values and attitudes, the church requires basic and practical skill, which is outer competence.

#### **4.4 Outer HIV Competence**

The previous section discussed two components that constitute inner HIV competence that is needed if the church is to move towards becoming HIV competent. However, inner competence will not exclusively lead to an HIV competent church. Outer competence

also has a pivotal role to play in building an adequate response by the church to HIV (Parry 2008:44).

Parry (2008:9) asserts that outer competence can be understood as basic and relevant skills that enable a practical response by the church to HIV. Additionally, “outer competence moves through theological and technical competence to looking at the relevance of our response to the scale of the problem and to sustainability and scale-up” (Parry 2008:9).

Outer competence involves seven components. The first component is theological competence with regard to HIV (Parry 2008:44). This component emphasises the necessity of theological reflection on a range of difficult questions that challenge theological rigidity and the image of God in the context of HIV. However, Parry argues that “we may never find answers that satisfy us completely, but a church that is theologically competent will never tire in its search” (2008:49). Being theologically competent is calling the church to proclaim the gospel of life rather than one of condemnation.

In order to become theologically competent the church needs to seek to construct a life-giving theology of HIV. This will enable the church to formulate an adequate theological response to the HIV epidemic. The church should be able to offer theological responses to the questions that challenge their faith through the HIV epidemic. Parry argues that “HIV and AIDS invite us to discover what kind of God we need” (2008:46). This invitation includes two opportunities for critical reflection. The first is to consider “how we bring our theological and spiritual understanding of our relationship with God to bear in our work of prevention” (Parry 2008:46). The second is to re-think “how we effectively bring Christ’s healing presence to those infected and affected” (Parry 2008: 46). These questions challenge the church to discover the kind of God that is needed in the era of HIV. While the church is wrestling with these theological questions, seeking to become theologically competent, Parry suggests nine principles that the church needs to explore in the process of formulating a life-giving theology of HIV. These include a deeper understanding of God, enabling the church to view HIV from God’s perspective



(Parry 2008:49). From this perspective the nature of God is revealed through HIV. Parry (2008:49) further asserts that the significance of God's creation and how gender relations are constructed should be examined in the process of developing a life-giving theology of HIV. God's perspective on creation is that it is good and that both male and female are to participate in this goodness. To be a participant in God's creation, a vision of love and redemption is what defines our humanity (Nurnberger 1997:3-4). Thus, when discussing the concept of sin and punishment, it must be done within the framework of a redemptive vision of humanity (Parry 2008:49). A truly life-giving theology of HIV enables the church to deal with myths surrounding HIV and judgemental statements that lead to discrimination against those who are HIV positive. As discussed in Chapter One, linking HIV with sin and punishment is a missed opportunity for the church to respond positively to the devastating threats and challenges posed by the epidemic. Furthermore, the church needs to find ways of studying the Bible from a non-judgemental perspective. In the past, the church used the Bible to judge and condemn people who were HIV infected, leading to their rejection. Parry asserts that becoming a theologically competent church includes proclaiming "forgiveness as a route to inner peace and harmony" (2008: 49). It is the role of the church to show compassion and to embrace people living with HIV with unconditional love, as discussed in Section 4.2.

Parry further argues that churches can "become more theologically competent if they learn to ask the right kind of questions and to courageously reflect upon them" (2008:49). Amongst others, this includes challenging all Christians "to embrace the gospel message and to live it out in all areas of life. To live faith, not simply to talk about it" (Parry 2008:49). Becoming more theologically competent is a new trajectory that challenges the church to develop a theological discourse that is more life-giving in the era of HIV. This theological discourse will encourage "those living with and affected by HIV to come and share their stories" (Parry 2008:49). HIV is, thus, demanding the church to become a more prophetic community where a commitment to reflect love, compassion and action is at the centre.

The second outer competence is a call for the church to develop “technical competence” (Parry 2008:50). Becoming theologically competent requires technical competence. This involves the ability to “plan, implement, coordinate, monitor and evaluate HIV programmes effectively” (Parry 2008:50). An adequate church response to HIV should have a proper plan with simple and achievable objectives. A well-structured and coordinated church-based HIV programme should be built on strong principles that include “vision, mission and values” (Parry 2008:51). Vision, mission and values will provide direction for the endeavours of the church. There must be a clear explanation as to why the church is embarking on this trajectory, what it is that the church wants to achieve and how this will be achieved (Parry 2008:51). Technical competence begins by formulating HIV policy built on existing policies that can bring transformation in the attitude of church leadership and members (Parry 2008:51). This process requires consultation with different professionals and stakeholders in order to improve on the shortfalls of existing policies (Parry 2008:51). Church-based HIV policy should uphold Christian values but be consistent with the laws of the country (Parry 2008:51). As discussed in Chapter Three, church-based HIV policies will assist the church in mainstreaming HIV into their existing programmes. In the context of ART adherence, church-based HIV policies should provide technical competence that is compatible with the dynamics and complexity of ART adherence.

The articulation of church-based HIV policies should be strategically grounded and guided. This means that the church needs to plan strategically (Parry 2008:52). This involves setting goals, determining actions to achieve these goals, and mobilizing resources to execute the actions. Strategic planning has core principles that should ensure synthesis and synergy in the process to avoid any element that might “compromise sensitivity, effectiveness, sustainability and credibility” (Parry 2008:52). These involve “respect for human rights to ensure that the strategy does not stigmatize people living with HIV” (Parry 2008: 54). The programme should ensure a synergy with “Christian values and social teaching” (Parry 2008:54). The strategy should be evidence-based through a synthesis of information gathered from knowledge and training, general and specific experiences, and valid research (Parry 2008:54). The very first objective of the

strategy should be openness to allow community cooperation and collaboration. This should include a community participatory process to ensure that the programme is driven from below by community members in order to enhance collaboration with other stakeholders and to ensure better usage of community assets (Parry 2008:55). The final principle of strategic planning is accountability for decisions and funding (Parry 2008:56). This includes sound management of funds, as potential funders are skeptical about finance programmes that lack integrity in terms of financial management and decision making procedures.

The third aspect of outer competence is “social relevance” (Parry 2008:69). This competence challenges the church to “build social cohesion” (Parry 2008:69). This concept of social cohesion promotes a culture of affirming each other as human beings and sharing in suffering through openness. In Chapter Three I discussed the issue of the structural sins of society, where the poor fail to maintain optimum ART adherence because they cannot reach health care facilities for their repeat doctors’ appointments. Unemployment, low education levels, language barriers and long distances to health facilities are the issues that the church should address in the process of becoming relevant. Parry challenges the church to open their doors and buildings to “become centres where people can find an identity, a shared vision, shared challenges and be part of a caring accepting community” (2008:72). In agreement with Parry, Munro argues that “the people of God, the suffering body of Christ, are being called and invited, challenged and urged, to live our common humanity, to be wounded proclaimers of the kingdom of God among a people that is struggling with its identity, its beliefs, and its values” (cited in Chitando 2007a:22). The social relevance of outer competence is congruent with the idea of community ART adherence programmes. The church and its members who are skilled in medicine and community work should be requested to use church premises to conduct church-based ART adherence programmes. This might include medication literacy classes, ART adherence strategies, dispensing of ART, etc. This will strengthen the relevance of the church response to the HIV challenge. The church needs to uphold the dignity and human rights of those who are HIV positive and,

in the process, become a redemptive community. This should include lobbying for human rights and rights for vulnerable children who are left with no supporting programmes.

The fourth aspect of outer competence is “inclusiveness” whereby the church is called to become welcoming to all people (Parry 2008:75). Parry asserts that “Jesus was inclusive in his relationships and his dealings with people” (2008:75). The church as the body of Christ should grant unconditional fellowship to everyone regardless of culture, gender or HIV status. This inclusiveness should be integrated into all activities of the church. This begins with including people living with HIV in all programmes of the church who have relevant experience that the church can use to formulate HIV programmes (Parry 2008:75). Parry further asserts that in order to safeguard effectiveness and maximise accountability in the HIV response, the church should include people living with HIV in the process of formulation of church-based HIV policies and strategies (2008:75). This will ensure ownership of the programme and provide motivation to break the silence caused by denial and the stigmatisation of people living with HIV. Greater integration of people living with HIV from the conceptual phase of a programme affirms their dignity and acknowledges their capabilities. In the context of ART adherence, including ART users in the process of designing adherence supportive programmes has emerged as a positive predictor of optimum adherence. Embracing and collaborating with people living with HIV ensures sustainable church-based ART adherence strategies and affirms that the church is in solidarity with ART users.

The fifth outer competence is a call for the church to “network” through collaboration with other stakeholders that are doing HIV and AIDS work, as “faith communities are not an island” (Parry 2008:76). In order to address the HIV epidemic effectively, there is a need to collaborate with the “government sector, the non-government sector, civil society and other community-based groups” (Parry 2008:76). Networking as an act of reaching out and sharing ideas is necessary to coordinate “experiences, what works and what does not” (Parry 2008:76).

Furthermore, churches must collaborate with other churches that have different resources, skills and competencies on HIV treatment. Such collaboration might make it possible for

churches to improve their response to HIV treatment challenges. Provision of ART is an activity that compels the church to network with other organizations that might provide technical support. Churches can forge indelible relationships and partnerships with parallel stakeholders such as government through the Department of Health, non-governmental organizations and business enterprises.

The sixth outer competence is “advocacy” which calls the church to become the voice of the voiceless and to collaborate with other organizations to fight against the injustice and suffering experienced by people living with HIV (Parry 2008:77). The rightful position of the church in society includes “becoming a prophetic voice”, proclaiming good news, life and hope to people who are living with HIV and to those who are ART users (Parry 2008:77). Parry highlights five issues that the church should advocate. First, the church should put more pressure on calling for universal access for prevention, treatment and care (Parry 2008:78). If large sections of the population are still struggling to access ART the church should hold relevant authorities accountable and be the voice of those in need of treatment. The church should put pressure on government to provide free ART and remind them that they are guilty of injustice to those who cannot afford to pay for ART. This includes fighting against patent laws that are continuously pushing up the prices of ART and making them unaffordable. Secondly, the church should advocate inclusion in HIV planning and governance structures (Parry 2008:78). Because of the integral link the church has with suffering people and people living with HIV, the church must play a major role in any discussion about HIV planning. In Chapter Three I discussed the contribution made by medical scientists to the battle against HIV. However, the fight against HIV is no longer an issue of medical scientists alone: it has to be fought at every level and the church has a vital part to play. Thirdly, the church should confront stigma, discrimination and denial (Parry 2008:78). Stigmatization has devastating effects and has facilitated silence around HIV. Women have experienced rejection and have suffered immensely at the hands of those who perpetuate stigmatization. The church must play a meaningful role in advocating the protection of women and children, quality provision of health care services and reversal of the frontiers of poverty and economic imbalances. Fourthly, the church should engage in the process

of providing correct and consistent information (Parry 2008:78). This includes information about available services and how to access those services. The church should also take a leading role in teaching people about the spread of HIV, transmission and prevention strategies. Fifthly, the church should engage with communities to prevent new HIV infections (Parry 2008:78). This includes facilitating community workshops, disseminating correct information about “responsible sexual behaviour and ensuring access to sexual and reproductive health services’ (Parry 2008:78).

The final aspect of outer competence focuses on “compassion and the restoration of dignity and hope” which includes the quality of understanding the suffering of others and wanting to do something about it (Parry 2008:79). This principle of outer competence calls the church to be in “solidarity with those who suffer from the effects of HIV” (2008:79). The church should journey along with people who are infected with and affected by HIV. This journey should ensure a serious commitment and “firm determination to commit oneself to the common good” (Parry 2008:79). The Christian virtue of compassion challenges the Christian community to practice a theology of love and hope. This call forces the church to move beyond proclamation to act in love, care and unconditional acceptance. In the era of HIV and ART adherence difficulties, the response of the church should be based on compassion to bring hope to the hopeless and show solidarity through church-based ART adherence programmes such as the “buddy system” as discussed in Chapter Three. The HIV competent church has a moral obligation to be sympathetic towards those who are affected by HIV and towards ART users who are struggling to optimise their ART adherence. This is an ideal opportunity for the church to engage in its core mandate, namely to participate in the suffering and struggles of the people it claims to serve.

#### **4.5 Linking inner and outer HIV competence**

In order for the church to move from inner competence to outer competence there is a need to build a bridge that will connect inner transformation of attitudes and approaches to HIV with a practical response by the church to HIV (Parry 2008:32). Parry says that “leadership, knowledge and resources” are three key cornerstones that connect inner competence with outer competence (2008:32).

The first cornerstone is leadership (Parry 2008: 32). Leadership involves “commitment, passion, and courage, going the extra mile, having audacity, showing the way and staying the course” (Parry 2008:33). These leadership attributes suggest that leaders should possess indispensable knowledge and a willingness to embark on action. Leadership also includes understanding, accountability, commitment and engagement (Parry 2008:34). These four attributes of leadership have an important role to play in ensuring a sufficient and meaningful response to HIV. In all forms of leadership, the leader should show understanding through encouragement of progressive attitudes, inspire different opinions from different people and support progressive HIV policies and laws. Parry argues that “leaders should be called to account and held responsible to fulfil their roles and responsibilities” (2008:34). This includes accountability for the implementation of programmes and the creation of an enabling environment in which these programmes can be conducted (Parry 2008:34). Leaders are required to be accountable not only for the programmes and strategies but for the usage of funding. Leaders are required to be transparent and keep accounting books on how money has been spent.

The HIV competent leader should have the boldness to keep church members committed to contributing to the process of deconstructing old attitudes towards HIV. A competent church leader should encourage church members to volunteer with their skills in constructing a new HIV church response.

The second cornerstone is “knowledge” (Parry 2008:35). Knowledge includes “credible factual knowledge about HIV, its transmission and other social factors that facilitate the spread of the virus, treatment and viral management” (Parry 2008:35). Church leaders are trusted, respected and are listened to by church members. It is important that church leaders know about “HIV acquisition”: that HIV is mainly contracted through unprotected sex, contaminated blood and needles (Parry 2008:36). It is also important that leaders have factual knowledge of other factors that facilitate the spread of HIV, as I have discussed in Section One of this chapter. Parry, Chitando and Dube discuss several different ways to assist church leaders to acquire the relevant knowledge about HIV. Parry (2008:35) suggests that a strong engagement with people living with HIV, to

understand their context and experiences, can assist church leaders to accumulate the relevant knowledge. It is precisely the affected or infected people with HIV who can testify and teach church leaders about their challenges and struggles with stigmatization, access to treatment, treatment adherence, etc. Through this knowledge transferring exercise churches and church leaders will become HIV competent and this exercise will facilitate the process of linking attitudes and practical activities to formulate an adequate church response to HIV.

In agreement with Parry, Chitando suggests that knowledge acquisition is largely an academic exercise. He calls for “HIV mainstreaming in theological education” (2008:6). Chitando (2008:6) asserts that some theological institutions in Africa have incorporated HIV discourse into their academic themes but this is not enough as many institutions have not. It is with this in view that I argue that theological seminaries have a responsibility to challenge and transform the thinking of the church leaders and enable them to lead by example in reflecting positively on HIV. The church should reconsider its attitude and viewpoint on HIV. However, training and relevant knowledge are paramount to facilitate the process of change.

Dube has joined Parry and Chitando in formulating a “method of integrating HIV and AIDS into theological programmes” (2003c:11). This is an important attempt to provide the church with the necessary tools that will contribute to knowledge acquisition and assist in moving the church from inner competence to outer competence.

The third cornerstone of the bridge is “resources” (Parry 2008: 37). There are six resources discussed by Parry to assist the church in the process of becoming HIV competent (2008:37). The first resource that the church should focus on is the “financial resource” (Parry 2008:38). It has been argued that churches are often encouraged to restructure their programmes to incorporate HIV related activities into their traditional programmes. However, this process has led to the challenge of shrinking donor funding (Parry 2008:37). The increase in social organizations that support HIV programmes, lack of accountability and corruption have contributed to the shrinking of donor funding (Parry 2008:37). In the context of ART adherence, the church has a meaningful role to



play in developing and implementing programmes that will ensure optimal ART adherence. However, the success of programmes such as ART adherence relies on the availability of monetary support. Therefore, the church should demonstrate a high level of competency in fundraising and financial administration in order to attract potential donors.

The second focus should be on better use of “structural resources such as church buildings and properties” (Parry 2008:38). According to Parry (2008:39) churches and FBOs own schools, universities, hospitals, etc. These resources are underutilised in HIV programmes. In cases such as church buildings and other resources that are underutilised “the church needs to devise creative channels to ensure that its members make optimum use of its infrastructure” (Chitando 2007b:17). This will ensure a better transition of inner competence to outer competence through allowing church members to redirect usage of the church’s infrastructure to benefit people living with HIV. In Chapter Three I discussed the problem of long distances between the health facility and the home of the patient as one of the predictors of poor adherence. In the context of ART adherence programmes church buildings can be used as centres where treatment adherence literacy workshops are conducted and those buildings can also be used as ART dispensing centres to cut short the travelling distance to health care facilities.

The third resource that the church should put more focus on is the “human resource” (Parry 2008:39). The church has skilled members and many are not used adequately to support church-based programmes (Parry 2008:39). The church has a large pool of retired nurses, doctors, pharmacists, teachers, social workers, etc. who can be encouraged to volunteer and start church-based ART adherence programmes to support ART users. Chitando argues that “church members skilled in medicine and teaching could be asked to use church premises to impart basic knowledge about HIV and AIDS prevention, treatment and care” (2007b:17). Programmes such as these can make a difference by assisting overcrowded healthcare facilities. The success of church-based ART programmes and community ART adherence clubs relies on skilled church members who are willing to volunteer their skills.

The fourth resource is “spiritual resources” that include “tangible and intangible ways in which religion contributes to healthy well-being” (Parry 2008:40). Tangible spiritual resources involve “compassionate care, material support and curative interventions” (Parry 2008:40). Intangible spiritual resources involve hope, faith, prayer and trust (Parry 2008:40). Furthermore, Parry argues that intangible spiritual resources are important factors that help to “build inner resistance and inner strength to deal with crises in which people may find themselves” (Parry 2008:40). Parry notes that these include spiritual gifts such as praying with people who are suffering due to different illnesses, reading the Bible and laying-on hands on the sick to bring hope and trust (2008:40). These resources are often forgotten due to their nature of being immaterial and invisible, however they increase value in the lives of those who are sick (Parry 2008:40). In the context of ART adherence, the church should use both tangible and intangible spiritual resources through formulating church-based psychosocial support groups and ART adherence clubs to conduct home Bible studies, donate and prepare food for the sick, directly observe medication intake and conduct home-based care activities. The church can also use these groups to provide its intangible spiritual resources through proclaiming hope, love and trust.

The fifth cornerstone is “resource materials” (Parry 2008:40). A lack of theologically-based resource material is a concern which has a negative impact on the efforts of formulating a life-giving theologically-based response to HIV. Parry (2008:75) acknowledges the contribution that has been made by the World Council of Churches (WCC) to fill the shortage of resource material. The WCC has produced “liturgical resources and HIV-sensitive sermon guidelines” and other faith-based organisations have also contributed to breaching the gap (Parry 2008:40). However, Parry argues that this contribution is still regarded as insufficient since the current theologically-based resources are still not translated into local languages (Parry 2008:40). Parry (2008:41) appeals to FBOs to collect more credible information, as FBOs work closely on the ground with vulnerable groups. Furthermore, young people need to be encouraged to volunteer their skills and energy in the process of collecting more data (Parry 2008:41).

The inclusion of young people and the involvement of people living with HIV in this process of data gathering is essential to formulating a relevant church response to HIV.

The shortage of resource materials, including a lack of data gathering and dissemination, can improve if the church embarks on strengthening “links to the international community” (Parry 2008:41). Parry (2008:41) suggests that the church should intensify its programmes through joining hands with international churches and FBOs that share similar ideas. The flow of information between the churches of the North and South will strengthen relationships between the two. In addition, this will affirm the commitment of churches in the North to those in the South (Parry 2008:41). Through the sharing and exchanging of ideas the church can learn new strategies and competencies to formulate a meaningful response to challenges posed by HIV.

#### **4.6 Conclusion**

This Chapter has discussed Parry’s framework of action in order to become an “HIV competent church”. Parry (2008:9) argues that an HIV competent church framework describes fundamental transformation that the church needs to consider in order to become more relevant to the HIV epidemic. In the chapter, the three components of this framework were discussed, namely, inner competence, outer competence and the bridge of competencies that link these two aspects.

Drawing on this framework, the following Chapter will discuss the findings of the fieldwork of this study. Qualitative research interviews were conducted in the Vulindlela region outside Pietermaritzburg to ascertain the potential role that church leaders could play in enhancing antiretroviral treatment adherence.

## **Chapter Five**

### **Engaging Vulindlela church leaders**

#### **5.1 Introduction**

The previous chapter outlines the theoretical framework used in this study, with a focus on the “HIV competent Church”. Parry (2008) suggests that if church leaders are serious about responding to HIV and AIDS, an informed and theologically sound approach is fundamental. Taking stock of what has been done to curb HIV, what lessons have been learned in this process, and building on existing programmes is important.

This chapter will present the fieldwork findings of the study as it engages with Vulindlela church leaders on issues of HIV. The fieldwork seeks to understand the competence of church leaders with regards to ART adherence programmes and the potential role they could play in the future.

In Chapter One, I outlined four research questions that are pivotal to this study. This chapter seeks to respond to these questions: what knowledge do Vulindlela church leaders have of ART? What knowledge do Vulindlela church leaders have about adherence to ART? Are any of these church leaders involved in ART adherence programmes? And what potential future role can they play?

#### **5.2 Research process**

In 2005 and 2006 Haddad (2006a) conducted a baseline study in Vulindlela, outside Pietermaritzburg. The objectives of her study were to undertake an audit of existing churches in the area, to map their physical location in the study area and to understand the positive and/or negative role that the leadership of these churches was playing in responding to the HIV epidemic (Haddad 2006a:4). She concluded that church leaders were struggling to deal with the HIV epidemic (Haddad 2006a:6). In the early days of HIV and AIDS the response of the church was ambiguous, sometimes causing more problems than providing solutions. This ambiguous response has not ceased to exist but

through programmes that have been modeled on HIV competence, attitudes and practices in some churches have changed.

A key to understanding how this is possible was the realization that there is theological confusion within the ranks of the church leadership (Haddad 2006b:83). This confusion comes from a perception that talking freely about sexuality and sex is culturally unacceptable, particularly publically where both men and women are present (Haddad 2006b:83). Cultural practices and behaviours have hindered channels of communication between church leaders and church members as culture has propagated secretive behaviour and silence (Haddad 2006b:84). The inflexibility of church traditions and ceremonies has thwarted inclusiveness and acceptability of new ideas, resulting in people who are living with HIV feeling that they are not welcome in the church (Haddad 2006b:90). Restrictions on talking openly about sex and sexuality, negative culture and rigid church liturgy are the main prohibitors of communication. But, at the same time, church leaders want to curb the epidemic despite feeling hindered by these restrictions. Furthermore, as many of these leaders are from churches where healing is a common practice, the fact that they cannot heal HIV causes theological confusion (Haddad 2006b:87).

In the era of ART and ART adherence it is important to see if there has been any improvement in communication and any shift in theological confusion, leading to an increased response to the HIV epidemic, given the rollout of ART and increased public awareness campaigns. Thus, this study seeks to investigate the knowledge of ART and whether church leaders have engaged in ART adherence programmes. The findings of the study that was conducted by Haddad in 2005/2006 laid the foundation for this study.

The fieldwork of this study was conducted five years later in the same geographic area as the Haddad 2005/2006 study. After this study, the Ujamaa Centre for Community Development and Research (Ujamaa Centre) conducted an intervention that included six weeks' training on HIV and AIDS information. Since then, there has been a roll-out of ART at the public health facilities in Vulindlela. In order to assess the potential role of church leaders in ART adherence, the same participants in Haddad's study were recruited

for this study. This was to ensure continuity and build on existing knowledge, since these participants had undergone a short training course in HIV and AIDS which included theological input. Five years later, it was of interest to note whether these leaders were aware of ART and the necessity of adherence to treatment and also to understand if there was any engagement with existing HIV programmes offered by stakeholders in the public health sector.

As discussed in Chapter One, this study is qualitative in design. All the data was gathered orally. Semi-structured interviews with open-ended questions were used in the process of data gathering (see Appendix B). A tape-recorder, alongside the interview guide, was used. The tape recorder was used for pragmatic reasons such as uninterrupted interaction with the interviewee and to ensure maximum engagement with the participants (Rapley 2007:18). Using an interview guide was to ensure quality and that the same standard results were attained. All study participants were requested to sign informed consent (see Appendix A). Because participants sometimes provided short and incomplete responses, I then used additional probing questions in order to get clarity on certain responses.

The total number of study participants was ten (see Section 5.2). All ten participants were interviewed voluntarily. Nine of the participants were interviewed at their homes at their convenience and one opted to be interviewed at work in Pietermaritzburg central during his lunch time. The initial plan was to conclude all ten interviews within a period of three months. However, the actual period of fieldwork took five months (March 2011 – July 2011). This resulted from the fact that the process of scheduling appointments was complicated, due to some contact details changing while others had relocated and were not easily available.

Thematic content analysis was chosen as the method by which to analyze the data obtained from the interviews. As discussed in Chapter One, Ibrahim (2012:43) argues that thematic content analysis provides a systematic method of examining and presenting interview content by identifying themes within the interviews. I categorized themes as the starting point for the analysis and four themes were identified. These were: (a) knowledge

of HIV and AIDS; (b) involvement in HIV and AIDS church programmes; (c) HIV treatment and ART adherence; and (d) knowledge and skills to assist with a better response to treatment adherence.

### 5.3 Demography of Study Participants

#### 5.3.1 Age

All study participants were above the age of thirty five: the youngest participant was thirty-eight years old and the oldest participant was eighty five years old. The table below illustrates the participants' age categories (see Table 1).

<i>Age</i>	<i>Number of leaders</i>
30 – 39	1
40 – 49	1
50 – 59	2
60 – 69	3
70 – 79	2
80 – 89	1

Table 1: Ages of participants

It is noteworthy to see the variables of the ages of the participants as three participants were older than others and indicated that they had little formal education. Age has somehow negatively influenced their responses and participation in the study. This was witnessed when the eighty two years old participant was asked about networking with other churches and he had this to say:

I am very old now, I am in a grace period. I mean God has given me a bonus. Starting a network or involving myself in networks will not work at this age”.<sup>8</sup>

This participant excludes himself from existing networks due to his age. This statement shows that age can be a barrier and can hinder the participation of church leaders in HIV and AIDS programmes.

<sup>8</sup> Interview with Bishop Matoho, 10 March 2011

### 5.3.2 Church Affiliation and Responsibilities

The participants in this study were recruited from different churches within the area of Sweetwaters and had different titles and responsibilities (see Table 2).

<i>Church Affiliation</i>	<i>Responsibilities</i>
Kush Church in Zion	Bishop
Baptist Church in Zion	Bishop
Seventh day Church of God	Bishop
St John's Church	Reverend
Anglican Church	Reverend
Inkanyezi Zion City	Reverend
Zion Christian	Reverend
Holy Mission Church	Reverend
Kush Church in Zion	Pastor
Roman Catholic Church	Preacher

Table 2: Participants' affiliations and responsibilities<sup>9</sup>

### 5.3.3 Educational level

There was a large disparity in the levels of education amongst participants. Three categories of educational levels were captured (see Table 3).

<i>Levels of education</i>	<i>Number of leaders</i>
Grade 0 – 7	5
Grade 8 – 12	3
Post Matric certificate	1
Tertiary education	1

Table 3: Participants' educational level

<sup>9</sup> All names used in this study are pseudonyms to ensure anonymity



### 5.3.4 Employment

The employment statuses amongst the participants were distributed unevenly (see Table 4).

<i>Employment status</i>	<i>Number of Leaders</i>
Pensioners	4
Formally employed on a permanent basis	3
On short term contracts	2
Unemployed	1

Table 4: Participants' employment information

### 5.4 Research Findings

As indicated earlier, the findings of this study were categorized according to four themes that emerged through the data analysis process. Using thematic content analysis as discussed in Chapter One and in Section 5.2 of this chapter, the themes identified were: a) knowledge of HIV and AIDS, b) involvement in HIV and AIDS church programmes, c) HIV treatment and ART adherence and d) knowledge and skills to assist better response to treatment adherence.

#### 5.4.1 Knowledge of HIV and AIDS

Regarding HIV and AIDS training, all ten participants reported that they had attended HIV and AIDS training. Six of the ten reported that they had had training on HIV and AIDS more than once from different organizations or training institutions. Two participants reported that the training they received from Ujamaa Centre in 2007 was their first exposure and that they have not since received HIV training. One participant reported that he completed the Ujamaa Centre training on home-based care, lay counselling and antiretroviral treatment literacy. One participant indicated that the training he received from the Ujamaa Centre was sufficient, as he had also attended a "healing" training organized by the senior leadership of his church.

However, only five participants had something to say about knowledge of HIV and AIDS and these participants saw the value and necessity of attaining information on HIV and AIDS. These participants were Reverend Nxele, Reverend Zwane, Bishop Zondo, Reverend Bhungane and Pastor Nsele. Despite the fact that all ten participants had undergone HIV and AIDS training, the other five participants did not have much to say about the knowledge of HIV and AIDS.

Reverend Nxele commended the value of the training by saying:

I have four certificates in HIV and AIDS. I like these trainings because we get a lot of relevant information, we meet with many different people and find time to discuss issues that are affecting people who are living with HIV and AIDS.... Now I know how to preach to people who are living with HIV and AIDS without discriminating against or without judging them.<sup>10</sup>

Rev Zwane described knowledge of HIV and AIDS as a necessary tool for church leaders and he suggested that information on HIV and AIDS should be compulsory for all church leaders:

The organization of churches [SACC] should pass a law that will force all Bible colleges to teach about HIV and AIDS and to teach *Abefundisi* [Ministers of Faith] how they can use the Bible without offending people living with HIV and AIDS. In my church I don't preach about HIV and AIDS every Sundays because other congregants say I am boring them...but when I do [preach about it] I always choose the correct text because I am trained.<sup>11</sup>

Bishop Zondo narrated his story of being empowered by basic knowledge of HIV and AIDS and said:

There are many people who are sick these days. Some of them are living with this virus [HIV] and others have *ushukela* [diabetic] or *high high* [hypertension]... because I am trained on HIV and AIDS I feel empowered to deal with all other illnesses as well. I don't tell people that they are *bathakathiwe* [bewitched] or *banamadimoni* [possessed by demons] but I tell them the truth and I advise them correctly.<sup>12</sup>

Rev Bhungane commended and valued the content of the training. In his response, he requested that basic information on HIV and AIDS should be free:

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<sup>10</sup> Interview with Reverend Nxele, 10 March 2011

<sup>11</sup> Interview with Reverend Zwane, 07 April 2011

<sup>12</sup> Interview with Bishop Zondo, 8 May 2011

I am happy that I got this training for free. Nowadays this training is for sale: they ask too much money for this training. And I am not happy that we are not getting updates about new knowledge about HIV and AIDS. If you want new knowledge you have to pay because there are people and organizations that make money, they do business by selling knowledge about the disease. The government should stop *amaqola* [these opportunists]: the information should be freely available.<sup>13</sup>

Pastor Nsele argued that knowledge of HIV and AIDS is necessary since HIV and AIDS challenges their faith and belief. He narrated that they were struggling to understand HIV and AIDS and they were struggling to respond appropriately to HIV and HIV. Getting knowledge about the science of HIV transmission, prevention and treatment, has empowered them with knowledge. Being trained on using the Bible in times of HIV and AIDS was a breakthrough for some of them (Pastor Nsele, 25 March 2011). He further commended the value of the training and he told his story about how he uses the Bible to deal with HIV and AIDS:

This was prophetic [referring to the HIV and AIDS training] because we conduct funerals every Saturday... people talk...they know that HIV is the primary cause of death and they look up at you as a Pastor, they listen to you...wanting to hear from you what you will say, how you are going to respond. However, the HIV and AIDS training equipped me on how I can use the Bible and how I can comfort the bereaved.<sup>14</sup>

The five responses discussed above show that basic information on HIV and AIDS was received differently. Nevertheless, these five leaders all showed that they had gained knowledge, testified that the training was informative, commended the content of the training and asked for more training programmes with updated information on HIV and AIDS. This indicates that HIV and AIDS training indeed broaden knowledge dissemination in times of HIV and AIDS.

#### **5.4.2 Involvement in HIV and AIDS church programmes**

There were four participants who indicated involvement in HIV and AIDS church programmes; three participants did not initiate any HIV and AIDS church programmes due to their theological convictions and church teachings; two participants did not initiate

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<sup>13</sup> Interview with Rev Bhungane, 7 May 2011

<sup>14</sup> Interview with Pastor Nsele, 25 March 2011

any HIV and AIDS church programme in their respective churches because they felt that they did not have the energy as they were old; and the last participant felt that people are tired of being told about HIV and AIDS and he did not initiate nor was he involved in any HIV and AIDS church programme.

The four participants who indicated involvement in HIV and AIDS programmes are Reverend Zwane, Pastor Nsele, Bishop Zondo and Reverend Bhungane. Below are the responses that were given by these participants when they were asked about their initiatives or involvement in HIV and AIDS church programmes.

Reverend Zwane narrated how he gained support and trust from his congregation when he started HIV and AIDS ministry in his church:

I had minor issues at the beginning because there were people who did not understand what I was talking about and some of them thought that I was also HIV positive and that was the reason I started to preach about HIV and AIDS related issues. But that thinking faded away after a workshop that was conducted by PACSA [Pietermaritzburg Agency for Community Social Action] in my church; actually I organized two workshops the other one being facilitated by ECAP [Evangelical Community AIDS Project]. These workshops paved the way to start a psychosocial support group... our support group is open to community members who are not church members... we do home-based care, vegetable gardens, counselling, and many other things.<sup>15</sup>

Pastor Nsele reported on the HIV and AIDS youth ministry in his church:

I was fortunate enough in my church because our youth league had a social committee. I requested the youth to incorporate HIV and AIDS into their social programmes. This was not easy because all committee members were not trained and they were afraid of stigmatization and discrimination. I was fortunate again because we had church members who are nurses. I asked them to help the youth with training. I also motivated our youth to start HIV peer education...now we have a big programme with a registered organization. Our HIV and AIDS programme mostly reaches out to vulnerable children and adults [referring to orphans and old age persons].<sup>16</sup>

Bishop Zondo asserted how he started a support group for HIV negative people and spoke of himself as an activist for justice:

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<sup>15</sup> Interview with Reverend Zwane, 7 April 2011

<sup>16</sup> Interview with Pastor Nsele, 25 March 2011

I needed a beginning, and for me a beginning was to have a buy in of those who were negative. I organized and brought together a few people and talked with them about HIV and AIDS and about my ambitions to stop stigmatization of and discrimination against people living with HIV. Fortunately, all these people supported my project and we started from there to fight stigma... we have trained many people about HIV and AIDS. People now have a better understanding about HIV and AIDS. My support group was only for strong men [*amadoda aqotho*] ... I wanted to see men's contribution. These trainings have leveled the field for HIV positive people to speak openly about their HIV status...many people have disclosed their HIV status either to me or to their family members because we have created a safe space ... people have a feeling that talking about HIV at the church is safe.<sup>17</sup>

Reverend Bhungane has described how he has organized church workshops and individual presentations:

I believe that HIV and AIDS information and knowledge should be freely available... I have been inviting different people from different walks of life to come to my church and provide us with HIV and AIDS related information and I have included TB because there are many people who are suffering with TB. If I do not have anyone to talk about HIV, I preach about it... I have prepared different sermons...I also organize annual candlelight prayers in memory of all those who have died and as a symbol of hope to those who are infected or affected. In December we join the whole world by organizing our own World AIDS Day. This is very important because I give people freedom of choice after they have received the truth about HIV and AIDS.<sup>18</sup>

The three participants who did not start HIV and AIDS church programmes because of their theological convictions and church teaching include Reverend Moyo, Reverend Nxele and Preacher Ntombela. Below are some of the examples of the responses that were given by these participants. Reverend Moyo has narrated his beliefs and the teachings of his church about healing and prayer:

In my church we believe in prayer... we pray for the sick and cast out all evil spirits and dark shadows that are responsible for sickness. We also believe that our ancestors are interceding on our behalf [*amadlozi ayasixhusela*]. We, therefore, are not prone to sickness.<sup>19</sup>

Reverend Nxele spoke about the belief of his Zion church and inherent teachings of the church. He said:

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<sup>17</sup> Interview with Bishop Zondo, 8 May 2011

<sup>18</sup> Interview with Reverend Bhungane, 7 March 2011

<sup>19</sup> Interview with Reverend Moyo, 12 April 2011

We as Zion, we believe in holy water. If someone is sick, we baptize that person in the river [*emfuleni ohambayo*]. This is our teaching and we grew up with our fathers doing this.<sup>20</sup>

Preacher Ntombela emphasized the importance of prayer and being faithful to God.

We believe that when the time is right, God will take away all suffering and illnesses...we will be clean... God is just testing us. In the history of the Israelites, God allowed snakes to bite them because He wanted them to remain faithful to Him...even today if we pray to God, He will hear our prayers and take away all these diseases.<sup>21</sup>

Reverend Mlaba describes why he decided not to start any HIV and AIDS church programmes at his church:

I know that people have information about HIV and AIDS. I have not initiated any church programmes that teach people about HIV and AIDS... people have HIV fatigue. When you open a radio, TV or newspaper you find HIV, HIV and HIV. But I do have those isolated moments where I correct misconceptions or myths if I overhear people spreading wrong information and I sometimes preach about it because I have knowledge of this disease...usually I preach about it when I am conducting a funeral of a person who is known to have been living openly with HIV.<sup>22</sup>

Bishop Matoho and Bishop Mkhize did not have much to say and both of them did not start any HIV and AIDS church programmes in their respective churches.

This section reveals the disparity in how Vulindlela church leaders respond to HIV and AIDS. This includes four church leaders who have used HIV and AIDS knowledge to start church-based programmes and those who did not do anything new in their respective churches due to their theological convictions and teachings.

### **5.4.3 HIV treatment and ART adherence**

In analyzing the data, it became clear that all ten participants had some understanding of HIV treatment. ART adherence was a new concept to eight of them while the other two

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<sup>20</sup> Interview with Reverend Nxele, 7 March 2011

<sup>21</sup> Interview with Preacher Ntombela, 16 July 2011

<sup>22</sup> Interview with Reverend Mlaba, 15 May 2011

participants had some understanding of its meaning. In this section, I only discuss the responses of Pastor Nsele and Reverend Bhungane as they were the only participants who provided responses on HIV treatment and ART adherence.

Pastor Nsele emphasized the role of a stable support system for somebody who is on the ART programme. He argues that:

If someone is on HIV treatment [referring to antiretroviral treatment] that person will need support, not only spiritual support but I mean physical support. Knocking on the door is a lengthy process [referring to ART adherence classes] and after starting ARVs it is another long process...actually you need someone to walk with you... along the way there are side effects, you miss a dose by forgetting to take your pill, you need good nutrition and above all you need to feel that you are still a human being with friends and family.<sup>23</sup>

Reverend Bhungane stresses the role of family, friends and the church in formulating a support system for ARV users. He says that:

Patients that get support from their friends and their families respond well to treatment. We need to support each other. If you know someone who is using this medication [referring to ARVs] it should be our duty to accept that person and welcome him into the church. In my church we have people who are using this medication, we know them, we support them and we encourage them to continue with their medication. I believe we are playing our roles correctly as the church.<sup>24</sup>

The second theme that emerged from these two participants in this section is antiretroviral treatment as a gift of life. Both Pastor Nsele and Reverend Bhungane have commended antiretroviral treatment as a lifesaving gift from God. Pastor Nsele reports that:

ARVs are a big blessing to us as church leaders...we need to thank God for this wonderful gift He gave us...in the past we have tried many things including *amabhodlela* [traditional medicine] but we did not get it right. The availability of ARVs means that God has responded to our prayers...ARVs are given to help us live longer and ARVs understand our bodies, but we need to understand them as well. Understanding ARVs is a long process...you need *umlingani* [a buddy-supporter] to assist you with this long process.<sup>25</sup>

Reverend Bhungane associates the ART programme with lifesaving intervention and he argues that:

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<sup>23</sup> Interview with Pastor Nsele 25 March 2011

<sup>24</sup> Interview with Reverend Bhungane, 7 March 2011

<sup>25</sup> Interview with Pastor Nsele 25 March 2011

ARVs are lifesaving medication that is different from other medications. I have seen people getting better. Some of them were already bed-ridden but with ARVs they are back to their normal lives. We must thank God for giving doctors knowledge to create ARVs and now we are praying for a vaccine or a cure.<sup>26</sup>

It emerged that Pastor Nsele and Reverend Bhungane were the only two participants who have initiated the church-based ART adherence programmes, as discussed above. These two participants were the only participants that have knowledge and understanding of HIV treatment and ART adherence. Pastor Nsele spoke about a church psychosocial support group that provides different services to people that are on ART. He argues that:

One of the activities of the psychosocial support group we have established is to provide treatment support services to people who have disclosed their HIV status and who are willing to be assisted through our services. If a person is due for treatment literacy classes, we assign a treatment supporter who will be a “treatment buddy”. Treatment buddies attend treatment classes together with their “clients” [referring to a person who is due for ART]. The role of the treatment buddies is to remind their “clients” to take their pills in time and provide general advice about nutrition and positive living.<sup>27</sup>

Reverend Bhungane spoke about the HIV and AIDS church ministry that he started in his church. He outlined ART adherence programmes that are part of their broader HIV and AIDS ministry. He says:

In the beginning we didn't know what we were doing or what we should do but we felt that we needed to do something to support people who were taking ARVs. There were many stories about treatment failure if there is poor nutrition or a dose skip. Our home-based care team were reporting these stories each time they came back from the field...we decided to approach an organization that operates at the old bus depot sponsored by Msunduzi Hospice and Tapelo Ministries...this organization provides us with food parcels and we distribute these parcels to those people who are in need. Because we know that food parcels are a short-term relief we also assist them to access government disability grants. Recently we have started a small chicken project and vegetables garden. We also provide people who are not ready to disclose their HIV status to their family members with *Abalingani* [Treatment buddies].<sup>28</sup>

Bishop Zondo is amongst the eight participants who indicated that they have some knowledge of and understanding about HIV treatment and ART adherence. He reported

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<sup>26</sup> Interview with Reverend Bhungane, 7 March 2011

<sup>27</sup> Interview with Pastor Nsele, 25 March 2011

<sup>28</sup> Interview with Reverend Bhungane, 7 March 2011



about the ART adherence programme that is being conducted by the members of his church. He argues that:

In the church we have very few people that are taking ARVs. We provide wide treatment support to the community. Our outreach programme committee has started a community support group that distributes food parcels. The support group works as a fellowship safety space; they read the Bible with members of the group and try to find meaning of life, as these pills are giving them a second chance to live again. Support group members give each other support to deal with side effects and they remind each other to take pills. Starting a support group was a blessing to many people in the community who do not have support from their families and from their churches. We do not discriminate against people; we support and embrace everyone since our outreach programme is mostly working in the community.<sup>29</sup>

Activities and programmes that were discussed by three Vulindlela church leaders indicate that with the availability of relevant information and resources these church leaders could become more involved.

#### **5.4.4 Knowledge and skills to assist with better response to treatment adherence**

Given that there was little knowledge and understanding of HIV treatment and ART adherence, participants were asked about what kind of knowledge and skills they might need. Six participants said they would value training on HIV treatment and ART adherence. Four participants of those who are already engaged in ART adherence church programmes, had this to say:

I don't want to be a nurse or a doctor...but I think it is a good thing to understand different kinds of ARVs and know how they work in the body. We need to be able to understand side effects because some people end up defaulting due to side effects.<sup>30</sup>

Reverend Zwane argues that:

We motivate people to stay on treatment and we teach them about good nutrition but we need refresher training as many people are complaining about heartburn and acid. This might be scientific but we need to understand these side effects as this will help enable us to respond better to ARVs adherence.<sup>31</sup>

Bishop Zondo adds that:

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<sup>29</sup> Interview with Bishop Zondo, 8 May 2011

<sup>30</sup> Interview with Reverend Nxele, 10 March 2011

<sup>31</sup> Interview with Reverend Zwane, 7 April 2011

...I am not sure about the specific training that I need...but I would like to be trained on different strategies of adherence ... Clinics don't have other strategies except pill count. At least we are better than the clinic because we also do family visits and send text messages as reminders but we still need to learn more.<sup>32</sup>

Reverend Bhungane is in agreement with other three participants:

Getting fresh knowledge is empowering. You must get the correct information. There are many people who are misleading people by convincing people to stop taking their ARVs because they will pray and HIV will disappear...I think we need to get training that will explain how medication fights the virus and how the virus becomes undetectable in the blood after taking antiretroviral for a long time.<sup>33</sup>

Although the other participants did not have much to say about the kind of training they might need in order to respond better to antiretroviral adherence, it emerged that all participants had the same opinion that training on HIV treatment and ART adherence would be valuable. HIV treatment adherence is a new concept. Participants indicated that gaining new knowledge and understanding about ART adherence would assist them to formulate improved strategies to respond to HIV.

## 5.5 Conclusion

This chapter reported the responses of the ten Vulindlela church leaders that participated in the study. These responses included four themes that emerged from the data analysis process of the fieldwork. As discussed in Chapter One, this study attempted to investigate what knowledge Vulindlela church leaders have of ART and adherence to ART; to understand if any of these church leaders were already involved in ART adherence programmes; and, lastly, to ascertain what potential future role they could play. Findings discussed in this chapter are responses to the above questions.

The study findings reveal that all ten participants were trained on basic information on HIV and AIDS. Findings further revealed that two participants had attained ART literacy training and eight participants indicated that ART adherence was a new concept to them. However, four participants had been able to initiate church based HIV programmes.

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<sup>32</sup> Interview with Boshop Zondo, 8 May 2011

<sup>33</sup> Interview with Reverend Bhungane, 7 March 2011

These findings affirmed that if church leaders are well equipped with adequate HIV knowledge they would impart that knowledge to formulate positive responses to HIV as discussed in Chapter One. Furthermore, findings revealed that theological convictions and church teachings have hindered three participants from initiating church-based HIV programmes. This affirms that different theological hermeneutics have a direct impact on how church leaders respond to HIV challenges. As a result, churches in Vulindlela respond differently to HIV. Regarding new knowledge and skills, findings revealed that this will be valuable in assisting with a better response to HIV treatment and ART adherence.

In the next Chapter I will attempt to analyze the findings of this study as presented in this chapter, using the theoretical framework discussed in Chapter Four.

## **Chapter Six**

### **Vulindlela church leaders and HIV competency**

#### **6.1 Introduction**

Chapter Five discussed the research process and findings. This chapter seeks to analyze these findings in more detail. I begin by summarizing Parry's (2008) framework of HIV competence, as discussed in Chapter Four. Thereafter, I analyze the findings using Parry's (2008) framework.

#### **6.2 A brief summary of an HIV competent church**

In Chapter Four, I discussed the three components of an HIV competent church. The first component is inner competence (Parry 2008:24). This component includes two main principles. The first is to acknowledge the scope and risk of HIV (Parry 2008:24). This process involves personalizing the risk in an open and honest way, recognizing the impact, considering long-term consequences, confronting stigma, discrimination and denial associated with HIV, and assessing the risk factors that increase vulnerability (Parry 2008:24). There are various risk factors and these include structural and social risks (Parry 2008:25). Examples of structural and social risks are social control, discrimination, inequalities, individual choices, etc. (Parry 2008:25). Other risk factors include gender imbalance, gender-based violence, negative cultural practices, economic risks and political challenges (Parry 2008:26). The second principle is to "accept the imperative to respond appropriately and with compassion" Parry (2008:29). This includes prevention of the spread of HIV, maintaining and improving quality of life, overcoming stigma, mitigating against the impact of HIV, restoring human dignity compassionately and bringing hope to communities (Parry 2008:29).

The second component of being an HIV competent church is the need for outer competence (Parry 2008:45). This includes theological competence on HIV (Parry 2008:45). In order to construct a theology of HIV there is a need to ask theological questions and to discover the kind of God that is needed in the time of the HIV pandemic

(Parry 2008:46). This process involves deep spiritual questions such as the meaning of our existence and the meaning of suffering (Parry 2008:46). In moving towards a theology of HIV the church is challenged “to examine how we bring our theological and spiritual understanding of our relationship with God to bear in our work of prevention” (Parry 2008: 46). Secondly, the church is challenged to scrutinize “how we effectively bring Christ’s healing presence to those infected and affected” (Parry 2008: 46). These questions are important to the church and to those who are currently ministering to those affected and infected by HIV (Parry 2008:47). Technical competence is another aspect that the church should develop and nurture in order to effectively respond to HIV (Parry 2008:50). This includes strategic planning that is grounded in Christian faith and values. The church should have an AIDS policy with clear vision, mission and values (Parry 2008:51). The process of formulating a strategic plan should involve the experiences of people living with HIV as this will ensure respect and promote their humans rights (Parry 2008:54).

Social relevance is another principle of outer competence (Parry 2008:69). This involves calling the church to become a caring community that will nurture the rights of vulnerable groups, including orphans, women and children (Parry 2008:71). The church has a duty to be welcoming and promote unconditional acceptance of people living with HIV (Parry 2008:72). This involves formulating programmes that will facilitate social coherence and expose structural injustices (Parry 2008:71). Chapter Three discusses factors that lead to poor adherence to ART. Economic factors and long traveling distances to health care facilities are the examples of structural injustice that promote poor ART adherence. The church should expose these structural issues rather than focusing on the morality of people living with HIV (Parry 2008:72). Inclusiveness is another principle for outer competence (Parry 2008:75). This principle calls the church to become a home for all, including ART users, where factors that fuel poor ART adherence are discouraged. The church needs to be a place that reinforces the voice of the voiceless (Parry 2008:75). This includes compassion, love and non-stigmatizing behaviour. This will lead to optimum ART adherence (Parry 2008:76). The other principle of outer competence is networking in order to reach out and mobilize resources (Parry 2008:76).

This includes mobilizing resources from government and non-government sectors. Such collaboration ensures better planning, coordination, sharing of ideas and effective use of different skills (Parry 2008:77). Another principle that is related to this is advocacy (Parry 2008:77). In Chapter One I indicated the growing concern about resistance to ART and in Chapter Three I discussed the need for scaling up access to ART and the formulation of strategies to ensure optimum ART adherence. The church should use this opportunity to advocate provision of ART to all qualifying people, to advocate accessibility to health care facilities and to advocate more strategies to maximize ART adherence (Parry 2008:78). In doing this, the church will become a prophetic church and a voice for the voiceless. The final principle of outer competence is compassion and the restoration of dignity and hope (Parry 2008:79). The church has a duty to show compassion and embark on a journey in solidarity with ART users as they struggle with ART side effects and dietary requirements.

Leadership, knowledge and resources play an important role in connecting inner competencies with outer competencies (Parry 2008:32). Decisive leadership plays a large part in promoting a meaningful response to HIV. Competent church leadership can play an important role in encouraging the formulation of church-based ART adherence strategies. However, this requires church leaders to be informed with accurate information and to be willing to make a positive impact, be accountable and be in a position to create an enabling environment (Parry 2008:34). Knowledge is another key aspect of linking inner and outer competencies (Parry 2008:35). This includes “acquisition of correct and up-to-date information on HIV transmission, detection, effects and management” (Parry 2008:36). Chapter Two discusses different types of HIV treatment, including how these regimens function in suppressing the virus in the body. This knowledge is important in order to assist the church in formulating relevant strategies for ART adherence. Furthermore, the church needs to have a fundraising model with an emphasis on transparency and accountability in order to attract funding for ART adherence programmes (Parry 2008:38). Chapter Three discusses factors that negatively impact on optimum ART adherence. A shortage of health care facilities is one

of those factors and structural resources such as church buildings can function as counselling and dispensing centres or as centres for ART adherence clubs.

### **6.3 A critical analysis of Vulindlela church leaders' HIV competence**

As was discussed in Chapter Five, Vulindlela church leaders know about HIV and AIDS. They acknowledge the scope of HIV in their context. The findings further revealed that Vulindlela church leaders have personalized the risk posed by HIV and they have recognized the negative impact of HIV in their churches and in the community as the following examples demonstrate.

The response of Bishop Zondo exemplifies inner competence when he describes his initiative where he organized HIV negative men to start a support group (see Footnote 17). One of the objectives of their support group was to confront stigma, discrimination and denial associated with HIV. To involve men in HIV and AIDS programmes, to sensitize men about the scope and risk of HIV attitude change and to make them recognize that HIV is an acquired virus that affects them as well was a huge stride. Bishop Zondo recognized that men do not associate themselves with HIV initiatives and are reluctant to talk openly about their vulnerability to HIV infection (see Footnote 17). Starting this support group for men was an attempt by Bishop Zondo to engage men and to embrace the dictum that says “if one part of the body of Christ suffers, we all suffer” (Parry 2008:24). This was his acknowledgment that men need to be more involved as partners in the struggle against HIV.

Furthermore, engaging men was a direct response to the factors that contribute to gender-based violence and gender inequality. Parry (2008:25) argues that gender-based violence and gender inequality are major risk factors that increase vulnerability to HIV. Such a men's support group can act as a vehicle to confront patriarchal ideologies and negative hegemonic masculinities that fuel the abuse of women and children.

Pastor Nsele also showed concern about the negative impact that HIV is imposing on individuals, families, communities and the church. He mobilized the youth ministry in his

church to start an HIV and AIDS psychosocial group that would be open to community members who were not members of his church (see Footnote 16). Pastor Nsele's actions can be interpreted as twofold. First, he wanted to sensitize young people about the negative impact of HIV. Secondly, he wanted to sensitize young people about risk factors that increase vulnerability to HIV infection. The process that Pastor Nsele opted for included acknowledging that as a young person himself he might have personal issues related to HIV and AIDS. He recognized that the formation of a psychosocial group that deals with psychological perceptions, attitudes, fears, ignorance and anxieties was necessary for laying a foundation to grow inner competence (see Footnote 16). In my view, psychosocial support groups have a role in facilitating personal issues that might hinder the development of inner competence. Pastor Nsele was conscious of this fact when he advocated a psychosocial support group.

The findings also revealed that HIV trainings organized by Reverend Zwane are examples of inner competence. Reverend Zwane invited different locally based non-governmental organizations (including PACSA and ECAP) into his church to conduct HIV and AIDS workshops (see Footnote 15). These workshops were his direct intervention to show his concern and commitment to confronting stigma, discrimination and denial associated with HIV. These trainings dealt directly with negative attitudes, ignorance and prejudice. According to Parry (2008:27), judgmental attitude is the most dangerous aspect that needs to be dealt with in striving towards inner competence. She argues that "these attitudes are to be found within our churches and within ourselves, negating our authenticity and credibility as people of love seeking to serve others" (Parry 2008: 27).

Reverend Bhungane was concerned in the same way as Bishop Zondo, Reverend Zwane and Pastor Nsele. He was also concerned about beliefs, feelings, values and dispositions at his church. Personally, he had clear understanding about issues around HIV and AIDS and he knew there was an urgency about an adequate response to the epidemic. Concerned about myths surrounding HIV and AIDS, ignorance, stigma and discrimination and unavailability of relevant information on HIV and AIDS, Reverend



Bhungane opted to initiate HIV information sharing sessions in order to encourage openness about HIV in the public realm (see Footnote 18).

The examples discussed above indicate that Bishop Zondo, Reverend Bhungane, Reverend Zwane and Pastor Nsele have to some extent shown important elements of inner competence. These include the effort of exposing HIV risk factors, concern about the spread of HIV prevalence and incidence, social imbalances, stigma and discrimination and encouraging speaking about HIV in the public realm. The findings also revealed that the four church leaders have initiated church-based support groups and other programmes that are community-based, as part of their immediate response to HIV and AIDS. Some of the reasons that motivated these leaders to initiate such programmes were that they wanted to scale-up open dialogue about issues of HIV testing, transmission and treatment. Furthermore, they wanted to have a tangible role in programmes that contributed to the prevention of the spread of HIV.

The initiation of church-based and community-based HIV programmes shows, in addition, that to some extent Vulindlela church leaders have HIV outer competence. It has emerged from the findings that Reverend Zwane is using the Bible to deal with issues related to HIV (see Footnote 11). Pastor Nsele also narrates how he uses the Bible to deal with HIV and AIDS. Although these church leaders did not provide detailed theological statements or examples of Biblical texts that they frequently used, this is a positive step towards a life-giving theology of HIV. Appropriate use of the Bible is important when examining how a theological and spiritual understanding of God relates to HIV. The training that was offered to these church leaders by the Ujamaa Centre (see Section 5.2) assisted these church leaders in developing theological competence on HIV. Findings revealed how Bishop Zondo was theologically empowered by this training and how he currently uses the Bible to minister to those who are infected and affected, without stigmatizing them or blaming them for contracting HIV (see Footnote 12).

With regard to ART, Pastor Nsele has called ART “a gift of life” (see Footnote 25). This epitomizes an attitude that encourages people living with HIV to continue with antiretroviral therapy. Utterances like this give hope, compassion and meaning to people

living with HIV. In addition, findings indicated that in Pastor Nsele's church they pray about ART (see Footnote 25). This is done in part to affirm that science has created ARVs using the minds that God gave them. As a result, people do not view using ART as a taboo or something that is outside the Christian faith but they view ART as an intervention by God. This demonstrates both inner and outer competence in relation to ART.

There is also some evidence of technical competence amongst the four church leaders who reported that church-based programmes were initiated in their churches. These programmes are strategically planned and are governed by a formal constitution. For example, Reverend Bhungane revealed that their psychosocial support group is registered as a non-profit making organization (see Footnote 28). Their organization has a mission statement and objectives that guide their activities. This is in line with Parry's assertion that the church should have a "clear HIV policy with vision, mission and values" (2008:51). She further argues that "the process of formulating an official and accepted policy can make a critical difference to the attitude of the members and leadership, as it can involve widespread collaboration, encourage buy-in to the process, create a sense of ownership and thus become a motivating force for action" (Parry 2008:51).

The psychosocial support group that was created by Reverend Zwane to deliver services including HIV counselling, home-based care, vegetable gardens, and other services, epitomizes social relevance (see Footnote 29). These services are important in ensuring that the "church becomes a center where people can find an identity" (Parry 2008:72). As some of these activities were meant to alleviate poverty and bridge the travelling distance between health care facilities and people, the structural issues hindering access to services and the need for social coherence has been recognised. Furthermore, the men's support group initiated by Bishop Zondo was reported to have reduced stigma and discrimination and facilitated HIV disclosure (see Footnote 17). This support group imparted compassion and non-judgmental principles. Through this support group the church became a home for all HIV positive people, a home that preached unconditional acceptance and demonstrated inclusiveness.

The collaboration between the support group that was started by Reverend Bhungane and the local NGOs that were dispensing food parcels and home-based care materials was a meaningful example of church collaboration with other stakeholders (see Footnote 28). Findings revealed that Reverend Bhungane's support group assists people who qualify to access social grants. They do this through collaboration with government departments. Parry argues that "churches can collaborate with organizations that provide technical support" (2008:77).

Findings reveal that advocacy and compassion are evident in four Vulindlela church leaders who have started support groups and community outreach programmes that are meant to raise awareness and advocacy for people living with HIV.

In Chapter Four, I discussed how, in order for HIV inner competence to move to outer competence, "leadership, knowledge and resources" are the key principles (Parry 2008:32). Church-based HIV programmes that some Vulindlela church leaders have started are evidence that they are showing responsibility and are concerned about the HIV epidemic in their context. These initiatives also show that these church leaders are committed to formulating a positive response to HIV.

In Chapter One I discussed the concerns raised by WHO about the looming problems relating to HIV treatment resistance. Findings show that some Vulindlela church leaders have responded to this call by initiating programmes. These include motivating ART users to meticulously adhere to treatment, providing treatment supporters [treatment buddies] and food. Parry (2008:34) argues that leadership qualities involve understanding of public dialogue and support of public policy. It emerged from the findings that some Vulindlela church leaders are well-informed about the living conditions of their church members, including knowing the rate of unemployment, the number of people in need of social assistance and the impact of HIV in the community. These church leaders also demonstrated knowledge of risk factors that expose people to HIV. Parry (2008:32) argues that knowledge is one of the key links between inner and outer competence.

Another important link between inner and outer competence is recognition of available resources to support church-based HIV programmes. Some Vulindlela church leaders recognise the importance of their structural resources, such as church buildings, being used for HIV counselling, ART adherence classes and support group meetings. They also draw on human resources, such as members of their church who are trained as nurses, to act as facilitators in HIV counselling sessions. Furthermore, the intangible resource of prayer is being used by some as they pray with ART users. According to Parry (2008:40), prayers form an integral part of spiritual resources that are available at the church, provided, as Watt et al. (2009: 392) have warned, it is used together with medical care.

#### **6.4 Missed opportunities to initiate HIV treatment adherence programmes**

While it is recognised that four of the Vulindlela church leaders show a measure of both inner and outer HIV competence, it must be noted that the other six participants did not initiate any programmes. In fact, not a great deal was carried out generally with regard to HIV treatment programmes with the exception of a few participants. This is a missed opportunity to respond positively, practically and theologically to the potential of the gift of life amidst challenges posed by HIV.

Church-driven HIV treatment programmes should go beyond the normal help that is provided in health care centres by providing the unconditional love of God through Christian compassion:

In the face of HIV and AIDS, the church's endurance and credibility are a critical resource. Communities are more favourably disposed towards HIV and AIDS programmes run by the church because it has demonstrated its commitment. Communities have come to know and trust the church as an abiding presence, unlike some NGOs that run programmes for a fixed number of years. This is a major advantage that the church enjoys over other social actors in the context of HIV and AIDS (Chitando 2007a:23).

In addition, Maluleke (2003:65) argues that "failure to probe the theological significance of this moment [HIV and AIDS moment] will be not only a missed opportunity but also

irresponsible.” Churches are in a strategic position to impart HIV knowledge and the necessity of adherence to ART since they have access to diverse communities. There is, thus, much more that needs to be done to ensure HIV competence within the church leaders of Vulindlela.

Findings revealed that in order for ART adherence programmes to be initiated by church leaders, there needs to be greater knowledge made available to them on the subject. Furthermore, for these programmes to be effective, younger church leaders need to be drawn into any HIV training that is initiated in Vulindlela. The findings show that those leaders who were elderly did not initiate any programmes, despite being knowledgeable about the negative impact of HIV, factors that increase vulnerability and issues of discrimination. Theological questions and church traditions also need to be addressed as these can pose a stumbling block to relevant involvement in current HIV issues. Those Vulindlela church leaders who said they believed in “holy water” and “prayer” were asserting their theological conviction and unwillingness to change. ART adherence was a new concept to some of the Vulindlela church leaders and their lack of starting ART adherence programmes was motivated by lack of knowledge.

## **6.5 Conclusion**

Vulindlela church leaders have shown that there is potential to enhance ART adherence, provided the necessary knowledge, support and theological training is provided. Four church leaders who have initiated ART adherence programmes in their churches have shown commitment and competent leadership. However, some of these leaders will need more training and assistance in order to develop these programmes further. Given this potential, there is a need for non-governmental organizations and other key stakeholders to engage church leaders on issues of HIV treatment and ART adherence.

In this chapter, the findings of the study were analyzed using Parry’s (2008) HIV competent church framework. In the next chapter, a summary of the study will be presented and recommendations for further research will be made.

## **Chapter Seven**

### **Conclusion**

#### **7.1 Introduction**

This study was largely motivated by evidence that the growing numbers of South Africans who are using ART daily are facing resistance to treatment because of a lack of proper adherence to their treatment regimen. Given that South Africa has the largest number of people on ART in the world, this good news story could become a story of sorrow. With this growing concern about treatment resistance, the gains that South Africa has made in saving lives could soon be lost. Religious leaders have increasingly been involved in mitigating the epidemic and it was, thus, important to investigate their potential contribution to reversing this looming tragedy. This concluding chapter of the study attempts to present a summary of the key findings and offer recommendations for further research.

#### **7.2 Summary of the study**

Chapter One introduced current concerns about HIV treatment resistance, including the motivating factors that encouraged the researcher to undertake this study. Different phases of the response to the HIV epidemic in South Africa generally and the current specific response of the church was briefly discussed. It was shown that theologians have called for a new theological curriculum, as well as the mainstreaming of HIV and AIDS into church programmes. In addition, the research process, including the study design, objectives, and research methodology was outlined. Finally, the study's theoretical considerations, drawn from Sue Parry's (2008) framework of being an "HIV competent church", were introduced. The chapter concluded with an outline of the structure of this study.

Chapter Two discussed the context of the study: the Vulindlela region, a rural community under the Msunduzi Municipality, Pietermaritzburg. In this chapter, essential socioeconomic, political and cultural issues were discussed in depth. Through mapping

the community in this way, it emerged that some of the social issues in Vulindlela were politically crafted by the previous government's administration that was responsible for social services prior to liberation in 1994. The unique geographical nature of Vulindlela that has promoted HIV prevalence and current statistics of HIV and AIDS were also presented. Due to the high HIV prevalence in Vulindlela, this region has attracted different research by various institutions, including university-based research centres, individual independent researchers and postgraduate university students. Some of these research findings contributed to this discussion, particularly with regard to the response of churches in the area to the HIV epidemic.

Chapter Three discussed HIV treatment in South Africa generally and ART adherence specifically. An historical account of the different stages of HIV treatment development, dating from 1987 when AZT was developed to the present day, was outlined. Since ART is a lifetime therapy, optimum ART adherence is necessary. Different understandings of "optimum adherence" were discussed. Four common treatment barriers were identified: medical, personal, family and community, and socio-economic related factors. Having discussed these barriers different ART adherence strategies were outlined. These strategies include pill counting, self-medication reporting, a medical event monitoring system, directly observed therapy and community support programmes. This chapter provided the medical background to the discussion on the importance of adherence to ART.

Chapter Four outlined Parry's (2008) theoretical framework of being an "HIV competent church". There are three main components that Parry indicates are necessary to becoming HIV competent. These include inner and outer competence and the particular skills necessary to linking these two competencies. It was noted that "HIV competence" is needed amongst church leaders in order to reduce stigma and discrimination and also, as I have argued, to enable church leaders to become engaged in ART adherence.

Chapter Five presented the findings of the field work conducted with ten church leaders in Vulindlela. The findings discussed covered four major factors that emerged during the data gathering process: knowledge of HIV and AIDS, involvement in HIV and AIDS

church programmes, HIV treatment and ART adherence, and knowledge and skills to assist with a better response to treatment adherence. Findings revealed that there were four church leaders who had initiated church and community-based programmes that were HIV and AIDS related. Other church leaders indicated different challenges that had prevented them from initiating HIV and AIDS related programmes. Two were specifically involved in ART adherence.

Chapter Six analysed the research findings, using the “HIV competence” framework outlined by Parry (2008). The analysis revealed that Vulindlela church leaders had the potential to support ART adherence programmes. However, there were challenges that were noted indicating that training and mentoring will be needed. The complexity of the concept of ART adherence emerged as a challenge that Vulindlela church leaders will have to deal with as a matter of urgency.

### **7.3 Key findings of the study**

There are five key findings that have emerged from this study. Firstly, Vulindlela church leaders are concerned about the spread of HIV and AIDS in the community. Some of them have demonstrated their concern by sensitizing their churches and the community about the negative impact of HIV. These sensitization activities include imparting HIV knowledge through training workshops and mass mobilization campaigns.

Secondly, of all ten participants, only four of the Vulindlela church leaders started general programmes that were meant to deal with social factors that promote the spread of HIV. These included engaging with factors that prohibit optimum ART adherence. So, in a limited way, there is a willingness to act against structural factors that facilitate treatment resistance. In some instances, participants attempted to formulate legal entities with constitutions that responded to HIV. The programmes that were initiated were regarded as platforms to lobby on behalf of people living with HIV. Furthermore, these programmes worked as centres of social cohesion which helped to reduce stigma and discrimination against people living with HIV and also provided a space to mitigate factors that negatively impact on ART adherence.



Thirdly, it became clear that the six Vulindlela church leaders that did not initiate any programmes did not do so for a variety of reasons. In some instances, the leaders were elderly, suggesting that any further training needs to be carried out with younger church leaders. In other instances, church traditions were a stumbling block, suggesting that more systematic theological training needs to be introduced that will assist leaders in dealing with the epidemic in a more positive theological way. Further training, therefore, that is initiated in Vulindlela needs to be much more focused on the particular stumbling blocks outlined in the findings of the study.

Fourthly, through the field work process, it became clear that church leaders find it difficult to talk about sex and sexuality. It emerged during the field work process that none of the interviewed participants mentioned the word “sex” or “sexuality”. This silence confirms that church leaders regard talking publicly about sex as an offensive subject. This issue, too, needs to be addressed in a sensitive way, taking into account cultural taboos and providing helpful theological insights into the subject.

Lastly, the field work process revealed that Vulindlela church leaders have little medical knowledge about ART and the importance of ART adherence. This was particularly the case for the six leaders who had not initiated any HIV programmes despite undergoing general HIV training in 2007. Unless, this information is imparted in a systematic way, with ongoing mentoring, there is little chance that the Vulindlela church leaders will fulfill their potential in engaging and contributing to ART adherence in their community. Only once they have this knowledge can they become more fully “HIV competent”.

## **7.4 Recommendations for further research**

**7.4.1** Studies on the potential of church leaders’ contribution to ART adherence should be carried out in other communities to assess whether these limited findings can be extrapolated to other settings.

**7.4.2** While theological curricula have increasingly addressed issues of HIV generally,

further research is needed on the extent to which the issue of ART adherence has been included.

**7.4.3** Action research needs to be carried with groups of clergy where training on ART and ART adherence is addressed.

## Bibliography

- April, M.D. Robin, W. Berkowitz, B.K. Paltiel, A.D. Anglaret, X. Losina, E. Freedberg, K.A. and Walensky, R.P., 2014. "The survival benefits of antiretroviral therapy in South Africa." *The Journal of Infectious Diseases*, 209(4), pp.491–9.
- Bangsberg, D.R. Hecht, F.M. Charlebois, E. D. Zolopa, A. R. Holodniy, M. Sheiner, L. Bamberger, J.D. and Chesney, M.A. 2000. "Adherence to protease inhibitors, HIV-1 viral load, and development of drug resistance in an indigent population." *AIDS Care*, 14(4), pp.357–66.
- Bottonari, K.A. Roberts, J. E. Ciesla, J.A. and Hewitt, R.G., 2005. "Life stress and adherence to antiretroviral therapy among HIV-positive individuals: a preliminary investigation." *AIDS Patient Care and STDs*, 19(11), pp.719 – 727.
- Burgess, R. 1998. "Vulindlela water supply project." In *24th WEDC Conference, Sanitation and Water for all*. Islamabad, pp. 313–314. Unpublished Conference paper.
- Calder, L. 2001. *Directly Observed Therapy (DOT) for Tuberculosis*. Wellington: Ministry of Health Publications.
- Chesney, M. A. 2003. "Adherence to HAART Regimens." *AIDS Patient Care and STDs*, 17(4), pp.169 – 177.
- Chirowodza, A. van Rooyen, H. Joseph, P. Sikotoyi, S. Richter, L. and Coates, T. 2008. "Using Participatory methods and geographic information systems (GIS) to prepare for an HIV community-based trial in Vulindlela, South Africa." *Journal of Community Psychology*, 37(1), pp.41 – 57.
- Chitando, E. 2007a. *Living with Hope: African Churches and HIV/AIDS 1*, Geneva: WWC Publications.
- Chitando, E. 2007b. *Acting in Hope: African Churches and HIV/AIDS 2*, Geneva: WWC Publications.
- Chitando, E. 2008. *Mainstreaming HIV and AIDS in Theological Education: Experiences and Explorations*. Geneva: WWC Publications.
- Cinti, S. K., Kaul, D. R., Sax, P. E., Crane, L. R., and Kazanjian, P. H. (2000). "Recurrence of Mycobacterium avium Infection in Patients Receiving Highly Active Antiretroviral Therapy and Antimycobacterial Agents." *Clinical Infectious Diseases*, 0378, pp.511–514.

- Dube, M. 2003a. "Towards Multi-sectoral Teaching in a Time of HIV/AIDS". In: Dube, M.W. *HIV/AIDS and the curriculum: Methods of Integrating HIV/AIDS in Theological Programmes*. Geneva: WWC Publications, pp. vii – xiii.
- Dube, M. 2003b. "An HIV and AIDS Curriculum for Theological Institutions in Africa." In: Dube M.W. *HIV/AIDS and the Curriculum: Methods of Integrating HIV/AIDS in Theological Programmes*, Geneva: WWC Publications, pp.152-153.
- Dube, M. 2003c. "Methods of intergrating HIV/AIDS in Biblical Studies." In Dube, M.W. *HIV/AIDS and the curriculum: Methods of Intergrating HIV/AIDS in Theological Programmes*. Geneva: WWC Publications, pp. 10 – 23.
- Durrheim, K. 2006. "Research design." In Terre Blanche, M. Durrheim, K. and Painter, D. *Research in practice: Applied methods for the social sciences*. Cape Town: UCT Press, pp.29-53.
- Ecumenical Pharmaceutical Network, 2009. "HIV and AIDS Treatment literacy guide for church leaders." Nairobi: Ecumenical Pharmaceutical Network.
- Elwyn, G. Frosch, D. Thomson, R. Joseph-Williams, N. Lloyd, A. Kinnersley, P. Cording, E. Tomson, D. Dodd, C. Rollnick, S. Edwards, A. and Barry, M. 2012. "Shared decision making: a model for clinical practice." *Journal of General Internal Medicine*, 27(10), pp.1361–1367.
- Fleischman, J. (2011). "Improving Women's Health in South Africa: Opportunities for PEEFAR." Center for Strategic and International Studies. Washington, DC. [http://csis.org/files/publication/111024\\_Fleischman\\_ImprovingWomensHealth\\_Web.pdf](http://csis.org/files/publication/111024_Fleischman_ImprovingWomensHealth_Web.pdf) \_Accessed on 8 November 2014
- Ford, N. Nachega, J.B. Engel, M.E. and Mills, E.J. 2009. "Directly observed antiretroviral therapy: a systematic review and meta-analysis of randomised clinical trials." *Lancet*, 374(9707), pp.2064–71.
- Frank, J. and Duncan, N. 2009. "Speaking to the experts and patients: Recommendations for improving ART adherence." *Health SA Gesondheid*, 14(1), pp.1–9.
- Garfield, S. Clifford, S. Eliasson, L. Barber, N. and Willson, A. 2011. Suitability of measures of self-reported medication adherence for routine clinical use: A systematic review. *Medical Research Methodology*, 149(11), pp.2 – 9.
- Gazzola, L. Tincati, C. Bellistri, G. M. Monforte, A. d'Arminio, and Marchetti, G. (2009). "The absence of CD4+ T cell count recovery despite receipt of virologically suppressive highly active antiretroviral therapy: clinical risk, immunological gaps, and therapeutic options." *Clinical Infectious Diseases*, 48(3), 328–37.

- Haddad, B. 2006a. *An audit of faith-based organisations and an assessment of their role in curbing or fuelling the HIV/AIDS epidemic in Vulindlela, KwaZulu-Natal*. Pietermaritzburg. Unpublished research report, University of KwaZulu-Natal.
- Haddad, B., 2006b. “We pray but we cannot heal: Theological Challenges Posed by the HIV/AIDS Crisis.” *Journal of Theology for Southern Africa*, 1(125), pp.80 – 90.
- Happonen, H. Jarvinen, and T. Virtanen, J. n.d. *Towards an HIV and AIDS competent church: An ecumenical handbook for defining HIV and AIDS competency*. CUAHA network and Tumaini University, Iringa University College.
- Heywood, M., 2009. “South Africa’s Treatment Action Campaign: Combining Law and Social Mobilization to Realize the Right to Health.” *Journal of Human Rights Practice*, 1(1), pp.14–36.
- Hlophe, H.I. 2010. “The Role of Treatment Buddies in the Public Sector Antiretroviral Programme in the Free State Province.” Unpublished PhD, University of Pretoria.
- Ibrahim, M. 2012. “Thematic analysis : A critical review of its process and evaluation.” *West East Journal of Social Sciences*, 1(1), pp.39–47.
- Jimmy, B. and Jose, J. 2011. “Patient Medication Adherence: Measures in Daily Practice.” *Oman Medical Journal*, 26(3), pp.155–159.
- Johansson, K. A. Robberstad, B. and Norheim, O. F. 2010. “Further benefits by early start of HIV treatment in low income countries: survival estimates of early versus deferred antiretroviral therapy.” *AIDS Research and Therapy*, 7(1), pp.2–9.
- Kharsany, A. B. M. Mlotshwa, M. Frohlich, J. Yende-Zuma, N. Samsunder, N. Abdool Karim, S.S. and Abdool Karim, Q. 2012. “HIV prevalence among high school learners - opportunities for schools-based HIV testing programmes and sexual reproductive health services.” *BMC public health*, 12(1), pp.1- 6.
- Khathide, A.G. 2003. “Teaching and Talking about our Sexuality: A means of Combating HIV/AIDS.” In Dube, M.W. *HIV/AIDS and the curriculum: Methods of Integrating HIV/AIDS in Theological Programmes*. Geneva: WWC Publications, pp. 1 – 9.
- Kogos, S.C. 2004. “Support Groups and Treatment Adherence in a Geriatric Outpatient Clinic.” *Journal of Clinical Psychology in Medical Settings*, 11(4), pp.275–282.
- KwaZulu-Natal Provincial Government, 2005. “KwaZulu-Natal traditional leadership and governance act, 2005 (ACT NO. 5 of 2005)” *KwaZulu-Natal Legislature*. Pietermaritzburg
- Li, L. 2009. “Understanding Family Support for People Living with HIV/AIDS in Yunnan, China.” *AIDS and behavior*, 10(5), pp.509–517.

- Livingston, I.L. Johnson, M. and Smiley, S. 2009. "The Epidemic of HIV/AIDS in Sub-Saharan Africa and Selected Consequences." In *18th Annual Conference of the Global Awareness Society International*. Washington D.C.: Howard University, pp. 1–11.
- Luque-Fernandez, M.A. Van Cutsem, G. Goemaere, E. Hilderbrand, K. Schomaker, M. Mantangana, N. Mathee, S. Dubula, V. Ford, N. Hernán, M. and Boulle, A. 2013. "Effectiveness of patient adherence groups as a model of care for stable patients on antiretroviral therapy in Khayelitsha, Cape Town, South Africa." *PloS One*, 8(2), pp.1- 8.
- Lushaba, V. (2005). "Coping strategies of low-income households in relation to HIV/AIDS and food security." Unpublished MA, University of KwaZulu-Natal.
- Maenza, J. and Flexner, C. (1998). "Combination Antiretroviral Therapy for HIV Infection." *American Family Physician*, 58(11), 2789–2798.
- Maluleke, T.S.2003. "Towards an HIV/AIDS-Sensitive Curriculum." In Dube,M.W. *HIV/AIDS and the curriculum: Methods of Intergrating HIV/AIDS in Theological Programmes*. Geneva: WWC Publications, pp. 59–76.
- Maqutu, D. Zewotir, T. North,D. Naidoo, K. and Grobler, A 2011. "Determinants of optimal adherence over time to antiretroviral therapy amongst HIV positive adults in South Africa: a longitudinal study." *AIDS and Behavior*, 15(7), pp. 1465–1474.
- Mbali, M. (n.d.). *The Treatment Action Campaign and History of Rights-based, Patient-driven HIV/AIDS Activism in South Africa*, Durban. (pp. 1–23).Unpublished Paper, University of KwaZulu-Natal.
- Mboya, R. 2005. "The response of Holy trinity Church, Sweetwaters to HIV/AIDS: A Critical Analysis." Unpublished MTh, University of KwaZulu-Natal.
- Mills, J. Nachege, J.B. Buchan, I. Orbinski, J. Attaran, A. Singh, S. Rachlis, B. Wu, P. Cooper, C. Thabane, L. Wilson, K. Guyatt, G. H. and Bangsberg, D.R. 2006a. "Adherence to antiretroviral therapy in sub-Saharan Africa and North America: a meta-analysis." *The Journal of the American Medical Association*, 296(6), pp.679–90.
- Mills, E. J. Nachege, J.B. Bangsberg, D.R. Singh, S. Rachlis, B. Wu, P. Wilson, K. Buchan, I. Gill, C. J. and Cooper, C. 2006b. "Adherence to HAART: A systematic review of developed and developing nation patient-reported barriers and facilitators." *PLoS medicine*, 3(11), pp.2039–2064.
- Mtembu, M.L. 2008. *The accessibility to social assistance by persons living with HIV/AIDS in the Vulindlela area*. Unpublished MA, University of KwaZulu-Natal.

- Munyika, V. and Jarvinen, T. n.d. "Stigma." In H. Happonen, T. Jarvinen, J. Virtanen, eds. *Towards an HIV and AIDS Competent Church: An ecumenical handbook for defining HIV and AIDS competency*. Iringa: CUAHA, pp.39 – 41.
- Nachega, J.B. Knowlton, A.R. Deluca, A. Schoeman, J. H. Watkinson, L. Efron, A. Chaisson, R.E. and Maartens, G. 2006. "Treatment Supporter to Improve Adherence to South African Adults." *Journal of Acquired Immune Deficiency Syndrome (1999)*, 43(1), pp.127–133.
- Naidoo, D. 2010. *The Zibambele Rural Road Maintenance Poverty Alleviation Programme : A case study employing the livelihood approach as a tool to understand poverty alleviation in the Vulindlela area*. Unpublished MA, University of KwaZulu-Natal.
- Nel, A. Mabude, Z. Smit, J. Kotze, P. Arbuckle, D. Wu, J. van Niekerk, N. and van de Wiggert, J. 2012. "HIV incidence remains high in KwaZulu-Natal, South Africa: evidence from three districts." *PloS one*, 7(4), pp.1–8.
- Nozaki, I. Dube, C. Kakimoto, K. Yamada, N. and James, B. 2011. "Social factors affecting ART adherence in rural settings in Zambia." *AIDS Care*, 23(7), pp.831–838.
- Nunes, V. Neilson, J. O'Flynn, N. Calvert, N. Kuntze, S. Smithson, H. Benson, J. Blair, J. Bowser, A. Clyne, W. Crome, P. Haddad, P. Hemingway, S. Horne, R. Johnson, S. Kelly, S. Packam, B. Patel, and M. Steel, J. 2009. *Medicines Adherence: Involving patients in decision about prescribed medicines and supporting adherence*, London: NCCPC.
- Nurnberger, K.1997. *Faith in Christ: Invitation to Systematic Theology*. Pietermaritzburg: UNP Press.
- Osterberg, L. and Blaschke, T. 2005. "Adherence to Medication." *The New England Journal of Medicine*, 353(5), pp.487–497.
- Park, J. and Nachman, S. 2010. "The link between religion and HAART adherence in pediatric HIV patients." *AIDS Care*, pp.556 – 561.
- Parry, S. 2008. *Beacons of Hope HIV Competent Churches: A framework for action*. Geneva: WWC Publications.
- Paterson, D. Mohr, J. and Al, E. 1999. "How much adherence is enough? A prospective study of adherence to protease inhibitor therapy using MEMS." In *6th Conference on Retroviruses and Opportunistic Infections*. Unpublished Conference presentation, Chicago.

- Rapley, T. 2007. "Interviews." In Seale, C. Gobo, G. Gubrium, J.F. and Silverman, D. *Qualitative Research Practice* (1st ed., pp. 15–34). London: SAGE Publications LTD.
- Reaves, C.1992. *Quantitative research for the behavioral sciences*, New York: John Wiley and Sons, Inc.
- Sabate, E. 2001. *World Health Organization Adherence Meeting June 2001*. Geneva. <http://www.who.int/chp/knowledge/publications/adherencerep.pdf> \_ Accessed on 16 May 2013
- Scott, D. 2002. *The Impact of HIV / AIDS on rural households and land issues in Southern and Eastern Africa*, Pretoria.
- Shah, C. 2007. "Adherence to High Active Antiretroviral Therapy (HAART) in Pediatric Patients infected with HIV: Issues and Interventions." *Indian Journal of Pediatrics*, 74(1), pp.55 – 60.
- Shisana, O. Rehle, T. Simbayi, L. Zuma, K. Sean, J. Zungu, N. and Onoya, D. 2014. *South African National HIV Prevalence, Incidence and Behaviour Survey, 2012* (1st Ed.). Cape Town: HSRC Press.
- Snow, J. 2010. Adult adherence to treatment and AIDSTAR-one technical brief, Arlington: USAID.
- South African Government Department of Health, 2003. *Operational plan for comprehensive HIV and AIDS care, management and treatment for South Africa*, Pretoria.
- South African Government Department of Health, 2004. *National Antiretroviral Treatment Guidelines* (1st ed.). Pretoria: Jacana.
- South African Government Department of Health, 2010. *The South African antiretroviral treatment guidelines 2010*, Pretoria.
- South African Government Department of Health, 2012. *National Strategic Plan on HIV, STIs and TB 2012-2016*, Pretoria.
- South African Government Department of Health, 2013. *The South African antiretroviral guidelines 2013*, Pretoria.
- South African Government Department of Human Settlements, 2009. *The National Housing Code: Enhanced People's Housing Process*, Pretoria: South African Parliament.



- South African Municipal Demarcation Board, 2008. *Act No. 27 (2008)*. South Africa: Government Gazette. <http://www.westerncape.gov.za/Text/2003/a27-98.pdf>\_ Accessed on 5 June 2014.
- Udidi environmental planning and development consultants, 2011. *Msunduzi local municipality (Vulindlela community based plan report)*, Pietermaritzburg.
- Umgungundlovu Health District. 2014. *Umgungundlovu Health District Report: April - June 2014*. Pietermaritzburg.
- UNAIDS. 2013. *Global report: UNAIDS report on the global AIDS epidemic 2013*. Geneva: UNAIDS.
- Van Dyk, A.C. 2011. *Antiretroviral Adherence in South Africa : Are we burning our bridges?*, Pretoria: UNISA.
- Vella, S. Schwartländer, B. Sow, S. P. Eholie, S. P. and Murphy, R.L. 2012. “The history of antiretroviral therapy and of its implementation in resource-limited areas of the world.” *AIDS Care*, 26(10), pp.1231–41.
- Wanjohi, N.A. 2009. *Factors that influence non-adherence to antiretroviral therapy among HIV and AIDS patients in Central Province, Kenya*. Kenyatta University.
- Watt, M.H. Maman, S. Jacobson, M. Laiser, J. and John, M. 2009. “Missed opportunities for religious organizations to support people living with HIV/AIDS: findings from Tanzania.” *AIDS Patient Care and STDs*, 23(5), pp.389–94.
- Welz, T. Hosegood, V. Jaffar, S. Batzing-Feigenbaum, J. Herbst, K. and Newell, M. 2007. “Continued very high prevalence of HIV infection in rural KwaZulu-Natal, South Africa: a population-based longitudinal study.” *AIDS Care* 21(11), pp.1467–1472.
- Wilkinson, L.S. 2013. “ART adherence clubs : A long-term retention strategy for clinically stable patients receiving antiretroviral therapy.” *South African Journal of HIV Medicine*, 14(2), pp.48–50.
- World Health Organization, 2011a. *Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access Progress Report 2011*, Geneva.
- World Health Organization, 2011b. Combat drug resistance: no action today, no cure tomorrow. Director-General Statement, World Health Day 2011, Geneva.
- Wouters, E. van Damme, W. van Rensburg, D. Masquillier, C. and Meulemans, H. 2012. “Impact of community-based support services on antiretroviral treatment programme delivery and outcomes in resource-limited countries: a synthetic review.” *BMC Health Services Research*, 12(1), pp.1–17.

Wu, J.R. Moser, D.K. Chung, M.L. and Lennie, T.A. 2008. "Objectively measured, but not self-reported, medication adherence independently predicts event-free survival in patients with heart failure." *Journal of Card. Fail.*, 14(3), pp.203–210.

Zuyderduin, J. R. Ehlers, V. J. and M, van der W. D. 2008. "The Impact of a Buddy System on The Self-Care Behaviours of Women Living with HIV / AIDS In Botswana." *Health SA Gesondheid*, 13(4), 4–15.

### **Internet sources**

<http://www.besg.co.za/human-settlements/case-study-in-housing-intervention-vulindlela-rural-housing-project.html>. Accessed on 16 October 2013

<http://www.webmd.com/hiv-aids/news/20131030/early-hiv-treatment-a-win-win-researchers-report>. Accessed on 24 November 2013

Msunduzi Municipality, 2013. *Integrated Development Plan 2013/2014*. Pietermaritzburg. [http://www.msunduzi.gov.za/site/idp\\_](http://www.msunduzi.gov.za/site/idp_) Accessed on 5 June 2014.

Msunduzi Municipality, 2014. *Integrated Development Pan 2014 / 15*. Pietermaritzburg. [http://www.msunduzi.gov.za/site/idp\\_](http://www.msunduzi.gov.za/site/idp_) Accessed on 5 June 2014.

## **Appendix A**

### **Informed Consent Letter**

Dear Participant,

My name is Thulani Ngubane, I am a Research Masters student from the University of KwaZulu-Natal. I will be asking some people from your community to answer a few questions for my research which I hope will benefit your community.

I am conducting research regarding enhancing adherence to HIV treatment and the potential role of church leaders in Vulindlela.

We have chosen you because you are a local church leader and in 2006 you participated in another study that was conducted in this area. I hope that I can learn more about the issues that affect adherence to HIV treatment.

The interview will last around 45-60 minutes. I will be asking you a few questions and request that you are as open and honest as possible in answering these questions. Some questions may be personal or sensitive and you may choose not to answer these questions. I will also be asking some questions that you may not have thought about before, which involve thinking about the past and the future. Please know that there are no right or wrong answers.

An audio recorder will be used during the interview. The tape recorder will be used in order to assist me in gathering your view on the topic, so that I can carefully analyze and write down the information collected.

Your participation is voluntary and you can choose to withdraw from the interview at any time. There will be no penalties if you wish to withdraw.

The results of this study may be released in a journal article and presented at the postgraduate conference at the School of Religion and Theology. The university may also use the findings for future studies but confidentiality will be maintained by not referring to you by your real name. No personally identifying information or recordings will be released in any form and the recordings will be kept securely in a locked environment and will be destroyed after 5 years or erased once data capture and analysis are complete.

If you have any questions about any aspect of this study, you may contact the researcher, Thulani Ngubane, at the University of KwaZulu-Natal (School of Religion and Theology) on 0728712806 or you may also contact Dr Beverley Haddad at the University of KwaZulu-Natal (School of Religion and Theology) on: 033-2605560.

Your participation will be highly appreciated.

Thank you.

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**Consent**

I \_\_\_\_\_ (full names of participant)

Hereby confirm that I understand the contents and the nature of this study and I agree to participate. I understand that I am participating freely and without being forced to do so. I also understand that I can withdraw from this interview at any point should I not wish to continue.

I understand that my name will remain confidential.

-----  
Signature of participant

-----  
Date

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Additional consent to audio recording

I \_\_\_\_\_ (full names of participant)

In addition to the above, hereby agree to the audio recording of this interview for the purpose of data capture. I understand that no personally identifying information or recording concerning me will be released in any form. I understand that these recordings will be kept securely in a locked environment and will be destroyed after 5 years or erased once data capture and analysis are complete.

-----  
Signature of participant

-----  
Date

## **Appendix B**

### **Interview guide**

1. What training have you received in HIV and AIDS?
2. What programmes have you implemented in your church since you have received this training?
3. What do you know about adherence to ARVs?
4. Where did you obtain this knowledge?
5. What do you know about HIV treatment adherence?
6. Where did you obtain this knowledge?
7. What programs are available in your Church to enhance adherence to HIV treatment?
8. Would it be important to network with other groups, if so who?
9. What knowledge and skills will assist you to respond better to treatment adherence?