The Nature and Extent of HIV/AIDS-related Stigma Reported by Aspiring Faith-based Leaders

by

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ABSTRACT

More than 30 years after the first case of HIV/AIDS was reported, the disease continues to pose challenges for governments and communities across the world, but particularly in Southern Africa. Response to the disease is hindered by contextual influences, which vary between countries and cultural groups. With HIV/AIDS, one size does not fit all. The complexity of this disease is still not fully understood and information regarding its spread and prevalence is often fluid and unreliable. Communities' emotional reaction to HIV/AIDS, including stigmatising, plays a role in this scenario. FBOs (including churches) are uniquely positioned to provide HIV/AIDS education and prevention messages through their extensive networks that reach even the most remote villages. However, during the era of HIV/AIDS, FBOs or their members have been the target of criticism. They have been accused of promoting stigmatising and discriminatory attitudes based on fear and prejudice, of pronouncing harsh moral judgements on those infected and of reducing the issues of AIDS to mere moral issues.

The primary research question in this research focused on determining the nature and extent of HIV/AIDS-related stigma reported by aspiring faith-based leaders. The study questionnaires were completed by aspiring faith-based leaders who participated in *Choose Life* training programmes. These aspiring faith-based leaders were used as an indirect measure of stigma in their respective FBOs. The assumption is made that the attitude of faith-based leaders may affect the communities they serve. A KAP survey was used to determine the knowledge, attitudes and practices within these organisations. A group of 133 aspiring faith-based leaders who attended a HospiVision training programme, *Choose Life*, participated in the study. Non-parametric tests were used in the analysis of the data. Test include Spearman Rho correlations, Kruskal-Wallis and Mann-Whitney.

It was found that respondents are knowledgeable about HIV/AIDS. Despite their high level of knowledge, there is still fear and worry about sharing eating or drinking utensils with those infected. Unrealistic fear of HIV transmission is one of the building blocks of HIV-related stigma. Respondents were generally unaware of people living with the virus in their congregation. This demonstrates that disclosure of HIV status is relatively low. It may be a fear of stigma that

represents a barrier to disclosure. A high percentage of respondents (44%) indicated that they would feel ashamed should the virus infect them or someone in their family (28%). They were, however, more accepting of other people who are infected (only 12% indicated PLWHA should be ashamed). These contradictions make it difficult to understand the level of stigmatising and the reasons behind the responses. In spite of prevention campaigns run by various organisations, stigma and discrimination still exist and this may hamper our response to the illness.

The study was relatively small, but its results are similar to those of earlier studies conducted nationally among faith-based leaders. Stigma and discrimination remain factors that have to be considered in all programmes developed to address the current HIV crisis. Even when knowledge about the disease is significant and respondents are well educated, some stigma still prevails.

FBOs are amongst the institutions in society that shape the values and attitudes that guide responses to illness and vulnerability and that support appropriate and compassionate responses. This research shows that FBOs have an important role to play in promoting religious beliefs that confront stigma and in encouraging positive dialogue to counter damaging thought patterns in communities.

KEYWORDS

HIV/AIDS, Stigma, Discrimination, Knowledge, Attitudes, Practices, KAP survey, Faith-based Organisations, Faith-based Leaders

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ACRONYMS AND ABBREVIATIONS

AB	Abstain, Be faithful
ABC	Abstain, Be faithful, or use Condoms
ACSA	Anglican Church of Southern Africa
AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-retroviral Treatment
ARV	Anti-retroviral Drugs
BCC	Behaviour Change Communication
CADRE	Centre for AIDS Development, Research and Evaluation
CBO	Community-based Organisation
C&T	Counselling and Testing
CDC	US Centers for Disease Control and Prevention (in Atlanta, USA)
CHSRD	Centre for Health Systems Research and Development
DOH	Department of Health
FINIS	Framework Integrating Normative Influences on Stigma
FBO	Faith-based Organisation
GF	Global Fund
HIVAN	Centre for HIV/AIDS Networking
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
KAP	Knowledge, Attitudes and Practices
MARPs	Most at Risk Populations
MDG	Millennium Development Goals
NCOP	National Council of Provinces
NGO	Non-governmental Organisation
NSP	National Strategic Plan
PEPFAR	The President's Emergency Plan for AIDS Relief
PLWHA	People/Person living with HIV or AIDS
PLWHIV	People/Person living with HIV
SA	South Africa
SAG	South African Government
SPSS	Statistical Package for the Social Sciences
STD	Sexually Transmitted Disease
TB	Tuberculosis
UNAIDS	United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development
USG	United States Government
VCT	Voluntary Counselling and Testing
WAD	World AIDS Day
WHO	World Health Organisation

CHAPTER 1: INTRODUCTION

The study explores the nature and extent of HIV/AIDS-related stigma as reported by aspiring faith-based leaders attending a training programme. This provides an indirect measure of the prevalence of stigma in the faith-based organisations from which the trainees were drawn. The research context provides a background for the study and explains why it is necessary to pursue this information. This chapter introduces the research questions that formed the basis of this study.

1.1. CONTEXT OF THE RESEARCH

HIV, the virus that causes AIDS, has become one of the world's most serious health and developmental challenges. HIV/AIDS has been a part of life for many people during the past 30 years and has caused widespread devastation, especially in the sub-Saharan region. Huge unmet needs continue to exist in the fight against HIV/AIDS. People become infected or die from this disease every day (UNAIDS, 2012a). The drivers and risk factors associated with this disease are complex and diverse.

The quality of life of persons living with HIV/AIDS is influenced by the stigma that exists across the globe. Stigma is the devaluation of an individual or group based on a specific characteristic or association (UNAIDS, 2005). Stigma underpins the violation of the human rights of people living with HIV/AIDS. Despite being widely recognised, the stigma associated with HIV/AIDS remains a little understood phenomenon (Mahajan et al., 2008).

Now, 30 years after the disease became known, the HIV stigma continues to exist. The ability to accurately identify and measure HIV stigma is critical, as it "interferes with effective societal responses to AIDS and has imposed hardships on people living with HIV as well" (Herek, Capitanio, & Widaman, 2002, p. 371).

HIV-related stigma is widely regarded as a key impediment to effective prevention and care. The psychosocial challenges faced by a Person or People Living with HIV or AIDS (PLWHA) range from being exposed to stigma and discrimination, to dealing with the anger and fear of living with a serious health problem (Lekganyane & du Plessis, 2012).

Stigma is a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons (Goffman, 1963; Link & Phelan, 2001). There are various perspectives of stigma. Stigma can be felt and the subjective awareness of stigma (anticipated or internal) leads to an unwillingness to seek help and access to resources. Enacted stigma, the actual experience of a stigma is observed in discrimination based on HIV status or association with someone who is living with HIV. The persons who are stigmatised can then also accept and therefore internalise the stigma. The effect of the stigma and discrimination against PLWHA is a major hindrance in the struggle against the infection. Stigma interferes with the support, care, treatment, and prevention of the illness (Holzemer & Uys, 2004; Steward et al., 2008).

The National Strategic Plan (NSP) of 2012-2016 (Department of Health, 2012) supports a multi-sectorial approach in efforts to address the HIV epidemic. The NSP is an umbrella guide that informs national, provincial, municipal and community-level stakeholders regarding strategic directions to consider when developing implementation plans. A multi-sectorial approach combines the resources of all sectors of society in order to achieve goals and objectives, especially at local level where a community-centred, integrated approach is critical. The multidimensional nature of HIV necessitates a multi-sectorial response in order to prevent the disease from spreading any further. The complexities of the South African context, with its mixture of first- and third-world characteristics, exacerbate the difficulty of responding to the disease (Department of Health, 2012). In this study, the emphasis will fall on Faith-based Organisations (FBOs) as one of the partners in the multi-sectorial collaboration in addressing HIV/AIDS.

FBOs are of particular interest in the struggle for HIV prevention and service delivery because they often provide health-related infrastructure reaching into the rural areas. FBOs tend to be the custodians of values influencing members' behaviours. They may consequently play a key role in dealing with the challenge of HIV/AIDS.

FBOs have the advantages of an established following, an existing infrastructure to reach people and access to resources beyond the immediate community. Faith-based leaders are frequently respected as opinion leaders in their communities and, in religious ceremonies, have a public platform from which to challenge destructive prejudices that reinforce stigma, while conveying important information concerning HIV prevention and care (Lindgren, Schell, Rankin, Phiri, Fiedler & Chakanza, 2013). People tend to listen to what faith-based leaders talk about. FBO also have the capacity to care for people in

their community who are in need of care, such as HIV infected individuals. FBOs are instrumental in providing guidance to members of the congregation on what is right or wrong. With respect to AIDS in particular, religion deals with sexual morality and how to cope with illness and death (Krakauer & Newbery, 2007).

Churches have traditionally viewed discourse on sexuality as dangerous, preferring to treat it as a taboo subject confined to the most private spheres of our lives. This secrecy made it difficult for FBOs to engage in sex education. It can be assumed that stigma associated with HIV/AIDS stems inter alia from the fact that it is a sexually transmitted disease associated with various forms of promiscuous and morally unacceptable behaviour (Delius & Glaser, 2005). PLWHA may feel self-blame, guilt, and shame because of their infection and may be expected to feel ashamed. In an African context, stigma is built on a series of beliefs that HIV is associated with immoral behaviour, religious punishment and lack of adherence to cultural norms (Visser & Sipsma, 2013). In many cases, fears are based on irrational beliefs about HIV transmission, in particular casual transmission (Valdiserri, 2002).   FBOs may advocate acceptance of PLWHA, but there remains an underlying aura of judgement and criticism. It is this sexual and moral connotation associated with HIV that can potentially affect the perception of FBOs as stigmatising entities.

Stigma, from this viewpoint, is rooted in sexual shame. Continued self-shame associated with HIV infection (in spite of a low reported blaming discourse) suggests that moral judgements are made regarding sexual behaviour and consequently regarding HIV status (Simbayi, Kalichman, Strebel, Cloete, Henda, & Mqeketo, 2007). Stigma often undermines or interferes with efforts directed at HIV and AIDS prevention, care and treatment. People who are most in need of such services often find themselves isolated, afraid and prone to self-stigmatising behaviour (Simbayi et al., 2007).

In policy discourse, the potential of religious organisations to play a role in harnessing the societal response to HIV/AIDS is often emphasised. From the highest political levels, support has been given to faith-based responses to the pandemic (Agadjanian & Soma, 2007). Agencies have channelled resources through these organisations in an attempt to fight the disease. Unfortunately human nature makes it difficult for individuals to adhere to, or even to acknowledge, faith-based insistence on premarital abstinence and marital fidelity. Where faith-based organisations insist on these principles as their sole response to HIV/AIDS and reason that support for using condoms may actually encourage promiscuity, they relinquish opportunities to convey the safe sex message (Agadjanian & Soma, 2007).

Bouwer (2007, p. 263) stated that discrimination is increased by "giving conflicting messages about condom use and by interpreting HIV/AIDS as God's punishment of sinners." Stigmatisation has also been reinforced by Christianity's condemning view on premarital and extramarital sex, which can contribute to feelings of guilt and shame. This has resulted in defensive behaviour, fatalism and self-stigmatisation among members of the religious community (Bouwer, 2007). Such behaviour make prevention and treatment difficult by establishing silence and by rendering those infected unwilling to disclose their status.

Unfortunately, very little work has been done in determining the role FBOs currently play in the countering of stigmatisation and regarding further assistance they can willingly render in the struggle against the scourge of HIV/AIDS. As it is important to employ all possible advantageous tactics in this struggle, particularly within the South African context, it was decided to embark on this enquiry into the level and expression of stigma in faith-based organisations. This research focused on the stigma expressed and observed by aspiring faith-based leaders attending the *Choose Life* training programmes.

Research about stigma in FBOs could contribute to the understanding of stigma as a global problem. It could also contribute to better cooperation between FBOs and other role players in HIV prevention and care. This could lead to the forming of a greater body of knowledge geared towards understanding stigma and discrimination. Such knowledge is crucial in decision-making processes, such as the channelling of funds through appropriate organisations. It is important to strengthen organisations that could make a difference in eradicating stigma and discrimination. Understanding the effect of stigma and discrimination could help to identify possible interventions to reduce stigma and eventually to curtail infection rates in South Africa.

1.2. OBJECTIVES OF THE RESEARCH

This research aims to explore the nature and extent of HIV/AIDS-related stigma reported by aspiring faith-based leaders. Stigma is measured by means of Knowledge, Attitudes and Practices (KAP) surveys among aspirant faith-based leaders participating in the *Choose Life* training programme.

1.2.1. Primary Objective

The primary objective of this research is to explore and understand the nature and extent of HIV/AIDS-related stigma reported by aspiring faith-based leaders. The assumption is that these attitudes may

impact in a direct or indirect way on the communities they serve. This may have an effect on the preventive behaviour in communities and may affect PLWHA within their communities.

1.2.2. Secondary Objectives

The secondary objectives are to:

- gain understanding of the extent of aspiring faith-based leaders' experience with HIV/AIDS in the church community;
- gain understanding of the nature and extent of feelings of shame, blame or judgemental attitudes associated with HIV/AIDS;
- gain understanding of the nature and extent of discriminatory or exclusionary practices/behaviours, specifically by religious leaders, towards people infected and affected by HIV/AIDS; and
- identify factors contributing to HIV/AIDS-related stigma and discrimination.

1.3.   STRUCTURE OF THE STUDY

The introductory chapter discussed the research context, orientation and justification as well as the research objectives and the importance of the research.

In Chapter 2, the literature review focuses on HIV/AIDS in the South African context. It compares South African statistics with those of other countries and highlights the social dimensions of HIV/AIDS. The concepts of stigma and discrimination are formally defined. FBOs are further defined, with regard to the role they play in HIV prevention, care and treatment. Factors leading to stigma are identified. Approaches that may lead to a better understanding of the impact of stigma and discrimination in SA are discussed. Four theoretical frameworks are highlighted in an attempt to assist in defining and understanding stigma and discrimination.

Chapter 3 introduces the research methodology used in the study. This is followed by a discussion of quantitative research as an appropriate research approach, along with the researcher's theoretical point of departure. The chapter concludes with a discussion of survey research and KAP surveys. Thereafter, the questionnaire development and sampling method are described. Finally, analysis of data and ethical considerations are discussed.

Chapter 4 presents the data analysis and statistical procedures, programmes and methods employed to reach meaningful conclusions and strategic recommendations.

In Chapter 5, the results are discussed and compared to the findings presented in existing literature. This chapter includes the conclusions of the research, its limitations, and recommendations for future research.

CHAPTER 2:   LITERATURE REVIEW

2.1.   INTRODUCTION

It has been more than 30 years since the first HIV cases were reported in 1981 (UNAIDS, 2011a). Since then, HIV has not faded in global significance. The viral epidemic was accompanied by a social epidemic of comparable severity (UNAIDS, 2011a). "Grounded in fear, ignorance, and social disapproval of groups heavily affected by HIV, the epidemic of stigma and discrimination frequently overwhelmed the ability and willingness of communities and countries to respond to HIV" (UNAIDS, 2011a, p. 19).

Before the study and data collection are presented, it is imperative to give some background on the extent of the pandemic in South Africa (SA) as well as the associated stigmatisation and discrimination. This chapter aims to provide a brief explanation of the constructs of stigma and discrimination. It highlights the multifaceted nature of HIV/AIDS-related stigma (or simply HIV/AIDS stigma). The research specifically focuses on how stigma manifests itself in the context of FBOs.

2.2.   HIV/AIDS IN CONTEXT

The HIV/AIDS pandemic has become an integral aspect of life worldwide. No country has been unaffected by the disease. At the end of 2011, an estimated 34 million people were living with HIV globally. This was up from 28.6 million in 2001, which reflects an increase of nearly 17% during the period of 10 years. The increase was a result of new infections, people with HIV living longer because of medication, and general population growth (UNAIDS, 2011b). In 2011, 1.7 million people died of HIV-related causes worldwide, a 24% decrease since 2005. The global prevalence rate (the percentage of people aged 15–49 who are infected) has levelled since 2001 and was 0.8% in 2011 (UNAIDS, 2012a).

The severity and nature of the pandemic differ by sub-region and by country, as illustrated by the prevalence rates in Figure 1 below (UNAIDS, 2012a). HIV/AIDS has devastated sub-Saharan Africa and SA in particular. Of the estimated 34 million PLWHA worldwide in 2011, more than 23.5 million people (69%) were from sub-Saharan Africa – a region with only 12% of the global population (UNAIDS, 2012a). Sub-Saharan Africa remains the epicentre of the AIDS epidemic, where nearly one in every 20 adults (4.9%) is living with HIV (UNAIDS, 2012a).

Adult Prevalence Rate by Region, 2011

East Asia — 0.1%
Middle East & North Africa — 0.2%
Western & Central Europe — 0.2%
Oceania — 0.3%
South and South–East Asia — 0.3%
Latin America — 0.4%
North America — 0.6%
Eastern Europe & Central Asia — 1.0%
Caribbean — 1.0%
Sub–Saharan Africa — 4.9%
Global — 0.8%
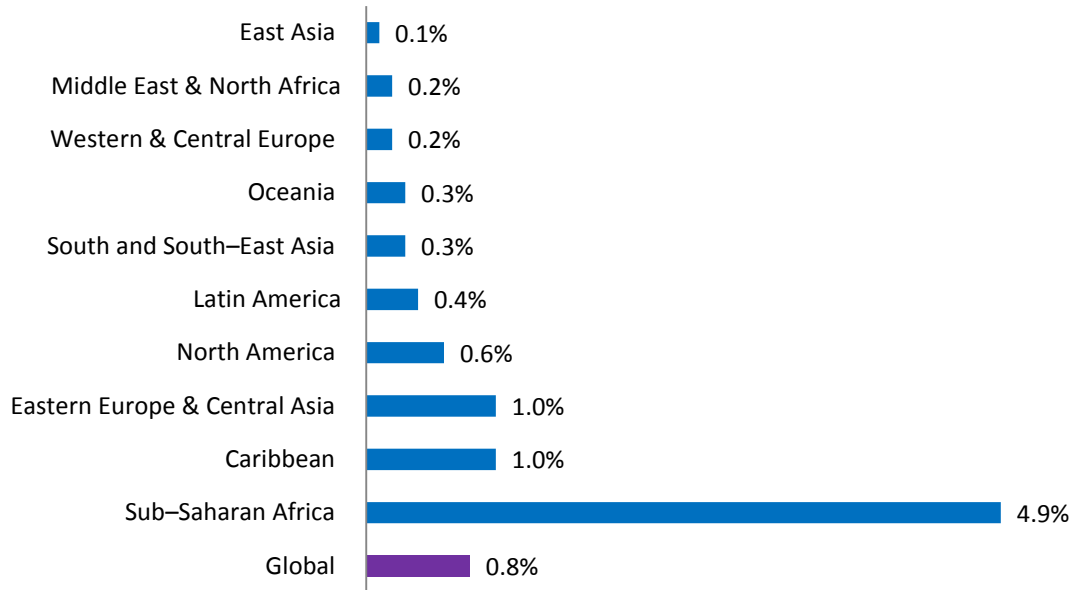
(UNAIDS, 2012a, p. 15)

Figure 1: Adult Prevalence Rate by Region, 2011

In 2011, Sub-Saharan Africa continued to account for 71% of all new HIV infections globally, with approximately 108 million new infections occurring in 2011 (UNAIDS, 2012a). In sub-Saharan Africa, women account for nearly 60% of adults with HIV infection – this is 10% more than the global average (UNAIDS, 2011b). Most children with HIV live in this region (94%). In 2009, more than 16.6 million children in sub-Saharan Africa were estimated to have lost one or both parents to AIDS (UNAIDS, 2010). The nine countries with the highest prevalence rates worldwide are all located in the sub-Saharan African region. These countries have an adult HIV prevalence greater than 10%.

South Africa was home to an estimated 5.6 million PLWHIV at the end of 2011 (UNAIDS, 2011b). Data from the Department of Health (DOH) 2011 antenatal survey suggests that the prevalence of HIV has plateaued over the past five years, albeit at the high level of nearly 30%. SA's estimated national HIV prevalence among the general adult population aged 15-49 is currently at 17.3% (Department of Health, 2011) and has remained stable for the past five years. The epidemic in South Africa can be described as hyperendemic, due to its high prevalence rate.

Hyperendemic HIV scenarios refer to "those areas where HIV prevalence exceeds 15% in the adult population, driven through extensive heterosexual multiple concurrent partner relations with low and inconsistent condom use" (UNAIDS, 2007, p. 2). In a hyperendemic HIV prevalence context, the overall risk per sex act involves a higher proportional likelihood of exposure to HIV, as every sex act has a far higher likelihood of involving at least one partner who is HIV positive.

However, by defining the epidemic as hyperendemic, the complexity of the disease and challenges in prevention are also highlighted. Focus on the key drivers of the disease entails a more intensified scrutiny of prevention on several levels. In South Africa, heterosexual sex is recognised as the predominant mode of HIV transmission, followed by mother-to-child transmission. Drivers of the epidemic include high levels of migration, low perception of risk and multiple concurrent sexual partnerships (Department of Health, 2009; UNAIDS, 2007). Drivers and risk factors associated with the disease are complex and diverse. Until recently, it was reported that all efforts directed towards curtailing the epidemic were fruitless and no significant results were evident because specific drivers and structural determinants had not been addressed (UNAIDS, 2008b).

Now, after 30 years of pandemic growth of the disease, there seems to be a global decrease in new infections (UNAIDS, 2012b). The national declines in HIV incidence in populations shows that sustained investments and increased political leadership for the AIDS response are paying dividends (UNAIDS, 2012b). However, the changing economic climate worldwide has resulted in downward pressures on funding sources. The Global Fund (GF) has reported that funding for overall development aid to fight HIV/AIDS has diminished since 2009 (Bland, 2011). Reduced funding by international donors such as GF, the World Bank and The President's Emergency Plan for AIDS Relief (PEPFAR) has again result in a changing landscape. Reduced funding may make it impossible for some countries to scale up or improve treatment programmes, as health ministries in many countries are dependent upon international donors to make up for any shortfall they may experience (PlusNews, 2011). Thus, despite huge unmet existing needs (UNAIDS, 2011a), decreased funding has resulted in a decline of domestic and international resources. The lack of financial resources influences the implementation of many HIV programmes, and of new or existing programmes that may also address stigma and discrimination. Reduced international funds will only increase the strain in the sub-Saharan region.

When planning an effective response to the increased HIV risk and vulnerability, societal factors also have to be considered. People affected by the virus are losing their jobs, homes and access to care.

There is a need to protect the human rights of PLWHA, as was emphasised by the recognition of the role that stigma and discrimination play in blocking the effective response to the disease (UNAIDS, 2010). Stigma goes beyond all set boundaries, affecting everyone in all social classes and racial groups. Due to high infection rates in South Africa, there is a strong probability that a large number of South Africans have experienced some form of discrimination based on their HIV status – and still many more may become vulnerable to stigmatisation.

Hyperendemic countries require broad-based societal mobilisation to address the socio-cultural and economic practices contributing to unsafe sexual behaviour. Interventions must complement intensive knowledge and behavioural change to address the drivers of the epidemic. For example, to reduce the number of people who have multiple concurrent sexual partnerships, this segment of the population must be educated about the risks they are taking (UNAIDS, 2008a).

It is therefore important that "all stakeholders should work to promote gender equality, women's empowerment, reduce HIV stigma/discrimination, and alleviate the social marginalisation of groups at highest risk of exposure to HIV" (UNAIDS, 2008a, p. 27). This is especially true for hyperendemic settings, where minor changes in risk behaviour to curb the spread of the disease are likely to have a limited impact on the epidemic's trajectory (Katsidzira & Hakim, 2011).

2.3. PREVENTIVE EFFORTS

A multi-sectorial approach was used in countries such as Uganda and Thailand, where early prevention has been relatively successful in the fight against HIV/AIDS compared to other countries (Ainsworth, Beyrer, & Soucat, 2003; Hogle, 2002; Punyacharoensin & Viwatwongkase, 2009; Shelton, Halperin, Nantulya, Potts, Gayle, & Holmes, 2004). The prevalence of HIV has declined significantly in Uganda, from 15% in 1991 to 5% in 2001. This has been the result of behavioural changes, as identified in several surveys and qualitative studies (Hogle, 2002). Key elements identified in the Ugandan success story seem to be absent in other countries such as Zimbabwe, Botswana, Kenya and South Africa where the HIV epidemic is still a serious problem. Hogle (2002) summarised these key elements as:

- High-level political involvement and support focusing on a multi-sectorial response.
- Decentralised planning and implementation for Behaviour Change Communication (BCC) that reached both general populations and key target groups.

- Interventions addressed women and youth, stigma and discrimination.

- Religious leaders and FBOs have been active on the front lines of the response to the epidemic.

- Condom social marketing has played a key but evidently not the major role.

- Sexually Transmitted Disease (STD) control and prevention programmes have received increased emphasis.

- The most important determinant in the reduction in HIV incidence in Uganda appears to be a decrease in multiple sexual partnerships and sexual networks.

The first South African NSP (2007-2011) built on lessons learnt so far across the African continent. This was followed by the current five-year plan, the NSP 2012–2016 (Department of Health, 2012). The current NSP could be viewed as the beginning of a new era in the response to HIV, tuberculosis (TB) and the social drivers of these epidemics in South Africa. The previous NSP (2007-2011) intended to drive the multi-sectorial approach implemented by the South African Government (SAG). Although the government adopted the plan, the Minister of Health at the time, Minister Manto Tshabalala-Msimang and President Thabo Mbeki resisted the implementation of it. Denial of the impact of the disease and different viewpoints to treat the disease did not result in cooperation of different sectors in addressing the epidemic. Some of the key interventions the previous NSP (2007-2011) proposed, such as a programme to provide voluntary medical male circumcision on a large scale, were delayed; the rollout of anti-retroviral treatment (ARVs) was slow for several years, and preventable infections and deaths continued. Five years later, the status has changed considerably. Since the last five-year plan, there has been a revolution in the response to AIDS.

South Africa's achievements in addressing the pandemic since 2007 are reflected in the fact that the number of people on ARV treatment has grown from less than 200 000 in 2006 to over 1.7 million in 2012 – an increase of 75% (UNAIDS, 2012b). In the last two years alone, fifteen million people have tested voluntarily for HIV. The vertical transmission of HIV from mother to child during pregnancy and birth has dropped from nearly 20% of pregnancies to 2.7% (Heywood, 2012).

The national decline in HIV incidence shows that sustained investments and increased political leadership for the AIDS response are paying dividends (UNAIDS, 2012b). Leadership from government is critical in the response against HIV/AIDS. Effective national responses depend on commitment and action from various groups, including community groups, FBOs, as well as private businesses.

Collaboration of various role players was reflected at the World AIDS Day (WAD) Stigma Summit held on 1 December 2009. Stakeholders from different sectors were brought together to engage actively with *The HIV/AIDS Charter*[1], focussing on responsibility: "I am responsible, we are responsible, and South Africa is taking responsibility." This initiative challenged stigma and discrimination, and called for mobilising community action.

The new global theme for WAD 2011 will run until 2015, and comprises three messages: "Zero new HIV infection, zero discrimination, and zero AIDS related deaths" (Khumalo, 2012). Stigma and discrimination continue to be highlighted in the WAD messages.

Many South Africans do not know their rights and are discriminated against based on their HIV status. Service providers may also not know the rights of those who are affected, and often unwittingly violate these rights. These behaviours are challenged by the WAD Stigma Summit, which has initiated a process for bringing *The HIV/AIDS Charter* to life by means of increased knowledge. The government is also taking responsibility for making sure that everyone who tests for HIV receives counselling about available condoms, and that all people have access to treatment for TB and HIV (SAG, 2009). This echoes President Jacob Zuma's address to the National Council of Provinces (NCOP) in Cape Town:

> All South Africans must know that they are at risk and must take informed decisions to reduce their vulnerability to infection, or, if infected, to slow the advance of the disease. Most importantly, all South Africans need to know their HIV status, and be informed of the treatment options available to them. Though it poses a grave threat to the well-being of our nation, HIV/AIDS should be treated like any other disease. There should be no shame, no discrimination, no recriminations. We must break the stigma surrounding AIDS (Zuma, 2009, p. 1).

The Millennium Development Goals (MDG) provide a common global vision, with the NSP's key strategic objectives providing further guidance to improve response mechanisms in South Africa. In the next five years, the key strategic objectives include:

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[1]The HIV/AIDS Charter outlines the basic human rights of people living with HIV.

- Addressing social and structural barriers increasing vulnerability to HIV, STI and TB infection;

- preventing new HIV, TB and STI infections;

- sustaining health and wellness and

- increasing protection of human rights and improving access to justice (Department of Health, 2012).

However, the situation in Africa is compounded by many additional factors. In Africa, HIV/AIDS is only one epidemic affecting the lives of many. It is therefore important to understand the African context and specifically the South African context when discussing HIV/AIDS. One has to recognise and identify the African realities of poverty, overburdened health services, other diseases such as TB, gender and cultural issues, youths engaging in high-risk sexual behaviour, double standards in sex education, rampant denial and stigma (Parry, 2003). These social realities have a profound effect on vulnerability to HIV.

Stigma comprises a number of components and differs by country. The purpose of the literature review is to explore the concept of HIV-related stigma as experienced by individuals affected by HIV/AIDS. A clearer understanding of HIV/AIDS-related stigma is the foundation for development of interventions that address HIV-related stigma.

2.4. STIGMA

HIV/AIDS-related stigma and discrimination are as old as the epidemic itself. In every social setting, people who are infected or assumed to be infected have been subjected to a variety of negative reactions. These have included physical and verbal abuse, loss of homes and employment, rejection by their families and friends, and violation of their basic human rights. These reactions do not only affect people's basic human rights, but can also have a considerable negative impact on the health of both the individual and the community (Foreman, Lyra, & Breinbauer, 2003; Paterson, 2005).

Although stigma exists in one form or another in all societies, it is a social construct that is understood in different ways around the globe. Stigmatisation is a dynamic process of devaluation of individuals or groups based on some characteristic, behaviour or aspect, and it is frequently linked to issues of power and social control within a particular society (EngenderHealth, 2004). HIV/AIDS is unlike any other disease of our time. It is perhaps the most serious global challenge the world is currently facing. Social

conditions have a profound effect upon people's vulnerability to HIV. The development of stigma related to HIV/AIDS within a society often builds upon and reinforces earlier negative attitudes and thoughts that exist within a society. Often people with HIV/AIDS are believed to deserve the disease because they have done something that is considered as wrong by society, such as engaging in homosexual behaviour or being promiscuous (EngenderHealth, 2004).

The people most affected by HIV/AIDS are the poor, living in townships, although the disease is not exclusive to the poor. Stigma is an important factor that may even contribute to individuals avoiding risk-reduction behaviours such as abstinence, partner limitation, disclosure of status to sexual partners or practising correct condom use, as these behaviours may be associated with being HIV positive (UNAIDS, 2008a). Heijnders and Van der Meij (2006) state that stigma is increasingly recognised as having a major impact on public health interventions. Stigma and the fear of discrimination can lead to a delay in seeking medical assistance and increased risk of transmission of the disease. This remains a risk since people do not want to test and disclose their status; they do not adhere to treatment and increase their risk of drug resistance. In fear of discriminative behaviour, people may be reluctant to be tested or to seek treatment (Foreman et al., 2003).

People with HIV, or belonging to high-risk groups, are therefore less likely to protect themselves and their partners from potential infection in fear of discrimination (Foreman et al., 2003). Heijnders and Van der Meij (2006) note that several programmes have been implemented specifically for stigma-reduction interventions at various levels. These include rarely evaluated interventions on intrapersonal, interpersonal, organisational, community and governmental levels. In spite of efforts to change negative attitudes and eliminate discrimination associated with the illness, it continues to be a highly stigmatised disease (Alonzo & Reynolds, 1995; Link & Phelan, 2001; Paterson, 2005). People are therefore reluctant to talk about the disorder, and this creates a barrier to the prevention and treatment of HIV/AIDS (Parker & Birdsall, 2005; Visser, Makin, & Lehobye, 2006).

There is general agreement on the existence of HIV/AIDS-related stigma and discrimination. However, several aspects of the phenomenon are poorly understood, partially because HIV/AIDS-related stigma and discrimination are multi-layered phenomena (Fenton & Easterbrook, 2008). These underlying components are often poorly distinguished and are often defined differently by researchers of different disciplines. This makes it difficult to compare results of already completed studies (Foreman et al.,

2003). Defining and understanding general stigma within the broader South African context – and not only related to health issues– is therefore essential.

2.5.   DEFINING STIGMA AND DISCRIMINATION

The term *stigma* is widely used in a number of diverse contexts, though a clearly defined and shared understanding about what *stigma* means (Green, 2009) does not exist. According to Link and Phelan (2001), there are wide variations in the conceptualisation of stigma, influenced by researchers' different frames of reference. This relates to their multidisciplinary backgrounds, diverse settings and the circumstances where stigma has been studied. In response to these findings Link and Phelan (2001) defined stigma as "the co-occurrence of its components: labelling, stereotyping, separation, loss of status and discrimination" in a context in which power is exercised (Link & Phelan, 2001, p. 363).

The word *stigma* stems from the Greek word referring to a tattoo mark branded on a person's skin and is a mark of disgrace (Mbonu, van den Borne, & de Vries, 2009). Today the term stigma is applied more to social disgrace than to any bodily designs (Mbonu et al., 2009).

As a point of departure, in defining and understanding stigma in social science research, the work of Erving Goffman is widely recognised. Goffman's classic book: *Stigma: Notes on the Management of Spoiled Identity* (1963) describes stigma as a *spoiled identity*. Goffman brands stigma as a socially constructed label of deviance, examining interactions between those who possess discrediting attributes and those who do not. He defines stigma as "a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons. When individuals fail to meet normative expectations because of attributes that are different and/or undesirable, they are reduced from accepted people to discounted ones. Stigma is not merely an attribute, but represents a language of relationships" (Goffman, 1963, p. 3). Goffman applied the term *stigma* to any condition, attribute, trait or behaviour that symbolically marked the bearer as unacceptable or inferior, resulting in feelings of shame, guilt and disgrace. Stigma negatively affects the way individuals perceive themselves and how others perceive them.

Even though Goffman defines stigma as an "attribute", he points out that stigma is not in fact a quality of a person, but a quality of a relationship (Goffman, 1963), as it represents a language of relationships

(Alonzo & Reynolds, 1995). Stigma is, unfortunately most commonly viewed as an attribute, as something in the person and not only a label others have affixed to them.

Goffman (1963) found it to be critical to recognise that the stigmatised individual holds the same basic beliefs about identity as other people and would, but for the stigma, view him- or herself as normal. This means that the person sees him/herself as an individual who deserves a fair chance, but the person may realise that others do not really accept him as a normal person or as an equal, and he/she may believe that something is wrong with him/her, since he/she displays attributes or behaviour that may violate accepted standards. Ultimately, stigma is responsible for creating outsiders – those who are stigmatised compared to "normal" individuals. Consequently, these marginalised individuals internalise this stigma (Visser, Kershaw, Makin, & Forsyth, 2008). These deviant forms of behaviour are therefore bound to a specific historical period and cultural context (Alonzo & Reynolds, 1995). This subjective sense of identity incorporates positive and negative, rational and irrational thoughts and emotions, defining how people see themselves in relation to others (Parker & Birdsall, 2005). The individual is "thus reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 3). Such people are not treated as individuals but as someone who belongs to a stigmatised category and through this process, the person is devalued because of the label attached to them (Green, 2009).

The attributes in question do not fit the normal mould or stereotype of a person. Therefore, an "undesired differentness from what we had anticipated" (Goffman, p. 5) has occurred. Stigma is a *deeply discrediting* attribute (Goffman, 1963, p. 3). It is this difference between what is viewed to be *normal* and those differences in the stigmatised individual that make that person different, limiting their level of acceptance in society and resulting in stigmatising behaviour (Alonzo & Reynolds, 1995).

Alonzo and Reynolds (1995, p. 304) describe the stigmatised as "[A] category of people who are pejoratively regarded by the broader society and who are devalued, shunned or otherwise lessened in their life chances and in access to the humanising benefit of free and unfettered social intercourse." The individual or group may accept these labels and believe that they deserve to be treated and labelled in such a way. They internalise the stigma as part of their identity and do not resist stigma and discrimination. The individual's reaction thus reinforces the stigma until it becomes an accepted way of interaction and it is then difficult to change these behaviours. This negatively affects the stigmatised group such as PLWHA and their significant others.

Stigma is multi-dimensional. Firstly, the cause of the stigma can be visible or hidden according to Goffman (1963). Goffman refers to visible stigma as being *discrediting* or hidden stigma as being *discreditable*, such as people with undisclosed HIV status. Goffman (1963) categorised attributes in three domains: (1) abominations of the body, e.g. physical disability or visible deformity, (2) blemishes of individual character, e.g. mental illness, criminal behaviour, homosexuality, or (3) tribal stigmas, e.g. race, gender, religion. Jones and colleagues (1984) distinguish six dimensions of stigma: concealability, course, disruptiveness, aesthetics, origin and peril.

From the dimensions identified above it is apparent why HIV/AIDS infection receives such a negative response. According to Alonzo and Reynolds (1995), individuals with HIV/AIDS are stigmatised because:

- their illness is associated with deviant behaviour;
- infected individuals are viewed to be responsible for their own condition;
- they are tainted by a religious belief in their immorality and are thought to have contracted the disease by immoral behaviour;
- sufferers are perceived as contagious and threatening to the community;
- they are associated with an undesirable and an unaesthetic form of death and
- infected individuals are not well understood by the lay community and viewed negatively by health care providers.

Two essential core elements of HIV-related stigma in Africa are the fear of transmission of the virus due to poor knowledge about the disease, and judgement created by asserting morality and assigning blame (Visser & Sipsma, 2013).

Shame and blame are often more strongly associated with the way the disease was acquired rather than the disease itself. HIV infection may be viewed by some members of the community as a just consequence of engaging in immoral, irresponsible or illegal behaviours, including homosexuality, sex work, promiscuity and drug use (Valdiserri, 2002). In general, societies view these behaviours negatively, so it is easy to attribute blame to PLWHA. Moreover, PLWHA may feel self-blame, guilt, and shame as a result of their infection and may be expected to feel ashamed. In an African context, stigma is built on a series of beliefs that HIV is associated with immoral behaviour, religious punishment and lack of adherence to cultural norms (Visser & Sipsma, 2013).

In many cases, fears are based on irrational beliefs about HIV transmission, in particular casual transmission (Valdiserri, 2002).

Fear may also be associated with the unalterable and degenerative nature of the disease and its progression, which ultimately leads to an unpleasant and unsightly death (Alonzo & Reynolds, 1995; Herek & Capitanio, 1998). For that reason, HIV/AIDS-related stigma is rooted in the fear of infection, with other factors such as negative cultural stereotypes and attitudes toward sexuality contributing to stigmatisation (Hutchinson, Mahlalela, & Yukish, 2007). Ignorance and the lack of knowledge of the mode of transmission are often associated with HIV-related stigmatisation. Communication programmes aimed at improving knowledge of the infection can potentially play a role in reducing stigma, as was found by Babalola, Fatusi and Anyanti (2009).

Stigma manifests itself in several ways, which can be broadly grouped as physical and social isolation or exclusion, verbal stigma such as gossip and insults, loss of role such as denied religious rites, and loss of resources such as their job and housing. Consequently, PLWHA may suffer social rejection, financial insecurity, shame and/or guilt, low self-esteem, depression, and other psychological problems. Not surprisingly then, PLWHA who perceive a stigmatising environment may be reluctant or even afraid to disclose their status to others, thereby minimising any negative consequences but also putting their sexual partners at greater risk. If HIV-infected people do not take care of themselves, they could contribute to further infections. Knowing one's status is an important aspect in the prevention of the spread of the infection. Delius and Glaser (2005) state that the suffering of people living with HIV/AIDS has been intensified by the stigma that surrounds the disease.

2.6. CLASSIFYING STIGMA AND DISCRIMINATION

As with defining stigma, classification of stigma is problematic, as there is no single way to classify stigma because of the complexity of the phenomenon. Herek (2007) and Steward et al. (2008) built their conceptual frameworks on Scambler's (1989) hidden distress model. This model emphasises three ways in which individuals experience stigma, and considers the importance of stigma management in the social interactions of PLWHA (**Figure 2**). Stigma can manifest itself as enacted stigma, felt stigma and internalised stigma (Herek, 2007; Steward et al., 2008).
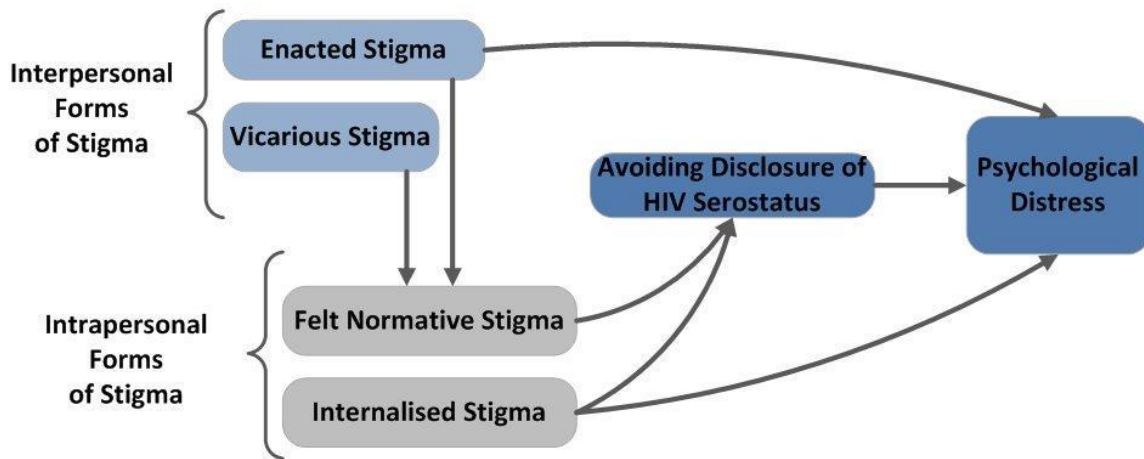
Steward, et al., 2008

Figure 2: Theoretical framework linking facets of stigma

2.6.1. Enacted Stigma

The first component encompasses interpersonal actions and is labelled *enacted stigma*. The infected person on an interpersonal level can define enacted stigma as the actual experience of stigma. This is the overt behavioural expression of stigma on the sole grounds of PLWHA's social unacceptability (perceived positive status) and can be experienced in the form of violence, being shunned by family and the community, to mention a few (Engender Health, 2004; Herek, 2007; Scambler, 2009; Steward et al., 2008;). Enacted stigma represents discrimination by others and how the stigmatised persons experience from their point of view (Scambler & Paoli, 2008).

By contrast, the second (felt stigma) and third (internalised stigma) components labelled as such to reflect intrapersonal experiences of stigma.

2.6.2. Felt Stigma

Felt stigma describes people's internal perceptions and expectations concerning how others will think and react to the seropositive status of the PLWHA. Another term for felt stigma is *perceived stigma*. It thus refers to the person's subjective awareness of stigma within the local community or the degree to which stigma is perceived as normative. This subjective awareness of stigma encapsulates the intrapersonal experiences of stigma and may provide a basis for individual behaviour (Steward et al.,

2008). PLWHA are ashamed and therefore try to hide the stigmatising condition because of fear of encountering enacted stigma. The general desire to avoid being the target of enacted stigma results in felt stigma affecting their behaviour. There is the realisation that certain behaviour is stigmatised (Herek, 2007; Scambler, 2009). Various stigma management strategies are used in an attempt to limit the extent to which PLWHA may be a target of enacted stigma, and to protect them. It is therefore important to realise that people need not be affected by enacted stigma in order for stigma to affect their lives. As people generally wish to avoid being the target of stigma enactments, felt stigma often affects behaviour (Herek, 2007).

Felt stigma, therefore, refers to the type of behaviour a stigmatised person expects to encounter, while enacted stigma refers to the actual behaviour they encounter. There may also be differences in the actual amount of enacted stigma or discrimination that a person with HIV/AIDS encounters, when compared to the amount of discrimination another person perceives. Felt stigma may also motivate others who may be HIV positive to enact stigma against others to prove to the congregation that they are HIV negative (Herek, 2007).

2.6.3. Internalised Stigma

Internalised stigma or self-stigma refers to the extent to which an individual accepts stigma as valid. "When stigma is internalised by members of the non-stigmatised majority, the result is prejudice toward the stigmatised. When it is internalised by stigmatised individuals themselves, the result is self-stigma" (Steward et al., 2008, p. 1226). Stigmatised individuals' self-concept is consistent with the stigmatising responses of the greater community. People accept the responses of others as valid, which results in increased psychological stress, as shown in **Figure 2**. They accept stigma as part of their own value system and self-concept (Herek, 2007). The impact of internalising stigma leads to negative self-worth, resulting in non-disclosure of status to significant others, social withdrawal, strained interactions with potential stigmatisers, symptoms of depression and reduced self-esteem, in turn resulting in a compromised quality of life (Link & Phelan, 2001; Visser et al., 2008). Stigma results in an internalised sense of shame and blame, accompanied by a fear of being discriminated against (Scambler & Paoli, 2008). Felt normative stigma results in PLWHA monitoring and modifying their behaviour by avoiding disclosure of their HIV serostatus, to try to avoid stigma in the future. The decision not to disclose could result in those who are affected by the disease to experience increased psychological stress directly and indirectly, as it prevents PLWHA from seeking social support and other resources.

Internalised stigmatisation or self-stigma is an individual's personal acceptance of stigma as part of their value system, which is congruent with the stigmatising responses of society – the expectation of stigmatised individuals as to how others will react to their condition (Herek, 2007).

2.7. THE PRODUCTION OF STIGMA

Link and Phelan (2001) describe the production of stigma. They portrayed the stigma trajectory as consisting of the components as summarised below:

- Labelling – human differences are noted and labelled
- Stereotyping – these labels are imbued with negative stereotypes
- Othering – labelled persons are clearly categorised as *other* or *them* in order to clearly separate *them* from *us*
- Status loss – labelled persons are perceived by others and by themselves as devalued and inferior
- Discrimination – labelled persons experience discrimination leading to rejection and exclusion
- Power – stigma will emerge only if there is a clear power differential between *us* and *them*

Just mentioning the word *AIDS* can elicit a range of feelings in people, such as fear, revulsion, anger, contempt and shame (Kalichman & Simbayi, 2003). HIV/AIDS is intimately linked to sex and death. The stigma around HIV/AIDS persists because it is deeply enmeshed with social and personal views, beliefs, fears and taboos regarding sex and death (Nyblade et al., 2003). Nyblade and colleagues (2003) affirmed that HIV-related stigma is dynamic because stigma changes as the individual progresses from HIV to AIDS and as the disease evolves within the specific community affected. It is thus difficult to change stigmatising attitudes.

In the next section, the role of FBOs in the prevention of HIV and care and support for PLWHIV will be outlined.

2.8. FAITH-BASED ORGANISATIONS

For an effective response in addressing the issues of HIV and stigma and discrimination, we have seen from the aforementioned that a multi-sectorial response is crucial. FBOs, which are active in even the smallest and most remote of communities as well as large urban centres, are able to reach people to

provide a range of services to those in need. In the developing world, FBOs are the major providers of prevention and care and support services to people living with HIV/AIDS. FBOs are uniquely positioned to spread HIV/AIDS education and prevention messages through their extensive networks.

In the era of HIV/AIDS, FBOs have been the targets of many accusations, such as promoting stigmatising and discriminating attitudes based on fear and prejudice or pronouncing harsh moral judgements on those infected, and of reducing the issues of AIDS to simplistic moral statements. Medieval churches were indeed places that excluded those who were suffering the consequences of their own moral sin (Green, 2003; Parry, 2003). Parry (2003) was of the opinion that some of these accusations have been justified. He would like to believe that 30 years of pandemic should have brought about more changes in the stances of FBOs. Whilst the moral debate – particularly around the condom issue – has raged in many circles, it has delayed action and in many eyes discredited FBOs commitment to tackling AIDS and saving lives (Parry, 2003).

2.8.1. Defining FBOs and Religious Leaders

FBOs range from "groups of individuals who have come together voluntarily around a stated spiritual or belief system that informs and guides their work together. FBOs range from small, grassroots organisations with simple structures and limited personnel to large, global institutions with highly sophisticated bureaucracies, wide networks, substantial financial resources, and significant human resources" (Green, 2003, p. 3). Defining FBOs can therefore be difficult. A FBO is defined by PEPFAR (2012, p.13) as: "an organisation that is influenced by stated religious or spiritual beliefs in its mission, history, and/or work." The Global Fund (2008) defines FBOs as:

- religious and religion-based organisations and networks;
- communities belonging to places of worship;
- specialised religious institutions and religious social service agencies; and
- non-profit institutions having a religious character or mission.

As a minimum, FBOs must be connected with an organised faith community either in the form of a particular faith ideology, in drawing of staff, volunteers, or leadership from a particular faith denomination (Scott, 2003).

Faith-based leaders, for the purpose of this study, are defined as men or women of faith who formally and informally reach community members through their roles as aspiring leaders, carers, gatekeepers, teachers, and advocates. The religious community recognises the role that these leaders play in their congregation. These leaders can be ordinary members of their congregation.

2.8.2. The Role of FBOs

The role and impact of religious leaders and FBOs vary and must be understood within their cultural context. Generally, religious leaders are trusted and respected in communities throughout the world. People turn to them for guidance on family and personal matters, including decisions about health, education and livelihoods. Religious leaders, along with their well-established networks of volunteers and community groups, have the potential to promote and sustain positive changes in the social norms, attitudes and behaviours that affect development. FBOs provide a structure to educate religious leaders from a variety of backgrounds on issues of common concern such as HIV/AIDS, translating preventive information into messages that people in local communities can understand and value (PEPFAR, 2012).

The significant role of FBOs in the response against AIDS was illustrated in the following research: The Centre for Health Systems Research and Development (CHSRD) at the University of the Free State and the Centre for HIV/AIDS Networking (HIVAN) at the University of KwaZulu Natal were commissioned by the Department of Health to develop a national database of HIV/AIDS organisations. This was done in an effort to develop a national database of HIV/AIDS organisations and to help mobilise resources in the fight against HIV/AIDS (Birdsall, 2005).

In their review of FBOs, the Centre for AIDS Development, Research and Evaluation (CADRE) found that FBOs play a significant role in the response against AIDS. In 2004, approximately 10% of the organisations in the national database classified themselves as being faith-based (Birdsall, 2005). This is a significant resource available in the fight against HIV/AIDS. Faith-based organisations of diverse types and profiles are involved with multiple aspects of AIDS response in South Africa, with particular focus on HIV prevention and care services (Birdsall, 2005).

The role of religion in the fight against HIV and AIDS is frequently talked about. It is often argued that religion discourages risky behaviour and therefore serves as a barrier to HIV infection. In particular, it is said that religious people are less likely to have multiple or casual sexual partners (Agadjanian & Soma, 2007). Religious organisations can also make an important contribution to raising public awareness of

HIV/AIDS by using their established channels and mechanisms. In poor areas, where secular institutions are relatively weak and ineffective, the role of religious organisations, with their social mobilisation potential and networks of committed activists, can be especially significant. Religious-based initiatives are pivotal to the success of prevention and care efforts globally. Churches are found in nearly all communities and have a significant level of cultural, political, social, educational and economic influence. Churches are respected within local communities and often have existing resources, structures and systems upon which to build. Churches possess the human, physical, technical and financial resources needed to support and implement small- and large-scale initiatives. They can undertake these actions in a very cost-effective manner, due to their ability to leverage volunteers and rally other resources (Green, 2003).

For these reasons, a multi-sectorial approach is advocated, and it is such an approach that has been used to underpin the NSP (Sub-Objective 1.7: Strengthening community systems). The NSP refers to HIV/AIDS as being addressed by numerous sectors and organisations at various levels of society in a coordinated way. This involves strengthening the capacity of community systems and expanding services to, among others, FBOs. This human resource networks are coupled with infrastructure, e.g. places of worship, halls, schools and hospitals, which can be used to enhance existing programmes and create new programmes and services, and to act as points of service delivery, information centres and points of referral to services (Department of Health, 2012). According to the UNAIDS (2008b), faith-based organisations play an integral part in expanding the treatment programme, making treatment accessible to individuals, while encouraging people to change their risky behaviour. With respect to AIDS in particular, religion deals with sexual morality and how to cope with illness and death (Krakauer & Newbery, 2007).

Green (2003) argues that religious leaders' emphasis on abstinence and monogamy led to a change in sexual behaviour, namely that the age of first intercourse increased, and the reports indicated that the incidence of multiple partners decreased, as evident in surveys undertaken in the past decade. FBOs tend to be the custodians of values influencing members' own behaviour as well as their behaviour towards others (Lindgren et al., 2013).

Unfortunately, the resources, capabilities and potential of the churches/FBOs being part of the solution and/or a driving force in the fight against HIV/AIDS have not been used to their full capacity. There is an increasing realisation of the influence of FBOs working within communities (Green, 2003).

Traditionally, the church has always been involved in the care and support of people in need and people affected by disease. With the HIV pandemic, it has been the same. FBOs have been providing care, support and counselling for people living with HIV/AIDS, including care for AIDS orphans, income-generating projects for people living with HIV/AIDS and their dependents, as well as HIV-prevention activities. FBOs have stepped forward and have made huge contributions in the fight against the disease. In recognition of the role they have been playing in the prevention of HIV/AIDS, funding has been channelled through these FBOs to help them fight the infection at the local level (Merson, O'Malley, Serwadda, & Apisuk, 2008). In mainstream media, FBOs have been praised for the health and support services they provide, yet chastised for their messages on sexual morality.

At the same time, religious leaders may disagree with the secular authorities on approaches to HIV prevention. Religious leaders may be particularly reluctant to directly accept (not to mention to promote) the notions of safer sex and condom use on the grounds of the perception that condom use may encourage extramarital and casual sex (Agadjanian & Soma, 2007).

The importance of faith-based organisations in dealing with the challenge of HIV/AIDS cannot be ignored (Bouwer, 2007). Many people who have been working in HIV prevention believe that religious leaders and organisations were/are antagonistic to what they set out to achieve. People view traditional religious leaders as conservative moralists who disapprove of non-standard sexual practices or any form of sexual behaviour outside marriage. In view of their on-going moral debate on the use of condoms, it is also believed that religious leaders disapprove of condom use as a way of preventing the HIV infection. Religious leaders prescribe abstinence and mutual monogamy in a relationship as preventive behaviour, even in the face of overwhelming evidence that these behaviours are not always the norm (Green, 2003). At a primary level, behaviour change could include fidelity to a single partner, sexual abstinence, or young people delaying the age at which they begin to engage in sexual intercourse. Secondary behaviour change involves the use of condoms or the treatment of sexually transmitted diseases. For AIDS prevention, most programmes promote behaviour changes such as abstinence, monogamy and the use of condoms – if the first two options fail. Behavioural changes compatible with prevention strategies promoted by FBOs have had a significant impact on risky behaviour and HIV infection rates in countries such as Uganda, Senegal and Jamaica (Green, 2003; Kareithi, Rogers & Mash, , 2005).

Increasingly, it is being recognised from both within and without, that the church is a key stakeholder in the HIV/AIDS epidemic in Africa. It is seen to have the moral authority to "speak and influence change in

people's lives. FBOs can therefore be useful partners in addressing stigma and discrimination within communities.

2.8.3. FBOs and Stigmatisation

Belonging to FBOs such as churches does not seem to be a protective factor against HIV infection, as many of those who are infected are part of a church community (Parry, 2003). Many members of faith communities associate HIV/AIDS with immoral sexual behaviour and sin committed by the individual. Such a view could distance the faith community from HIV-infected members of their own community. Resultant stigmatising could also reduce HIV prevention in cases where the return to traditional moral values and standards of sexual behaviour fail. This preventive style has not been successful in all communities and could have counterproductive effects on people who do not adhere to these moral values. It is believed that churches cannot address HIV/AIDS without first breaking the silence that surrounds issues of sex, drug addiction, sin and death. In an HIV/AIDS-supportive environment, disclosure is encouraged as it breaks the silence. It also allows PLWHA to tap into existing support services.

Judgemental attitudes reinforce denial and secrecy by PLWHA who are fearful of stigmatisation and discrimination by other community members. Those affected by the disease are often cast out of their villages and faith communities because of fearful community members (Haddad, 2005). Many religious organisations, while compassionately caring for patients with HIV/AIDS, refuse to promote condoms or provide sexual education to the youth, because they perceive this as condoning or encouraging promiscuity (Merson et al., 2008). These FBO viewpoints could undermine other efforts to mitigate the impact of HIV/AIDS and to prevent further spread of the virus.

Evidence shows that multiple concurrent partners and various forms of transactional sex are major drivers of the disease (UNAIDS, 2008a), as faithfulness has not yet been established as a predominant norm in Southern Africa. In reaching out to people with different believes, customs and/or practices, FOBs may be wise to acknowledge this state of affairs and the lifesaving role condom use may play in the process. Should FBOs deny current South African realities they could forego opportunities to strengthen secular prevention programmes.

The Most at Risk Populations (MARPs), which are those groups in which the prevalence of HIV is higher than in the general population, include sex workers and their clients, as well as migrant labour and truck

drivers (Shisana et al., 2009). At-risk populations are among the most marginalised and most likely to be stigmatised. These groups are more vulnerable to HIV infection due to a variety of factors such as more frequent exposure to the virus, involvement in risky behaviour, potentially weak family and social support systems, marginalisation, lack of resources, and inadequate access to health-care services (Shisana et al., 2009). The moral messages of FBOs are often not accepted in the contexts of high-risk populations to assist members of these at risk communities to protect themselves from HIV.

The church and FBOs have official sexual scripts and rules dictating how people should respond in specific situations. However, these do not coincide with the real sexual scripts or actions many people with risk behaviour act out in their lives. The "wrongdoers" find themselves being judged by the official script. This, of course, contributes to stigmatisation to which they have already been subjected by other sectors of society. Stigma often leads to exclusion and discrimination – and religion can influence the process. Stigma is dependent upon social, economic and political power, and it is in the power of the church to further or reduce stigmatisation, as was discussed earlier in the chapter (Link & Phelan, 2001).

UNAIDS (2003) acknowledged the contributions made by religious leaders and theologians in the care and treatment of people living with HIV infection and AIDS. For these leaders to contribute effectively, issues of stigma and discrimination must be confronted. Stigmatisation of people living with HIV/AIDS has been identified as a powerful obstacle to effective prevention, treatment and care (UNAIDS, 2003) of the disease.

In the fight against the AIDS pandemic, it is important to examine the viewpoints of leaders in faith-based organisations and the role these viewpoints could play in developing or curtailing HIV/AIDS-related stigma. Without doubt, these viewpoints could have a direct or indirect influence on the members in their specific faith-based group. The stigma and denial surrounding the disease have contributed to the growing crisis (Keough & Marshall, 2007). Faith-based organisations may contribute to the discourses about how to approach the disease and the ethical challenges that the disease presents. Discourses are searching for answers to questions such as: Should the focus be on changing behaviours that contribute to the disease, or should it accept behaviours and rather focus on prevention (Keough & Marshall, 2007)? By recognising the dynamic nature of the disease, there is a realisation that faith- based leaders' own values, judgements and morals may affect their attitudes and their prevention messages. Faith-based leaders are biased because of the impact of the disease on communities when

responding to issues related to the disease, it is therefore difficult to remain objective when HIV/AIDS are discussed.

One way of determining the potential role FBOs and religious leaders may play in the development and maintenance of HIV/AIDS-related stigmatisation can be determined by noting the discourse of faith-based leaders. Do faith-based leaders perhaps inadvertently increase stigmatisation and discrimination in communities because of the underlying behavioural scripts advocated by the church? On the other hand, do FBOs help in preventing stigmatisation and discrimination through education and propagating behaviour change? Do FBOs and religious leaders influence the attitudes of community members due to their influential position in communities? These are the questions underlying this research. Results of this study can help to identify potential communication strategies to prevent further stigmatisation specific in the South African context.

2.9.   THEORETICAL FRAMEWORKS EXPLAINING STIGMA

Various theories and models to understand stigma have been introduced in recent years. These range from the fields of critical social theory, to social psychology and sociology. These theories resulted in a debate about theory and methods used in stigma research. Stigma research has been dominated by attitudinal studies in psychology (Deacon & Stephney, 2007). These attitudinal studies are used to predict and explain health behaviour practices. According to Deacon, Stephney and Prosalendis (2005), theoretical approaches to stigma remain problematic. A theory, according to Baron and Byrne (2004), is defined as: "Frameworks constructed by scientists in any field to explain why certain events or processes occur as they do" (p. 576). There is a need for "a theory of stigma to explain why and how stigmatisation happens, what its functions and effects might be, whether it matters, who stigmatises whom, what constitutes stigmatising beliefs, and how the specific content of stigma is influenced by different factors" (Deacon et al., 2005, p. 29).

Parker and Aggleton (2003) argue that stigma and discrimination should be understood as a social process and not dependent on single individuals. Deacon et al. (2005) agree and state:

> We need to be able to explain the functions or effects of stigmatisation without resorting to functionalisms (defining stigma in terms of discrimination), and we need to understand the role

of the individual in stigmatisation without resorting to individualism (defining stigma as a problem of individual ignorance) (p. ix).

The term *stigma* is applied when elements of labelling, stereotyping, separation, status loss and discrimination co-occur within a power situation that allows the five above-mentioned, components of stigma to unfold (Link & Phelan, 2001). Discrimination is the basis for most concerns about stigma and relates to the power of the perpetrators. However, because AIDS is considered a contagious, degenerative and fatal disease, HIV infection is widely perceived as a person's own responsibility.

Deacon et al. (2005) state that there is a need to understand the causes of stigma separately from its effects, as not all stigmatisation leads to discrimination and not all discrimination is based on stigma. Stigma should be understood and explained as an emotional or as a social process.

For this study, theoretical models taking into account the interplay of individuals and social factors are considered in an attempt to understand/explain the nature and extent of HIV/AIDS-related stigma in FBOs. These theories include the PEN-3 Cultural Model and the Framework Integrating Normative Influences on Stigma (FINIS).These theories are described below, and the understanding of behaviour change according to the theory is indicated. The theories will be used to explain the results of the study.

2.9.1. The PEN-3 Cultural Model

This model was developed by Airhihenbuwa (1989) to offer a "strategy for organising and analysing complex and interlocking spheres of cultural identity and health behaviour" (Airhihenbuwa et al., 2009, p. 412). According to this theory, any educational programme has to consider the cultural dimension to be effective. The model centralises culture in the study of health beliefs, behaviours, and health outcomes. It focuses on the role of culture as a connecting web by which individual perceptions and actions regarding health issues such as stigma and discrimination are shaped and defined (Airhihenbuwa 2007), while acknowledging that these perceptions and actions are building blocks in constructing health beliefs that are reproduced to express their cultural beliefs. In the context of this study culture is not only a reflection of African versus Western, but are also considering the cultural aspect unique to FBOs. FBOs have their own culture with strong power relations to their congregation and the wider communities it serve. Any programme has to take into account the relationship between knowledge and power/cultural issues within these organisations as well as the greater community. The model comprises three interrelated and interdependent dimensions: cultural identity, relationship and

expectations, and cultural empowerment. Each of these dimensions has three domains, as illustrated in Figure 3 below.
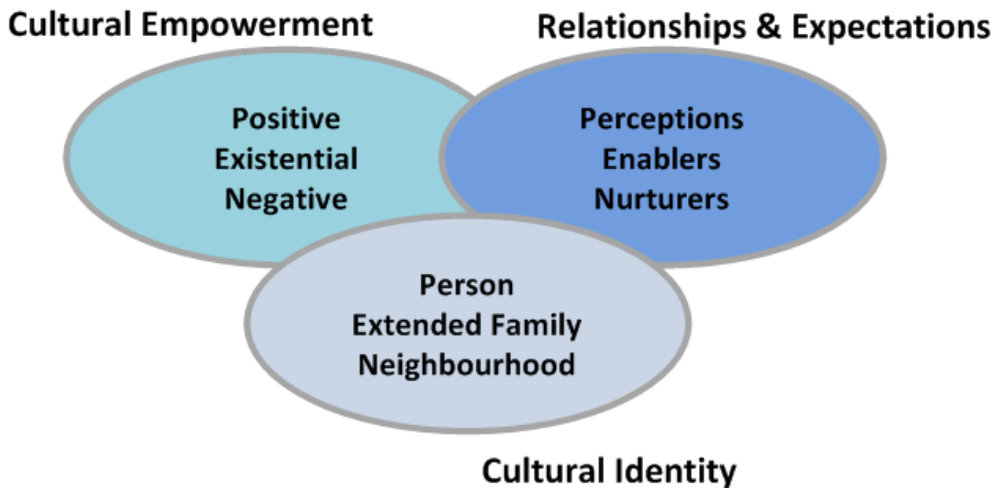
Airhihenbuwa, 1989

Figure 3: PEN-3 Cultural Model

The PEN-3 Cultural Identity domain highlights the intervention points of entry. These may occur at the level of FBOs, faith based leaders and church members. With the Relationships and Expectations domain, perceptions or attitudes about HIV and AIDS, the effect of FBOs views on the disease and the influence of church members on the exacerbation of stigma and discrimination related to the disease. With the Cultural Empowerment domain, problems are explored first by identifying beliefs and practices that are positive, exploring and highlighting values and beliefs that are existential and have no harmful consequences, before identifying negative practices that serve as barriers. In this way, cultural beliefs and practices that influence stigma and discrimination are examined. Solutions to the prevention of stigma and discrimination are encouraged and finally practices that are harmful and have negative consequences on community members are identified (Airhihenbuwa, 2007).

There are two phases in the application of the model – the assessment phase and the intervention phase. During the initial phase, cultural empowerment, relationship and expectation dimensions with their respective domains are crossed to generate nine cells. The PEN-3 model serves as a thinking tool by shifting the focus primarily from the individual to looking at the context and culture within which the

individual functions, in planning and implementing culturally appropriate programmes. The intervention phase is based upon the three domains of cultural identity, where researchers go back to the community and learn from the people, while sharing findings and deciding where to start with the implementation of the programme. This is a participatory method that requires community engagement (Airhihenbuwa et al., 2009).

By using the PEN-3 model culture is centralised in the study when explaining stigma and discrimination, and motivate for the integration of culturally relevant factors in the understanding of stigma and discrimination. For this study the researcher will not focus on all three domains as set out in the model but will only focus on the Cultural Empowerment domain to examine positive and negative health beliefs and practices held by faith based leaders, existential (unique) practices that have no harmful health consequences, and negative beliefs and practices that increase stigma and discrimination. This will help to increase the understanding of stigma and discrimination in relation to HIV and AIDS in FBOs (Airhihenbuwa, 2007)

This model allows for flexibility, which encourages intra-cultural diversity. The process should be used with every new programme or intervention being implemented in the community to assist in the understanding the programme-specific context. This model challenges implementers to address health issues at the traditional micro level as well as the macro level of heath programme interventions (Airhihenbuwa et al., 2009). Using this model, the root cause of stigmatised actions exhibited by individuals is better understood within their social and cultural contexts. In addition, using this analysis model, effective interventions can be developed to reduce and eventually eliminate HIV/AIDS-related stigma (Airhihenbuwa et al., 2009).

2.9.2. Framework Integrating Normative Influences on Stigma

The Framework Integrating Normative Influences on Stigma (FINIS) attempts to synthesise the variety of influences on stigma (Pescosolido, Martin, Lang, & Olafsdottir, 2008). To help unravel the complex network of potential influences shaping stigma, concepts from labelling theory, social network theory, the limited capacity model of media influence, the social psychology of prejudice and discrimination, to theories of the welfare state, as well as theories of the micro–macro link, were used in the development of the FINIS framework (Pescosolido et al., 2008). This framework creates a conceptual map of stigma that combines micro-, meso-, and macro-level factors, adding meso-level factors of organisations and

treatment systems and the macro-level factors of national and cultural contexts. The map's description focuses on cognitions, attitudes, and behaviours of individuals within these systems. FINIS starts with Goffman's notion that understanding stigma requires a language of social relationships, but acknowledges that individuals do not come to social interaction without any affect and motivation. Further, all social interactions take place in a context in which organisations, media and larger cultures structure normative expectations, which create the possibility of marking *difference* (Pescosolido et al., 2008).

Potential influences identified include race, gender stereotyping, social class and the role of the media, all of which tap into larger issues of social power. Pescosolido et al. (2008) use the framework to synthesise the variety of theoretical influences on stigma. They view stigma as a product of the interface of community and individual factors.

The focus of the FINIS framework is on the central theorem that several different levels of social life – micro, meso and macro (**Figure 4)** – set the normative expectations that play out in the process of stigmatisation (Pescosolido et al., 2008). Various levels of social life are described. The micro level is psychological, the socio-cultural level deals with individual factors and the meso level entails social networks and organisational-level factors. Finally, the macro level deals with society-wide factors. All these levels identify the normative expectations that play out in the process of stigmatisation (Pescosolido et al., 2008). The FINIS provides a point of view, a set of assumptions and a conceptual map to understand stigma as a pervasive process, sensitising researchers to the possibility of other influences (Pescosolido et al., 2008).

The complexity of the FINIS framework provides an opportunity to understand why stigma-reduction efforts often fail. However, contexts from both inside and outside the frame may operate to spoil the intended effects. On a micro level, it is the quality and nature of interactions that matter. On a meso level, past experiences of the individual with HIV/AIDS will affect his/her reaction to a stimulus.

The contact hypothesis integrated into the FINIS framework represents a complex set of possible configurations relative to stigma. The effect of having contact with PLWHA can only be configured when the positive and negative emotions are considered. If the overall impact of social interactions is troubling, harmful or otherwise disturbing, then contact will likely have a negative impact. If interactions are rewarding and enriching, the effect of contact will be to reduce stigma. Secondly, the complexity

and refuting evidence results in an understanding of the limits of stigma reduction. There may be an overall belief that stigma can be eradicated but as long as there is an *us* and *them* mind-set underlying the interaction processes, this may not be possible. Research on implicit attitudes as well as socialisation and identity theory indicates that this is the probable outcome (Pescosolido et al., 2008).

The framework highlights the complexity of the disease related stigma and discrimination and that is why the researcher suggests its use. The importance of viewing stigma and discrimination within a global context will help to make sense of the issue. In its most basic sense, like the response to illness and other social problems requiring action, stigma lies at the interface of community and individual factors and that must be understood. People should gain knowledge regarding the disease and be made aware of the possibility of stigmatisation. FBOs should transmit accurate messages that address people's concerns and actively work to mitigate harmful rumours and misinformation; and to model respectful and compassionate behaviour when interacting with stigmatised groups. The importance of building social and cultural-level processes into any future intervention that hopes to address stigmatisation and discrimination should be highlighted.

FINIS specifically notes the salience of stigma in the help seeking process. FINIS facilitates research on multi-level factors that likely influence stigma and their consequences. As noted by the authors, "The FINIS framework focuses on the central theorem that several different levels of social life – micro or psychological and socio-cultural level or individual factors; meso or social network or organisational level factors; and macro or societal-wide factors – set the normative expectations that play out in the process of stigmatisation" (Pescosolido et al, 2008, p. 433).

The researcher will therefore not assess all the dimensions as described by the framework as the focus of the study is on the nature and extent of HIV/AIDS-related stigma reported by aspiring faith based leaders, dimensions that influence HIV/AIDS-related stigma will be identified and explored with the assistance of the framework and will help to facilitate the discussions.

Adapted from Pescosolido, et al., 2008

Figure 4: Framework Integrating Normative Influences on Stigma

2.10. MEASURING STIGMA AND DISCRIMINATION

There has been limited research related to the extent of stigma and discrimination in society as a whole. There is also no standard measurement of stigma and discrimination to compare various communities and different times. Nyblade and MacQuarrie (2006) recognised the need for developing streamlined indicators to measure the impact of stigma-reduction programmes focussing on the African context. Attempts are now being made to standardise analyses of stigma and discrimination (UNAIDS, 2008b). Surveys do not measure all aspects of stigma. The ideal would be a comprehensive survey of stigma and discrimination in a community that would measure each component in accordance with a standardised analysis, stating its relationship to other components of the phenomenon.

In such a context, interventions can be tailored to address different dimensions of stigma. The way stigma is defined will influence the way it is measured. The design and evaluation of stigma interventions can help to contribute to a sustainable and coherent theory of stigma (Deacon & Simbayi, 2006). Stigma must be measured across many domains as are evident from the theoretical frameworks discussion in the previous section. The importance of culture, not only western versus African, but also the culture within different faith based organisations should also be considered. The interactions between the individual (micro) and organisations (macro) and in this case FBOs. The influence of faith on these interactions and the potential influences that can result in the formation of stigma and discrimination. Only then will it enable the researchers to understand fully why people think and behave in certain ways, and how our own value judgements and morals affect HIV/AIDS prevention messages. However, the possibilities for measuring stigma and discrimination are so vast that it will be unable to focus on all aspects in this study. The researcher will only focus on a couple of areas that will inform the domains of knowledge, attitudes and practices.

For this research, a survey was used for collecting data about stigma across different dimensions. It was decided to adapt an existing instrument (Deacon & Simbayi, 2006) to assess knowledge, stigmatising attitudes and discriminating behaviour. This instrument measures the same dimensions as a KAP survey; however, the focus of the questions in the current study was on dimensions of stigma and discrimination in a group of aspiring faith-based leaders.

KAP surveys can identify knowledge gaps, cultural beliefs, or behavioural patterns that may facilitate understanding the underlying issue. By exploring the target audience's knowledge about what causes

HIV/AIDS and how it is transmitted, help to explore perceptions of contagiousness and how individuals feel towards people with HIV/AIDS. The researcher can identify information that is commonly known and attitudes that are commonly held among faith based leaders. Exploring discriminatory behaviour or socially stigmatizing attitudes regarding people with HIV/AIDS and how those attitudes may differ towards family members, friends, co-workers and society at large will help to identify underlying causes of stigma and discrimination.

To some extent, these surveys can identify factors influencing behaviour that are not known to most people, reasons for their attitudes, and how and why people practise certain behaviours. KAP surveys can also assess communication processes and sources that are key to defining effective activities and messages in understanding HIV/AIDS-related stigma. KAP surveys may be used to identify needs, problems and barriers in programme delivery, as well as solutions for improving faith based related services in preventing stigma and discrimination.

Typical questions include knowledge about causes and symptoms of the illness under study. Attitude has been defined by Ribeaux and Poppleton (1978) as "a learned predisposition to think, feel and act in a particular way towards a given object or class of objects". As such, attitudes result from a complex interaction of beliefs, feelings, and values. Attitudes may be inferred from a variety of statements and answers, but direct asking is usually problematic since people often respond in terms of what they think is the 'correct' answer. Attitudes are therefore not easy to obtain. However, attitudes are central to understanding behaviour. Questions related to Practices in KAP surveys usually enquire about the use of preventive measures or different health care options available, however in this case the practice of stigma and discriminatory behaviour are investigated. This questionnaire generates information on people's normative behaviours or on what they know should be done (or they expect the interviewer wants to hear).Conclusion

In countries that have been effective in the fight against HIV/AIDS, FBOs were involved in the response against HIV/AIDS, providing impetus to local prevention efforts (Merson et al., 2008). These AIDS-control programmes had leadership from the highest level and were coordinated by the government. All levels of government, NGOs, CBOs and FBOs worked together. Because it was a multi-sectorial approach, it achieved a broad public consensus of support. Therefore, a multi-sectorial approach is considered the main driver of prevention of this epidemic, as used with great success in Uganda and Thailand. In these countries, factors making specific groups more vulnerable to HIV were fully considered, as well as the

impact of the disease on the local community. This resulted not only in individual behavioural change but also hastened a change in group norms of behaviour towards PLWHA (Shelton et al., 2004). This is in line with the government's HIV/AIDS NSP for 2012-2016 in response to the challenge of HIV and the impact of AIDS.

This study aims to contribute to understanding the role of stigma as a factor that can be a barrier to HIV prevention. Parker and Aggleton (2003) note that stigma is deeply rooted, operating within values of everyday life. Stigma plays into and reinforces social inequalities, which have been both directly and indirectly promoted by the actions of some FBOs. To a greater or lesser extent, religious organisations play a role in setting and maintaining moral boundaries even in largely secular societies. Because of the high prevalence of HIV and AIDS in South Africa FBO's have already played an important role in addressing HIV and AIDS related issues. FBOs are currently challenged to extend and deepen this work. The factors identified by participants in this study may help FBOs to understand factors that may contribute to and be associated with HIV/AIDS-related stigma and discrimination.

CHAPTER 3:   RESEARCH METHODOLOGY

3.1.   INTRODUCTION

This chapter highlights the methodological procedures used in this study. All research is based on some underlying philosophical assumptions regarding requisites for valid research and research methods appropriate to the particular study.   Knowledge regarding these assumptions are important in conducting and in evaluating the research. This chapter discusses the philosophical assumptions and the design strategies underpinning this research.   The researcher provides an overview of the project, followed by a description of the research process. This is followed by a discussion of cross sectional survey methodology, with specific reference to Knowledge, Attitudes and Practice (KAP) surveys. Questionnaire development, participant selection, sample size, reliability and data analysis are discussed.

3.2.   RESEARCH GOAL

The aim of this study is to explore the nature and extent of HIV/AIDS-related stigma reported by aspiring faith-based leaders by exploring these prospective leaders' attitudes towards HIV/AIDS. It is assumed that religious leaders may influence the community's attitudes directly or indirectly through their own attitudes. The research will thus gain understanding of the underlying attitudes that influence prevention messages of FBOs. This may give an indication of FBOs role and value in HIV prevention. The research focuses on whether FBOs contribute to the development and maintenance of stigma related to HIV or not.

3.3.   RESEARCH DESIGN

Kerlinger and Lee (2000) state that a research design has two basic purposes. Firstly, it is to provide answers to the research questions, and secondly, to control the variance. Sarantakos (2005, p.105) states "the purpose of the design varies according to the nature and purpose of the study, the type of population, the structure of the research, the number of researchers and research assistants and the ideological affiliation of the researcher, among other factors". The research design essentially describes the strategy, the plan and the structure to be used by the researcher when conducting the research project (Kweit & Kweit, 1981). In other words, the research design articulates the data that is required, the methods that are going to be used to collect and analyse this data, and the best strategy for

answering the research question (Babbie, 2005) taking into account practical and other constraints of the study. The purpose of the inquiry in this case is to explore issues related to stigma and discrimination.

Exploratory studies are the most useful and appropriate research design for projects that are addressing a subject presenting high levels of uncertainty and where the problem is not very well understood (van Wyk, 2010). Van Wyk (2010, p. 8) states that the main aim of exploratory research is "to identify the boundaries of the environment in which the problems, opportunities or situations of interest are likely to exist ... and to identify the salient factors or variables that might be found there and be of relevance to the research".

The research design provides the overall framework for collecting data, which is influenced by the problem statement as described by the researcher, and considering the nature of the data (Leedy & Ormrod, 2010). The research approach will help to visualise the data and any potential problems possibly associated with the utilisation of the data in the entire research project.

According to Terre Blanche and Durrheim (1999), the research approach has three major dimensions, which define the nature and enquiry of the research, namely ontology, epistemology and methodology. Guba and Lincoln (1994) define these dimensions as follows: Ontology refers to how reality is defined. Epistemology is defined as the nature of the relationship between the knower and what can be known. Methodology refers to how the inquirer goes about finding out whatever he or she believes can be known. Ontological and epistemological aspects are concerned with what is commonly referred to as a researcher's worldview (Terre Blanche & Durrheim, 1999). This has a significant influence on what the researcher believes about the world and what can be known. Based on this belief, Guba and Lincoln (1994) distinguish between positivist, post-positivist and postmodernist enquiry, and state that all human knowledge and all scientific research follow a set of procedures that begin with a group of assumptions or a set of beliefs.

Quantitative methods have been largely underpinned by positivist and post-positivist principles. These principles have contributed to the over-simplification or reduction of human experience (reductionism) and the objectification of the human person within social research (Sarantakos, 2005).

Cresswell (1994) defines a quantitative study as "an inquiry into a social or human problem, based on testing a theory composed of variables, measured with numbers and analysed with statistical

procedures, in order to determine whether the predictive generalisations of the theory hold true" (p.2). Figure 5 illustrates the general research process used in a quantitative research design process.

In a quantitative research design, social inquiry proceeds with a well-constructed design, following a sequence of closely interrelated steps as illustrated in figure 5 (Sarantakos, 2005). Quantitative methods focus on quantity, extent or strength of attributes, while suggesting some level of objectivity, accuracy, validity and reliability (all depending on the decisions made by the researcher). By measuring the variables, figures are produced which allow some judgements to be made.

For quantitative research, design facts or data are therefore crucial when doing research. Research seeks the *truth* by means of data. However, *truth* is representative of the beliefs of a particular group in a specific context and point in time. What may be true today may not hold up tomorrow, next week, and next year or further in the future. Channels of communication through which they may pass also distort data. These channels may include writing skills or mother-tongue differences and may create barriers in the research process (Sarantakos, 2005).
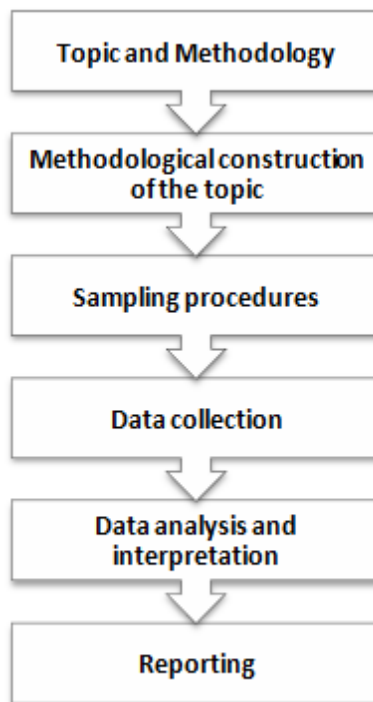
(Sarantakos, 2005, p108)

Figure 5: Quantitative Research Design Process

Therefore, the researcher's study position will have a direct impact upon the design considered in conducting the research. Theoretical points of departure are influenced by the researcher's own position, which will influence the way the research is structured. For this study, quantitative data could help the researcher to gather information, and to reach a greater understanding of individual knowledge, attitudes and practices or behaviours as a measure of stigma and discrimination in FBOs. The researcher considered the survey method the most appropriate to access knowledge, community opinions and attitudes as well as behaviour for this study.

3.4. SURVEY RESEARCH

Survey research is one of the most commonly used methods of data collection in the social sciences. Participating in surveys has become part of many people's life experience. Sarantakos (2005) defines surveys as "methods of data collection in which information is gathered through oral or written questioning" (p.239). Written questioning is carried out by means of questionnaires, which are administered to the respondents by mail or handed to them personally and are returned to the researcher after completion. These are also known as self-administered or self-completion questionnaires. Survey research methods can be used for a variety of research purposes and are an effective way to efficiently collect information about many individuals in a particular population. "A survey design provides a quantitative or numeric description of trends, attitudes or opinions of a population by studying a sample of that population. From sample results, the researcher generalises or makes claims about the population" (Creswell, 1994, p. 153).

SURVEY RESEARCH

Strengths

- Less expensive than other methods
- Produces quick results
- Completed at the respondent's convenience
- Offers greater assurance of anonymity
- Offers less opportunity for bias or errors caused by the presence or attitudes of the interviewer
- Stable, consistent and uniform measure, free of variation
- Offers a considered and objective view of the issue; many subjects prefer to write rather than talk about certain issues
- Allows a wider coverage; researchers can approach respondents more easily than by other methods

Weaknesses

- Does not allow probing, prompting and clarification of questions
- Does not provide opportunities for motivating the respondent to participate in the survey or to answer the questions
- It is not possible to check whether the question order – where required – was followed
- Does not provide an opportunity to collect additional information (e.g. observation) while questionnaires are being completed.
- Due to lack of supervision, partial response is quite possible.

(Sarantakos, 2005, p. 263)

The **purpose** of the survey research is to make inferences about the characteristics, attitudes and behaviour of the population (Babbie, 2005).

Deacon and Simbayi (2006) assert that there are a number of ways in which researchers have tried to measure stigma. These include the use of self-reported questionnaires where the researcher asks participants to report their own knowledge, attitudes and practices regarding aspects of HIV/AIDS. The researcher proposes the use of a Knowledge, Attitudes and Practices survey or, in short, a KAP survey to be conducted to describe the nature and extent of HIV/AIDS-related stigma reported by aspiring faith-based leaders.

3.5.   KNOWLEDGE-ATTITUDES-PRACTICES SURVEYS

The researcher will make use of KAP surveys to gauge the knowledge, attitudes and practices of a group of aspiring religious leaders in respect of HIV/AIDS-related stigma. The World Health Organisation (WHO) defines a KAP survey as "a representative study of a specific population to collect information on what is known, believed and done in relation to a particular topic" — in this case, HIV/AIDS-related stigma (WHO, 2008, p. 6). KAP is a standard term in which the word *knowledge* is implicitly used as a proxy for awareness, i.e. what respondents know about HIV/AIDS. The term *attitude* is used to refer to the perception or way of thinking about people with HIV/AIDS, and *practice* is used to refer to the actions or behaviour relating to HIV/AIDS, i.e. what they actually do. In their research on FBOs Deacon and Simbayi (2006) adapted a KAP survey to focus specifically on stigmatising attitudes and discriminatory behaviour towards PLWHA.

KAP surveys can identify knowledge gaps, cultural beliefs, or behavioural patterns that may facilitate a better understanding of the extent of stigma and discrimination, and can identify barriers to the prevention of stigma and discrimination in HIV/AIDS. KAP surveys can identify information that is commonly known and attitudes that are commonly held. Such surveys may be used to identify needs, problems and barriers in programme delivery, as well as solutions for improving services (WHO, 2008).

In KAP surveys, the knowledge section is normally used to identify risk behaviour. However, in this research it is used to assess accurate knowledge on the one hand and unrealistic fears that may be related to stigma. This is firstly done by measuring the extent of community knowledge of HIV/AIDS. In

this study, the *community* refers specifically to these aspiring faith-based leaders. They are members of a community who may have more knowledge about the disease than the public. Faith-based leaders are more exposed to training programmes and may have a greater awareness of other preventive interventions. Aspiring faith-based leaders from this group may also be involved in the support provided to those who are infected.

Measuring attitudes is the second part of a standard KAP survey questionnaire. The term *attitude* is usually used to refer to a person's general feelings about an issue, object, or person – in this case, HIV/AIDS and PLWHA. Attitudes are interlinked with the person's knowledge, beliefs, emotions and values. Attitudes can be positive or negative in nature (Colman, 2003). Negative attitudes towards PLWHA are often based on stigmatising attitudes.

Practice, a third and integral part of KAP surveys, relates to the investigation of stigma- and discrimination-related practices. These questions attempt to understand the logic behind people's behaviour. The questionnaire includes questions aimed to identify the actual practices inside FBOs that could be translated as stigma and discrimination.

The WHO advocates the use of KAP surveys to help design the content of health education programmes in developing countries. Survey research of this nature is useful to identify trends within a population. These surveys establish a baseline of understanding what these aspiring faith-based leaders know, feel and understand about HIV/AIDS.

To summarise, a KAP survey was adapted to focus on stigma would typically assess the following three areas:

- What do the community (aspiring faith-based leaders) know about HIV/AIDS? (Their current knowledge and understanding of the disease)
- How do the community (aspiring faith-based leaders) feel towards HIV/AIDS and people living with HIV (attitude relating to stigma)
- What stigma practices have the respondents observed in their congregations? (Practices).

3.6.   QUESTIONNAIRE DEVELOPMENT

The questionnaire used in this research was designed by the Human Sciences Research Council (HSRC) and Outsourced Insight, found in the public domain (Deacon & Simbayi, 2006). The HSRC questionnaire was designed in a collaborative process between the HSRC and the Anglican Church of the Province of Southern Africa (ACSA). In the development of the HSRC questionnaire, the research team was given feedback from stigma specialists and theologians, after which the tool was piloted. Items were randomly selected from previous instruments and the responses standardised for this instrument, however the psychometric properties for the instrument were not elaborated on in the previous research. Validity and reliability of the instrument are discussed later in this chapter.

Deacon and Simbayi (2006) administered an anonymous questionnaire to 748 regular Anglican churchgoers (the open sample) and to 129 people living with HIV and AIDS within Church structures. They sampled 45 parishes in five countries: Lesotho, Mozambique, Swaziland, Namibia and South Africa. The purpose of the project as a whole was to help reduce HIV and AIDS-related stigma and discrimination within the Church and to be more effective in responding to the disease (Deacon & Simbayi, 2006).

The questionnaire developed by Deacon and Simbayi (2006) was adapted for the context of the current research. The content of survey, which is given in Appendix A, will be briefly outlined as well as the adjustments made in the survey for the current research

The questionnaire consisted of two sections. Section A contains questions about the demographic data of participants and Section B contains questions related to knowledge, attitudes and behaviours towards people infected and affected by HIV/AIDS.

Demographic data such as the respondents' role in church, gender, age, employment, home language, marital and educational status was collected. This allowed the researcher to compare the stigma measured with characteristics of the respondents. Education was used as an alternative for socio-economic status, as it was assumed that the respondents would be reluctant to answer questions on income and social class (Deacon & Simbayi, 2006). In this study, the respondent's home language was used as a proxy for race. This was done to show sensitivity towards the respondents, as race was

traditionally used in South Africa for constructing racially defined communities and laying the foundation of social, political and economic discrimination.

The nature and extent of respondents' exposure to people with HIV were gauged by asking questions about how many people they know with the disease and their relationship with those they knew to be infected.

The KAP survey used questions to assess HIV-knowledge for example: In which of the following ways do you think people can get HIV/AIDS? (a) From sharing cups and plates with someone with HIV/AIDS? (b) From having sex without a condom with someone with HIV/AIDS?   (c) From kissing someone with HIV/AIDS?

Questions to determine respondents' attitudes included questions such as "Do you personally agree or disagree with the following statement?" "I would be ashamed if someone in my family had HIV/AIDS." How respondent would feel should anyone they know be infected, are they viewed in a positive or negative light?

Questions related to practice included, for example "Which of the following has happened in the last 12 months to anyone you know living with HIV/AIDS?" The focus of this questionnaire was not on individual risk behaviour, but on practices of individuals and observed in the community associated with stigma (Refer to Appendix   A for the questionnaire used).

Despite various advantages of self-report measures, the act of measuring attitudes via a survey has been criticised for many reasons. The researcher addressed some of the criticism to increase the validity of the findings. According to Deacon and Simbayi (2006) self-reported measures on stigma may create a social desirability bias, as people answer the questions in a way they believe to be correct or acceptable, rather than what they personally view to be correct. The effect of social desirability bias can be minimised but not entirely eliminated, by giving a neutral introduction to the questions and avoiding questions that suggest that one kind of answer is better and more desirable than another. With this approach, there is little personal risk associated with a negative response. The researcher thus tried to eliminate some criticism of self-report measures. There may be factors that the researcher did not consider during this survey – such as motivational factors and external barriers, for example financial constraints.

The researcher has carefully addressed the issue of anonymity in the introduction and consent form (Appendix B) accompanying the questionnaire (Appendix A). Questions were asked about people's own attitudes but also about attitudes and behaviours that they have observed in others.

The questionnaire consisted of mostly closed questions on knowledge about HIV/AIDS, sexual behaviour, attitudes; condom use, stigma, discrimination etc. (Appendix A), which only require a tick mark in the corresponding tick box. This produces highly descriptive data. This kind of data does not necessarily explain why participants do what they do. For that reason the questionnaire was adapted by adding some open-ended questions. These questions gave the respondents some opportunity to explain or elaborate on their viewpoints or responses on preceding questions. These open-ended responses were included to help clarify responses as given by respondents. For example, in question 13 where the researcher asked about the congregation's viewpoint on condom use, respondents were requested to give reasons for their viewpoints. Another open-ended question was included: "What do you think the church should do about HIV and AIDS?" The open-ended questions provided qualitative responses. The responses were limited and not suitable for any extensive thematic analysis as it only provided some background on the subject under discussion. The questionnaire was presented in English.

3.7. RESEARCH PARTICIPANTS

3.7.1. Sampling

In research, samples are expected to be representative. To achieve this, sampling procedures must comply with certain standards and methodological principles (Sarantakos, 2005). For this study, the focus was placed upon aspiring faith-based leaders attending a *Choose Life* training programme. The *Choose Life* training programme is a three-day value-based HIV and AIDS prevention-training programme for faith, NGO, community and youth leaders. The programme focus on training pastors, other leaders and community members to develop, facilitate and evaluate appropriate ethical and value-based Christian responses to HIV/AIDS and to facilitate an ethical community development programme in which a Christian response to HIV/AIDS is addressed.

HospiVision is a non-profit (section 21) Christian FBO established in 1997 to provide psychosocial and spiritual care, counselling and training, as well as physical support in the health care environment. HospiVision's *Choose Life* training programme has a unique focus on two key components. Firstly, an emphasis on values and a value-based lifestyle to support a personal commitment to HIV prevention and

behaviour change. Secondly, a desire to enable FBOs to partake more efficiently in the fight against HIV and AIDS.

The programme aims to promote the ABC approach to preventing the sexual transmission of HIV with the key components of abstinence and being faithful. By training faith and community-based leaders a value-based Abstinence and Be Faithful (AB) prevention programme HospiVision, will empower these leaders to implement AB programs in their various faith communities. The emphasis area for this intervention is training as well as community mobilisation. The researcher targeted the aspiring FBO leaders who were registered for the *Choose Life* training programme. Two, three day courses were presented per month. All participants were requested by the course facilitator to complete the questionnaire on the first day of the course.

This research therefore does not use a representative sample of FBO leaders, but a purposive sampling method was used. Respondents were recruited based on their enrolment for this specific course and their membership to a FBO, including church organisations. This specific sample is thus biased. The Christian orientation of HospiVision as presenter of the course could result in a selective representation of different religious denominations. The participants also showed a specific interest in HIV/AIDS in the context of the church, as is evident from their enrolment in the course. Results can therefore not be generalised to all other faith-based leaders.

3.7.2. Sample Size

The sample size in any study is directly related to the type of population, the methodology employed, availability of time and resources, the aim of the research, the type of instruments used, the accuracy required and the capacity of the research team (Sarantakos, 2005). The researcher had limited control over the sample size but invited all the participants in the *Choose Life* training programme presented during the period of three months from June to September 2009. During this period, six workshops were held with a total of 138 participants and all participants were asked if they would participate in the research. From the potential 138 participants, 133 completed questionnaires could be used in the analysis.

During the time the research was conducted, HospiVision underwent funding changes, resulting in alterations of the way their courses were structured and implemented. The research therefore did not include any participants who attended the course after September/October, as the organisation did not

receive any further funding from PEPFAR. The change in funding had an impact on the design and delivery of the content presented in the course for future workshops. Because of the expected changes to the *ChooseLife* programme content, only participants who enrolled for the workshops prior to the implementation of the changes were considered for participation in the study. This may have affected the outcomes of the research as this resulted in a smaller group of respondents than was originally planned.

3.7.3. Data Collection

The researcher collected quantitative data with the assistance of the *Choose Life* training coordinators through the administration of self-report questionnaires. The researcher prepared HospiVision staff to administer the questionnaire. The training coordinator was familiarised with the administration of the questionnaire prior to the workshop by HospiVision staff and the training coordinator administered the questionnaire prior to the start of the workshop. This questionnaire would soon replace their then current questionnaire.

An information letter (Appendix C) as well as a consent form (Appendix B) accompanied the questionnaire. These letters explained the purpose of the study, procedures for completion of the questionnaire, and the right to decline participation. The letter assured participants that their responses were confidential and that they could withdraw from the study at any time. After obtaining informed consent, the questionnaires were administered and collected immediately after completion. As the questionnaires were anonymous, the coordinators provided no assistance during the completion of the questionnaires. The training coordinators did not report any problems experienced during the administration of the questionnaires, or of participants refusing to complete the questionnaire.

3.8.   DATA ANALYSIS

3.8.1. Quantitative Data

Information was coded and captured into an Excel spreadsheet as the completed questionnaires were returned. The complete set of data was imported into SPSS (Statistical Package for Social Sciences) Version 21 and analysed statistically. Preliminary data analysis involved exploring the data to determine whether the assumptions for parametric data had been met. These assumptions include normal distribution of data, homogeneity of variance, interval or ratio data and independence (Field, 2006).

These assumptions were violated, as the data are ordinal in nature and not normally distributed. Histograms were found to be skewed in the initial exploration of the data and in all cases.

Sample sizes, means, and standard deviations pertaining to the demographic and other variables of interest are presented in Chapter 4. An examination of the scatter plots (not presented) suggested the presence of linearity for the variables of data analysed. The presence of linearity permitted the use of correlation coefficients. With respect to the distribution of scores underlying these measures, the standardized skewness coefficients (i.e., skewness divided by the standard error of skewness) and the standardized kurtosis coefficients (i.e., kurtosis divided by the standard error of kurtosis) revealed serious departures from normality for all variables of interest. Specifically, the standardized skewness coefficients were 0.210 for each respectively. Similarly, the standardized kurtosis coefficients were 0.417 for each of the responses respectively.

3.8.1.1. Kolmogorov-Smirnov

This was followed by the Kolmogorov-Smirnov test and Shapiro-Wilk of normality. The objective of the Kolmogorov-Smirnov is to test whether or not a distribution is normal. The Kolmogorov-Smirnov compares the scores in the sample to a normally distributed set of scores with the same mean and standard deviation. If the test is non-significant ($p>.05$) it tells us that the distribution of the sample is not significant different from a normal distribution. If, however the test is significant ($p<.05$) then the distribution in question is significant different from a normal distribution (Field, 2006). In this case the Kolmogorov-Smirnov and Shapiro Wilk test reveal a significance level of $p=.000$ for all variables.

3.8.1.2. Spearman's Correlation

The aim of the study is to explore associations or relationships between variables and to determine the strength of association between two or more variables. Spearman's Rank Order Correlation measures the strength of association between two variables that can be nominal, ordinal or continuous. These tests make no assumptions about which variable is either dependent or independent. Variables in this study are ordinal. For example, we are looking for a relationship between two statements made on a Likert scale. The Spearman's Rank Order Correlation calculates a coefficient, *r* (pronounced *rho*), that is a measure of the strength and direction of the association or relationship between two continuous or ordinal variables.

The value of the correlation coefficient must be between -1.00 and +1.00; larger correlation coefficients mean stronger relationships; squaring the correlation coefficient tells you the amount of variation in one variable that is accounted for by the other variable, this is called the coefficient of determination (Field, 2006).

Statistical significance refers to the unlikelihood that mean differences observed in the sample have occurred due to sampling error. Given a large enough sample, despite seemingly insignificant population differences, one might still find statistical significance. Practical significance looks at whether the difference is large enough to be of value in a practical sense (Field, 2006).

The effect size will be determined using Cohen's (1992) calculations. Effect size is simply a way of quantifying the size of the difference between two groups and is useful because they provide an objective measure of the importance of an effect. A correlation coefficient of 0 means there is no effect and a value of 1 means that there is a perfect effect. Cohen (1992) has made some widely accepted suggestions about what constitutes a large and small effect, $r = 0.10$ is a small effect, $r = 0.30$ is a medium effect and $r = 0.50$ is a large effect. These guidelines will be used to assess the importance of the study effects (regardless of the significance of the test). It must also be remembered that r is not measured on a linear scale so an effect with $r=0.4$ is not twice as big as one with $r = 0.2$ (Field, 2006).

Following these results, the analysis of data focused on non-parametric tests. These tests are also known as *assumption-* or *distribution-free* tests, as the statistical procedures do not rely on the restrictive assumptions of parametric tests, such as assuming that data come from a normal distribution (Field, 2006).

3.8.1.3. Non-Parametric tests

Non-parametric test or assumption-free test makes no assumptions about the distribution of the data. These test work on the principle of ranking the data: that is finding the lowest score and giving it a rank of 1, then finding the next highest score and giving it a rank of 2 and so on. This process results in high scores being represented by large ranks, and low scores represented by small ranks. The analysis is then carried out on the ranks rather than the actual data. During the analysis the Mann-Whitney test was used to determine whether the distributions (medians) of two populations are the same - the Kruskal-Wallis test is an extension of the Mann-Whitney test it tests whether the medians of 3 or more populations are the same (Field, 2006).

3.8.1.4. Bootstrapping

Bootstrapping has only recently been included into SPSS; however, the concept has been used for a while. Bootstrapping is a non-parametric resampling procedure that does not impose the assumption of normality of the sampling distribution. Bootstrapping is a computationally intensive method that involves repeated sampling from the data set that can be used to derive the standard error and confidence interval of a sample statistic by constructing a number of bootstrap samples (1,000 in this study) through random sampling with replacement from the original data and estimating the indirect effect in each re-sampled data set. By repeating this process thousands of times, an empirical approximation of the sampling distribution is built and used to construct confidence intervals. The bootstrap bias-corrected and accelerated percentile interval (BCaI) is a type of bootstrap interval designed to correct the skewness in the bootstrap distribution (Cui & Li, 2012; Preacher & Hayes, 2008). This procedure is used in cases of small samples when traditional methods cannot be used to obtain reliable statistics.

3.8.1.5. Reliability

Reliability is defined by Field (2006, p. 743) as the "ability of a measure to produce consistent results when the same entities are measured under the same conditions." Data generated through this questionnaire were mostly ordinal data. That is data in which an ordering or ranking of responses is possible but to assume that the distance between each point on the scale is equal is unreasonable. Therefore, no measure of distance is possible between the different responses (Leedy & Ormrod, 2010). Analysis of ordinal data, particularly as it relates to Likert scales in surveys, is not as straightforward and transparent as other types of data. In many cases, ordinal data from Likert scales are treated as interval data, although this practice remains controversial. This could be because interval data, which would result in parametric statistical tests, are viewed to be more powerful than non-parametric alternatives and to provide more information than the non-parametric alternatives. However, using parametric tests when non-parametric tests should be used could result in misrepresentation of the findings of a survey (Jamieson, 2004).

Determining reliability using Cronbach's alpha is controversial in such cases as this, according to Sijtsma (2009), has resulted in Cronbach's alpha repeatedly being misinterpreted and misused. Using Cronbach's alpha under circumstances that violate its assumptions may result in substantially deflated reliability

estimates, which could result in some misinformed inferences such as discarding a test due to its seemingly low reliability (Gadermann, Guhn, & Zumbo, 2012). For this study, non-parametric analysis was done and therefore a reliability coefficient cannot be calculated using SPSS.

3.9. ETHICAL CONSIDERATIONS

Permission to conduct the study was given by the Ethics Committee of the Faculty of Humanities of the University of Pretoria prior to the start of the study. HospiVision also consented to the research. It is important for researchers to consider the ethical implications and psychological consequences of their research. Guided by the principle that the study should be considered from the standpoint of all participants, potential threats to the participants' psychological well-being, health, values or dignity should be eliminated.

In a multi-cultural and multi-ethnic society and where investigations involve participants of different social backgrounds, the researcher may not always have sufficient knowledge of the implications of a study. Another consideration is that the researcher may not always be the best judge of whether an investigation will cause any offence to members of the population from which the participants in the study are drawn. To this end, there are several areas in which to consider ethical issues.

International and national professional organisations have established codes of conduct that affiliated members are expected to follow. Tertiary institutions have adopted ethical guidelines and established internal procedures and committees, assessing all proposed research projects to ensure that they adhere to the ethical standards of their institution (Sarantakos, 2005). Ethical principles set by the American Psychological Association (APA) and University of Pretoria are guidelines for the researcher to ensure ethical research. Three general ethical principles – respect for persons, beneficence and justice (Whitley, 2002) – guided this researcher.

3.9.1. Privacy, Confidentiality and Anonymity

These aspects are directed by the principle of respect for people, referring to privacy and freedom of choice, and are reflected in voluntary participation, informed consent and freedom to withdraw from research, as well as confidentiality of submitted data (Whitley, 2002). Participants were assured that the data would remain confidential and that even if the data were published, confidentiality would still be

maintained. This was done by means of the information sheet provided and confirmed by the facilitators.

3.9.2. Protection from Harm

The principle of beneficence refers to the protection of participants from physical and mental harm during the research (Whitley, 2002). It is the researcher's responsibility to ensure that the study will not entail any procedures that may cause harm to respondents. The risk of harm should not be greater than that of everyday life. Participants must be informed about factors related to the research that may create a risk for them (Sarantakos, 2005).

Participants were informed about the nature of the study. They were informed of their right to contact the researcher regarding issues to do with their well-being that may have arisen during the research process. If someone experienced discomfort, it would have been the researcher's responsibility to debrief the participants. Participants were also provided with the National AIDS help line's number contained in the information sheet that they took away with them.

3.9.3. Informed Consent

The third principle, justice, refers to the sharing of burdens of research participation, and that the benefits of the research are shared by all in society and are reflected in voluntary participation and informed consent (Whitley, 2002). Informed consent is extremely important. Participants should never feel pressured to take part in a study. Participants were informed of the objectives of the study and about all aspects of the research that might be expected to influence their willingness to participate. This was achieved by means of the accompanying research information sheet (Appendix C).

3.10. CONCLUSION

The chapter outlines the methodology followed in the research study. An overview of the project was provided and was followed by a systematic description of the research implementation. The aims, research design and methodology were followed by questionnaire development, participant selection, sample size, data collection, data analysis and finally, the ethical considerations taken into account during the project. Findings as derived from the above-mentioned method will be discussed in the next chapter.

CHAPTER 4:   RESULTS

4.1.   INTRODUCTION

This chapter presents the research results. Firstly, the sample population is described, followed by the presentation of results from the analysis.   The questionnaire attempted to understand the interrelationship of knowledge, attitude and behaviour, and in addition, how these three components affect stigma and discrimination among aspiring faith-based leaders. As with the Deacon and Simbayi (2006) study, this analysis will attempt to answer the following questions through the examination of the research data:

- What are the nature and extent of exposure to HIV/AIDS within FBOs?
- What are the nature and extent of knowledge of transmission methods for contracting HIV?
- What are the nature and extent of feelings of shame, blame or judgemental attitudes associated with HIV/AIDS?
- What are the nature and extent of discriminatory or exclusionary practices or behaviours towards people infected and affected by HIV/AIDS?

This chapter presents an analysis of the survey results. The results in this study are compared to results of a similar study conducted among FBOs (Deacon & Simbayi, 2006).

4.2.   SOCIO-DEMOGRAPHIC PROFILE OF RESPONDENTS

All participants attending *Choose Life* training programme during a specific three-month period were requested by facilitators to complete the questionnaire prior to starting the course. In all, 138 people were invited to participate in the survey. From the survey results, five questionnaires were discarded, as these respondents did not complete the questionnaire in full. The sample was not representative of the faith-based communities of South Africa.

Role in Congregation

The participants' role in the faith congregation was assessed by asking respondents what their role was within their congregation. Each one was asked whether he/she was a member of a congregation, a

member of a group within the church, a lay minister, a minister or a HIV and AIDS co-ordinator. Most of the participants (

1% 3%2%

- Church group member
- Minister
- HIV and AIDS CO-ordinator in the church
- other

94%
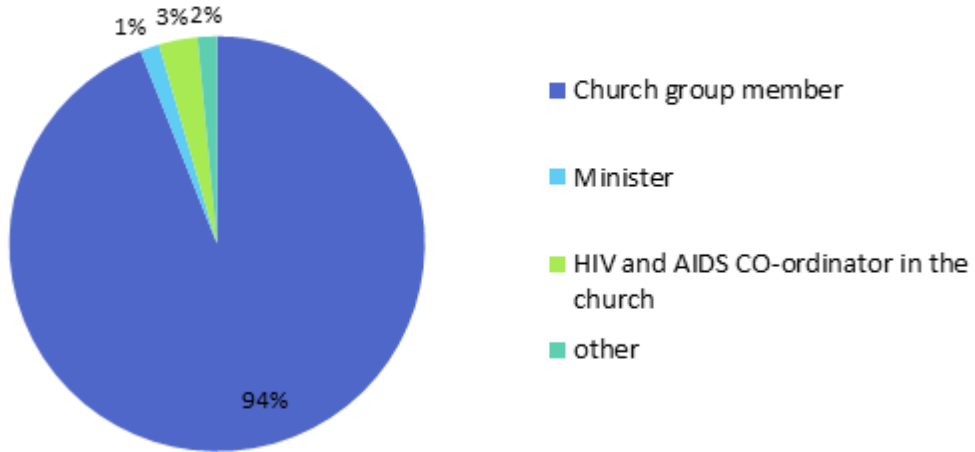
Figure 6) described their role as being a member of a congregation or belonging to a smaller church group within the congregation+. Other respondents classified themselves as a Sunday school teacher and counsellor.

1% 3%2%

- Church group member
- Minister
- HIV and AIDS CO-ordinator in the church
- other

94%
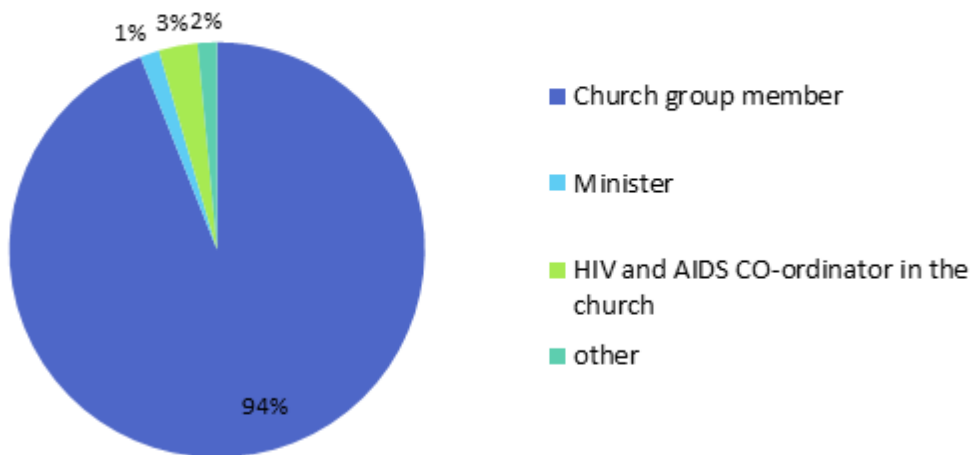
Figure 6: Role in Congregation

Language

The sample represented ten of the eleven official languages. None of the respondents' mother tongue was Tshivenda. The majority of participants in the sample were Setswana (n=29) and Sepedi (n=28) speaking, followed by isiZulu (n=21) and then Sesotho (n=18). Other language groups not mentioned above, were represented in smaller numbers (Figure 7). This study used language as a proxy for racial representation in the study and an examination of the group revealed that most of the respondents were black.
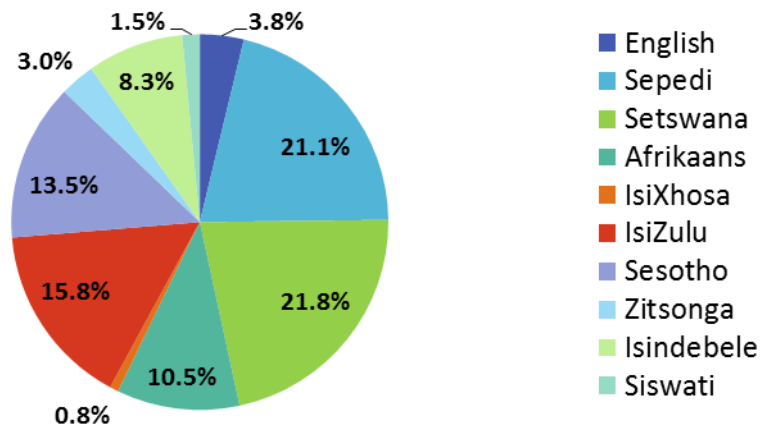
Figure 7: Mother Tongue

Gender

The majority of respondents were women, with one fifth of the respondents being male (Figure 8). As the focus was on aspiring faith-based leaders, one would have preferred the participation of men in the survey to be significantly higher, since men usually play a larger role in the church. The sample for the study may not be a true a reflection of the role division in congregations or in FBOs, since women are not always in formal positions of authority in these organisations.
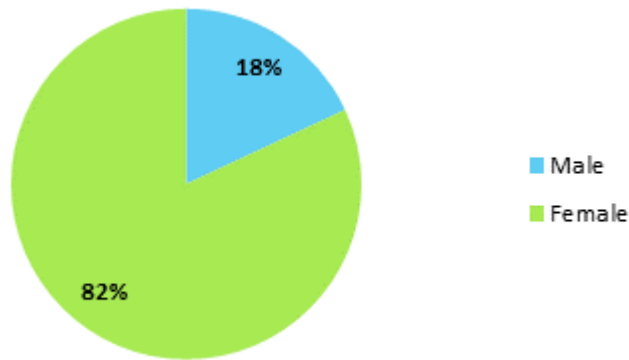
Figure 8: Gender

Women have proven to be very effective leaders in their own right, nevertheless, and are active in religious organisations through numerous avenues, often providing direct services to the community (Herstad, 2009). A higher level of female participation in this study was also expected, as the women in communities usually reach out to others, providing care and support for those congregation members affected by the disease – both physically or emotionally.

Age

Of the respondents, 37.6% (n=50) were between the ages of 18 and 24 years and 26.3% (n=35) between the ages of 25-34. A smaller group (15%) were above 50 years, all of them women (Figure 9). Half of the respondents have never been married, but this is to be expected, as most of the respondents were young adults. The survey result reflects youthfulness, which is representative of the general population most affected by the pandemic in South Africa. In the 35-49 age group, only 3% (n=4) were men, in the 25-34 age group 5.3% (n=7) were men, and in the 18-24 age group 9.8% (n=13) were men who participated in the study.
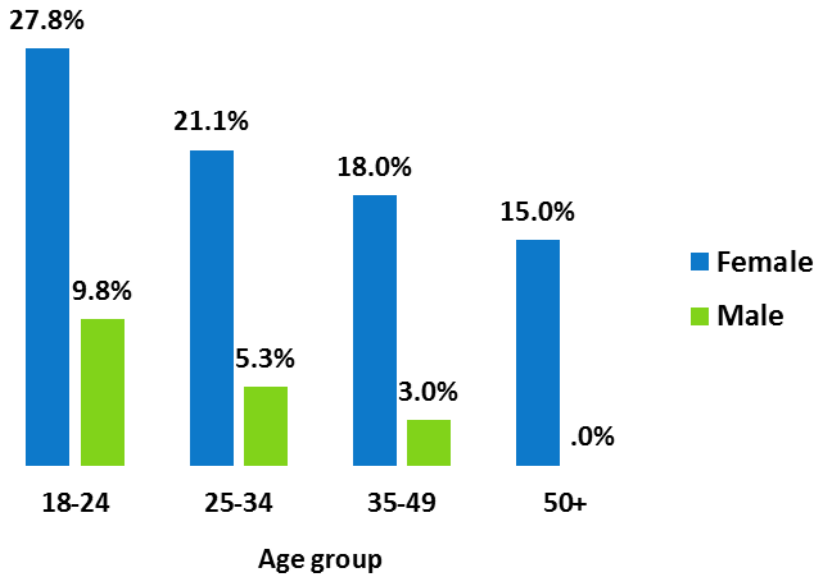
Figure 9: Gender Distribution per Age Group

Educational Level

Of the participants 30.8% (n=41) had completed a tertiary education, while another more than 60% (n=81) of participants had completed secondary school education. A small percentage (8.3% (n=11)) of the participants had only completed primary school (Figure 10). The overall education level of the sample is high, which the researcher should keep in mind when interpreting the data.
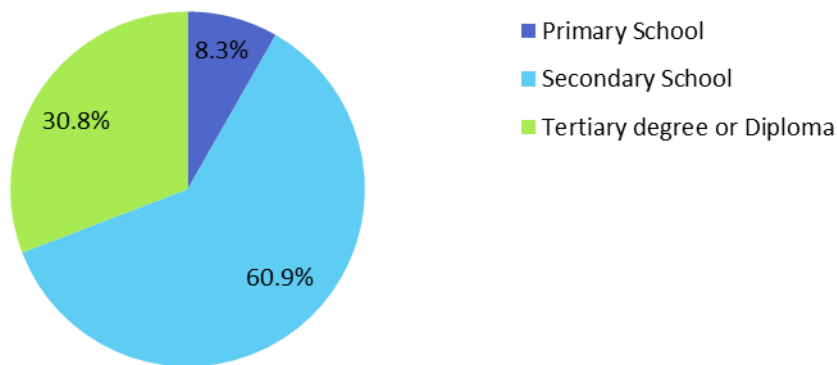
Figure 10: Education Level

Employment

Some recoding was done combing the unemployed and volunteers into one group, leaving the students separate as their motivation for participation may be different to those participants who does it because they are not employed. Students may be motivated by the level of experience they may gain by working within communities. Further recoding was done combing the employed and self-employed participants into one group (Figure 11). .
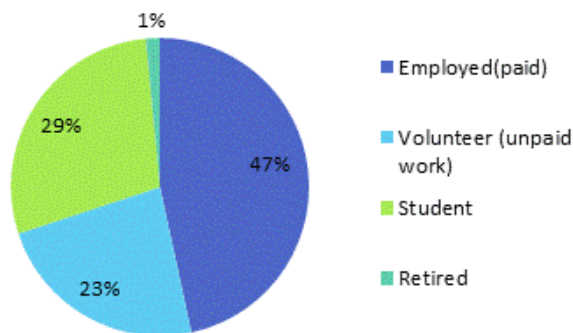
Figure 11: Employment Level

Marital Status

Half (49.6%; n=66) of the respondents had never been married, while 30.1% (n=40) of the respondents were married and another 4.5% (n=6) were cohabitating. Another 15.8% (n=21) were widowed or divorced (Figure 12).
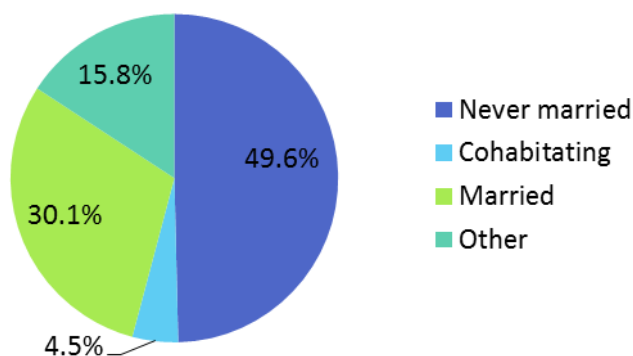
Figure 12: Marital Status

Religious Orientation

Most of the respondents reported their religious orientation as *Catholic* or *Christian* Figure 13. More than half of the participants were active as members of other sub-groups in their congregations. Half of the participants had previously attended a workshop on HIV/AIDS.
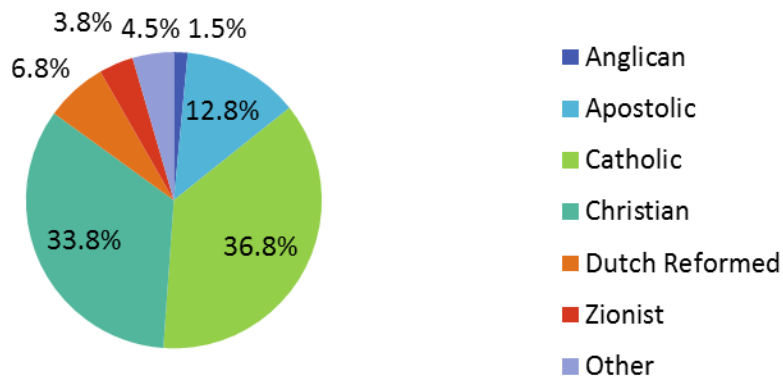
Figure 13: Religious Orientation

4.3. THE NATURE AND EXTENT OF EXPOSURE TO HIV/AIDS WITHIN FBOS

Knowing a PLWHA

Nearly 80% of the respondents know of someone who is living with HIV or AIDS (Figure 14). Of the respondents, 21.1% have never met anyone living with the disease. This is high in comparison to the 11% found by Deacon and Simbayi (2006) to not have had previous contact with someone with HIV. The difference could be explained by the fact that the course from which participants were drawn was aimed at supporting PLWHA. A third (30.8%) of respondents knows 10 or more people living with the disease. This is comparable to the 26.7% found by Deacon and Simbayi (2006). More than half of the respondents (52.6%, n=70) know of at least one person in their congregation who is living with HIV/AIDS. This is comparable to the 55.9% as reported by Deacon and Simbayi (2006).
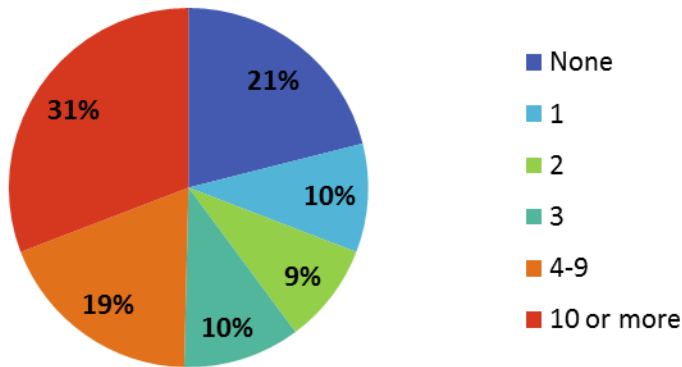
Figure 14: Number of People Known Who are Living with HIV or AIDS

Relationship with PLWHA

Figure 15 shows the relationship that respondents have with those people they know to be infected. Respondents knew more family members (33.1%, n=44) than friends (25.6%, n=34) who are infected. The reverse was true for the study done by Deacon and Simbayi (2006). In the current study, 21.1 % (n=28) of respondents did not know anyone who has the disease. This percentage correlates with the question asking about the number of people that they know who are living with HIV or AIDS, as shown in Figure 14. The *other* category in Figure 15 refers to PLWHA who the respondents have visited within their communities.
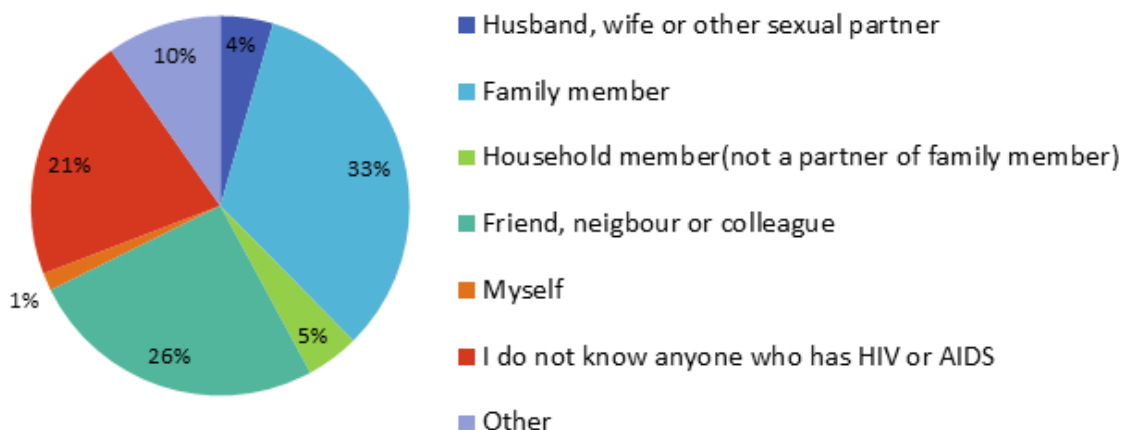
Figure 15: Relationship with PLWHA

	None	1-10 people	11-20 people	21-30 people	31-40 people	More than 50 people
■ Estimated % of PLWHA who have told everyone.	47.4	44.4	2.3	2.3	.8	3.0
■ Estimated % ofPLWHA who have told someone (but not everyone)of status	39.8	52.6	4.5	1.5	.8	.8
■ Estimated % of PLWHA who have not told anyone about their HIV status, but everyone thinks they have HIV or AIDS.	44.4	35.3	6.8	1.5	1.5	10.5
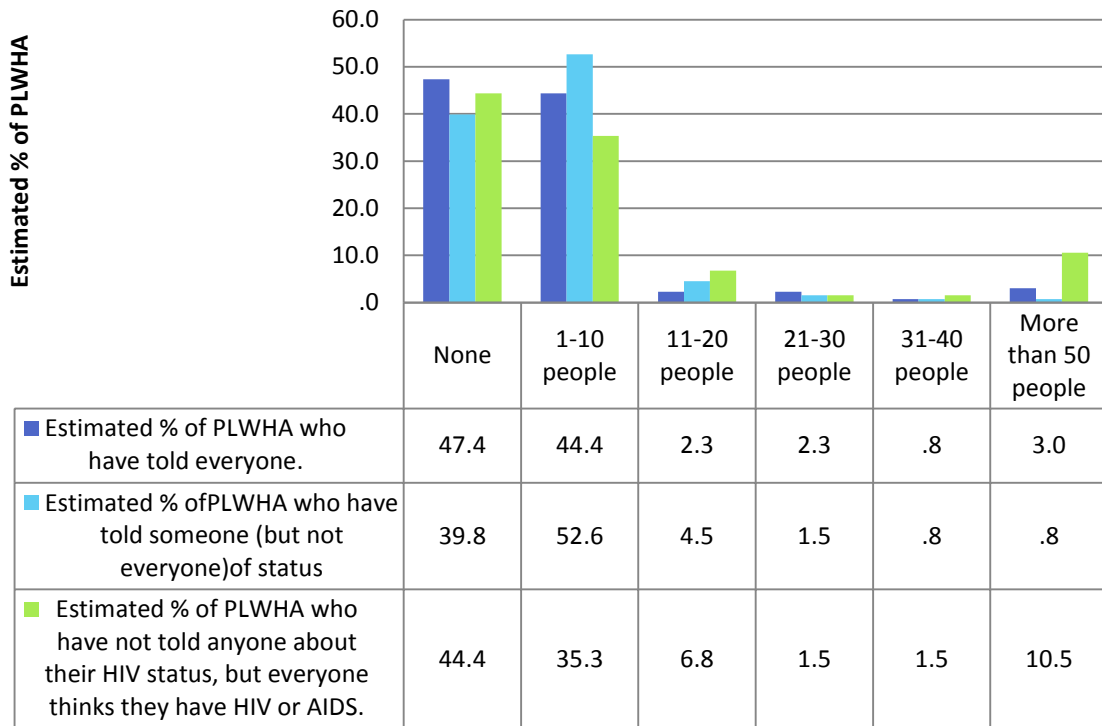
Figure 16: Estimated percentage of PLWHA who have disclosed their status

Disclosure

Due to the fear of stigma and discrimination that could result from disclosure of an HIV-positive, status people can be reluctant to disclose their HIV status. The level of HIV disclosure in a community can therefore be an indication of the level of felt or perceived stigma in that community.

In this study the level of disclosure was estimated by asking respondents to indicate how many people they know who are living with HIV or AIDS (Figure 14) and what their relationship is with the people who they know to be infected (Figure 15). In Figure 16 above, the respondents indicated the estimated number of PLWHA who have disclosed their status to everyone in the community or who have not told anyone.

Table 1: Spearman's rho correlation matrix for disclosure (*n*=133)

	How many people do you know who are living with HIV or AIDS?	Estimated number of people who have told everyone they are living with HIV or AIDS?	Estimated number of people who have told someone (but not everyone) that they are living with HIV or AIDS?	Estimated number of people who have not told anyone about their HIV status, but everyone thinks they have HIV or AIDS?
How many people do you know who are living with HIV or AIDS?	——			
Estimated number of people who have told everyone they are living with HIV or AIDS?	.499**	____		
Estimated number of people who have told someone (but not everyone) that they are living with HIV or AIDS?	.467**	.560**	____	
Estimated number of people who have not told anyone about their HIV status, but everyone thinks they have HIV or AIDS?	.308**	.394**	.433**	____

** p <0.01 level (2-tailed).

*p < 0.05 level (2-tailed).

As expected there was a significant relationship between the number of people faith based leaders know who are living with the HIV/AIDS with the number of people who have told everyone, those who have only told some and those who have not told anyone about their status but everyone thinks they have HIV/AIDS (Table 1). In general, the result suggest that the number of PLWHA faith based leaders know to be living with HIV/AIDS correlate with the number of people they know to be infected in their congregation. Faith based leaders are therefore more exposed to the PLWHA.

Table 2: Kruskal Wallis, grouped by "How many people you know who are living with HIV/AIDS?"

	Estimated number of people who have told everyone they are living with HIV or AIDS?	Estimated number of people who have told someone (but not everyone) that they are living with HIV or AIDS?	Estimated number of people who have not told anyone about their HIV status, but everyone thinks they have HIV or AIDS?
Chi-Square	38.144	31.752	17.662
df	5	5	5
Asymp. Sig.	.000	.000	.003

A Kruskal-Wallis test was conducted to evaluate differences among the number of people who have told everyone, those who have only told some and those who have not told anyone about their status but

everyone thinks they have HIV/AIDS grouping by the number of people who the faith based leaders reported to know who are living with HIV/AIDS. The number of people faith based leaders know to be living with the disease are significant affected by the number of PLWHA who have told everyone, those who have only told some and those who have not told anyone about their status but everyone thinks they have HIV/AIDS are significantly affected by (Table 2). Mann- Whitney tests were used to follow up this finding. It appears that FBL report of exposure to AIDS/HIV are significantly higher because of the number of people they know in the congregation and who have told everyone that they are living with the disease and therefore they have been reporting higher numbers of PLWHA they know U (66)= 360, p = .022, z=-2.298, r = -.28. This confirm that faith based leaders are very much exposed to the disease and this put them potentially in a unique position to influence others.

This does not reflect the actual level of disclosure as it is almost impossible to determine that in a community level survey study. The results show that it is perceived that PLWHA have only disclosed their status to a few people and did not disclose their status to everyone in the congregation. From the above it is evident that full disclosure, as perceived by the respondents, is very low in their congregations, but that HIV/AIDS coordinators are more aware of people's disclosure.

The respondents are not representative of the general population and are possible to be more involved in outreach work that involves PLWHA than the average members of FBOs. Some respondents (9.8%, n=13) indicated that those they know who are affected by the disease are people whom they visit in the community. An overwhelming 68% of respondents have a personal relationship with someone affected by the disease, such as being a husband or wife, sex partner, family member, household member, friend, neighbour or colleague (Figure 15). Thus, nearly 80% of the respondents know of someone close to them or in their community who is living with HIV/AIDS in the current study. Deacon and Simbayi (2006) found in their study that 86% of respondents have been exposed to PLWHA. These findings correspond to rates of exposure of PLWHA in other studies. These results therefore suggest that respondents are not only aware of HIV/AIDS but that the disease has a direct influence on their lives. Exposure of the respondents to the disease has therefore been on a close and personal level. Data on attitudes and behaviours should be interpreted with these facts in mind.

Two respondents disclosed their seropositive status in the questionnaire. At no stage was this questionnaire intended to measure prevalence among the respondents; however, the apparent prevalence rate of 1.5% (n=2) suggests that there may be other factors that have to be considered.

4.4. THE NATURE AND EXTENT OF KNOWLEDGE OF HIV TRANSMISSION MODES

This study assessed the respondents' knowledge level about possible HIV transmission methods. The respondents' overall knowledge of transmission methods was high even prior to starting the workshop (Table 3). It was expected that the respondents would have a higher than average degree of knowledge of HIV transmission modes, because of the role they play in their community. Faith-based leaders are more exposed to discourses about the disease in the church but also because half of the respondents have participated in previous courses on HIV/AIDS.

Table 3: Knowledge of transmission methods of HIV or AIDS

In which of the following ways do you think people can get HIV/AIDS		How far did you go in formal education			
		Primary School	Secondary School	Tertiary degree or Diploma	Total
Sharing cups and plates with someone with HIV or AIDS	No	11	78	40	129
	Don't know	0	1	0	1
	Yes	0	2	1	3
Total		11	81	41	133
Having sex without a condom with someone with HIV or AIDS	No	1	6	1	8
	Yes	10	75	40	125
Total		11	81	41	133
From kissing someone with HIV or AIDS	No	10	65	32	107
	Don't know	0	7	0	7
	Yes	1	9	9	19
Total		11	81	41	133

Table 3 shows the relationship between knowledge about transmission modes and highest educational level attained. Higher education level was not associated with better knowledge and less doubt about HIV transmission. The Spearman's rho revealed a statistically significant relationship between the different transmission methods (Table 4) as to be expected. However no correlations were found between educational level and transmission modes or overall knowledge.

Table 4: Correlations for knowledge of transmission methods (*n*=133)

	Sharing cups and plates with someone with HIV or AIDS	Having sex without a condom with someone with HIV or AIDS	From kissing someone with HIV or AIDS.
Sharing cups and plates with someone with HIV or AIDS	——		
Having sex without a condom with someone with HIV or AIDS	-.329[**]	——	
From kissing someone with HIV or AIDS	.358[**]	-.210[*]	——

**. p <0.01 level (2-tailed).

*. p <0.05 level (2-tailed).

Condom Use

Overall, 94% (n=125) of the respondents knew that having sex without a condom with someone with HIV or AIDS could result in being infected. Only 6% (n=8) (Table 3) did not think this was the case. Deacon and Simbayi (2006) found in their study that 9% of respondents were misinformed about the use of a condom to protect against HIV transmission. It is interesting to note that 94% of the respondents knew that sex without a condom could result in the transmission of HIV. Yet, when asked if two young people who are having sex before marriage and who are both HIV-negative could get HIV, 24% said yes and 5% did not know. The data may then reveal a lack of in depth knowledge in some (29%) of the respondents.
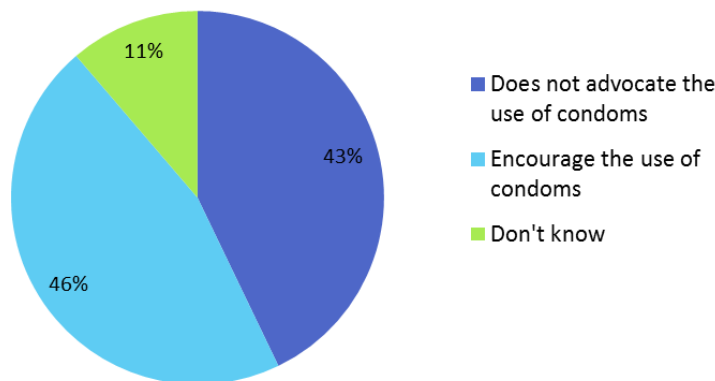
Figure 17: Congregation's Position on Condom Use

Respondents were asked what their congregation's position was on the use of condoms. Almost half (43%) of the respondents indicated that their congregation does not advocate the use of condoms while the other half (46%) indicated that the church encouraged the use of condoms. The perception varied from not addressing condom use at all to providing condoms at the gate of the church. When respondents were asked about their congregation's position on condom use, they indicated that the church made a differentiation between married and unmarried members of the church when talking about condoms. This opinion is expressed as:

They only talk to married people about condoms. I never had any topic or talks in terms of condom usage or issues in the church. Even Pastor I think maybe is afraid of saying inside the church cause I never heard anything discussed.

My church advises only those who are already HIV positive may use condoms when they are married.

The pastor says we must not use condoms.

Because the church supports one partner and faithfulness. They advise no sex before marriage. Statements are never carried out or followed, because teenage pregnancy is high at church [sic].

In my church it is felt that when you advocate condoms you are promoting sex before marriage.

Encourage the use of condoms to protect HIV and AIDS, because if you don't use condoms you can easily be infected or infect your partner.

They put boxes at the gate of a church on every Sunday.

It is therefore evident that the FBOs from which respondents came focus on prevention of HIV through abstinence. These aspiring faith-based leaders do have the knowledge regarding the disease and are mostly advocating abstinence as prevention strategy.

Sharing Cups and Plates

Only one (n=1) respondent or 0.8 % of all respondents reported being unsure about transmission of HIV by sharing cups and plates with someone with HIV or AIDS, and 2.3% (n=3) of respondents said yes, it

was possible. While an overwhelming 97% (n=129) knew that this was not possible (Table 3). One respondent clarified his/her response as:

Yes if he have a wound and you too and we use the cup the same time

Table 5: Sharing cups and plates, self, versus other.

	How worried are you about getting HIV or AIDS from sharing the communion cup with someone living with HIV or AIDS, are you:	How worried are you about getting HIV or AIDS from sharing the communion cup with someone living with HIV or AIDS and if the person with HIV or AIDS was visibly sick? Would you be:	How worried do you think OTHER PEOPLE are about getting HIV from sharing the communion cup with someone living with HIV or AIDS? Would most people in your congregation be:	How worried do you think OTHER PEOPLE are about getting HIV from sharing the communion cup with someone living with HIV or AIDS? And if the person with HIV or AIDS was visibly sick? Would most people in your congregation be:
Mean	1.66	2.90	2.70	3.10
Median	1.00	3.00	3.00	3.00
Std. Deviation	1.022	1.147	1.059	1.029
Variance	1.044	1.316	1.121	1.059

Table 6: Correlations – worry in self versus other (*n*=133)

	How worried are you about getting HIV or AIDS from sharing the communion cup with someone living with HIV or AIDS	How worried are you about getting HIV or AIDS from sharing the communion cup with someone living with HIV or AIDS and if the person with HIV or AIDS was visibly sick?	How worried do you think OTHER PEOPLE are about getting HIV from sharing the communion cup with someone living with HIV or AIDS?	How worried do you think OTHER PEOPLE are about getting HIV from sharing the communion cup with someone living with HIV or AIDS? And if the person with HIV or AIDS was visibly sick?
How worried are you about getting HIV or AIDS from sharing the communion cup with someone living with HIV or AIDS	____			
How worried are you about getting HIV or AIDS from sharing the communion cup with someone living with HIV or AIDS and if the person with HIV or AIDS was visibly sick?	.264[**]	____		

	How worried are you about getting HIV or AIDS from sharing the communion cup with someone living with HIV or AIDS	How worried are you about getting HIV or AIDS from sharing the communion cup with someone living with HIV or AIDS and if the person with HIV or AIDS was visibly sick?	How worried do you think OTHER PEOPLE are about getting HIV from sharing the communion cup with someone living with HIV or AIDS?	How worried do you think OTHER PEOPLE are about getting HIV from sharing the communion cup with someone living with HIV or AIDS? And if the person with HIV or AIDS was visibly sick?
How worried do you think OTHER PEOPLE are about getting HIV from sharing the communion cup with someone living with HIV or AIDS?	.186*	.121	____	
How worried do you think OTHER PEOPLE are about getting HIV from sharing the communion cup with someone living with HIV or AIDS? And if the person with HIV or AIDS was visibly sick?	.067	.289**	.411**	____

** $p < 0.01$ level (2-tailed).

* $p < 0.05$ level (2-tailed).

The Spearman's rho revealed a statistically significant relationship between the number of respondents who would be worried about getting HIV/AIDS from sharing the communion cup and sharing the communion cup with someone living with HIV/AIDS and are visible sick ($r_s(133) = .264$, $p < .01$). The effect size of this relationship was small (Cohen, 1992) and can in this case explain 6% of the total variance. However respondents feel that other people would be more worried than they would about sharing the communion cup with someone who are visible sick ($r_s (133) = .411$, $p < .01$). The effect size was small and can be used to explain 17% of the variance. There is thus a significant increase in how respondents view others' perception of the disease when people are visible sick.

Kissing

When asked if it was possible to be infected by kissing someone with HIV or AIDS, 14.3% (n=19) answered yes, and 5.3 % (n=7) did not know, while 80.5% (n=107) of respondents indicated that this was not possible (Table 3). Of the respondents who thought that one can get HIV or AIDS through kissing,

education was not a determining factor, as most of them had either secondary (47%, n=9) or tertiary education (47%, n=9). Reviewing the comments following the *yes* responses, one respondent explained:

> *Depends on the kind of kiss. Depends if the person has a cut and you also have a cut and you kiss then you can get it if the other person is positive or vice versa. But overall you can't get it from a mere kiss.*

Kissing someone who is infected carries a very low risk of infection in comparison to other modes of transmission (Younai, 2001).

Other Transmission Modes

Other reasons provided by respondents that could possibly result in transmission of the virus include:

> *Accident; if the infected blood goes to a wound of someone who does not have HIV*
> *When more people are using one razor blade or a needle*
> *From mother to child*
> *Blood to blood contact and sharing same needle*

The general knowledge of HIV transmission was high across all the different educational levels (Table 3). As with the study done by Deacon and Simbayi (2006), this study also found that HIV transmission through kissing resulted in the lowest number of "correct" answers.

Communion Cup

Respondents were asked how they take communion in their congregation. Of the respondents, 43% (n=57) stated that they take communion using a shared cup, and 46% (n=61) indicated that they used individual cups (Figure 18). As already mentioned, the respondents are very knowledgeable that sharing a cup or plate does not present a risk of transmission of the virus (97%) (Table 3).
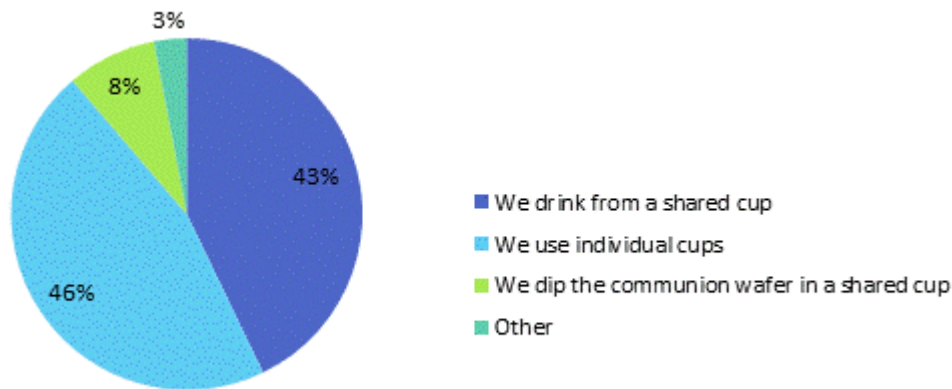
Figure 18: Use of Communion

When the 43% (n=57) respondents who are using a shared cup were asked about their own concern in sharing the communion cup with someone who might be living with HIV or AIDS, only 7% (n=4) said they were worried and 12% (n=7) of respondents were *a bit* worried. The percentage of respondents being worried increased significantly (28%, n=23), and those who were a bit worried doubled (23%, n=14) when sharing the communion cup with someone who is visibly ill with AIDS. This represents an unrealistic fear of HIV.

The 43% respondents who did share a communion cup reported that they perceive other members of their congregation to be more worried about sharing the communion cup than they are (Table 7). This may be because of social desirability bias. The respondents do not want to appear as judgemental about infected people, as this may affect their own status within the congregation. People are more likely to attribute socially unacceptable attitudes and behaviours to others than to themselves. This is because reports about other people's concerns about transmission, for example, are less subject to social desirability bias than reports of personal concerns (Ogden & Nyblade, 2005).

With a disease such as HIV/AIDS, people may be afraid to acknowledge their worries in relation to the disease. Worry about getting HIV from sharing the communion cup with someone living with HIV/AIDS was as high as 28 % (n=16) among respondents and this increased to 49% (n=28) if a person is visibly sick (Table 7). Although the overall knowledge about the possible transmission of the virus by using a shared cup is very high as only one person of the 57 respondents said that they think, a person can get HIV from sharing cups and plates with someone who is infected by the disease. A much higher number of

respondents (28%, n=16) perceived others to be worried that they may contract the virus when they share the communion cup with someone living with HIV or AIDS. Deacon and Simbayi (2006) reported similar results. In the current study, it was found that people's worry increased significantly when people infected by the virus are visibly sick.

Doubt was estimated by looking at the *don't know* responses to the knowledge questions. When asked about their own personal feelings the doubt responses were quite low. Only 9.8% (n=13) of respondents doubt their own feelings about how worried they are about getting HIV or AIDS from sharing the communion cup with someone living with HIV or AIDS. This is compared to the perceived doubt of other people (27.8% (n=37)). When a person is visibly sick, 7.5% (n=10) did not know if they would be worried, compared to the perceived doubt in others (21.1%, n=28) (Table 7).

Table 7: Reports of Own and Perceived Concerns and Practices around Sharing the Communion Cup

n=57		*%*		*n=57*		*%*
How worried are you about getting HIV or AIDS from sharing the communion cup with someone living with HIV or AIDS? Are you:				How worried do you think OTHER PEOPLE are about getting HIV from sharing the communion cup with someone living with HIV or AIDS? Would most people in your congregation be:		
Worried	4	7%		Worried	16	28%
A bit worried	7	12%		A bit worried	13	23%
Not at all worried	41	72%		Not at all worried	8	14%
Don't know	5	9%		Don't know	3	5%
How worried are you about getting HIV or AIDS from sharing the communion cup with someone living with HIV or AIDS, and if the person with HIV or AIDS was visibly sick? Would you be:				How worried do you think OTHER PEOPLE are about getting HIV from sharing the communion cup with someone living with HIV or AIDS, and if the person with HIV or AIDS was visibly sick? Would most people in your congregation be:		
Worried	23	40%		Worried	28	49%
A bit worried	14	25%		A bit worried	10	18%
Not at all worried	14	25%		Not at all worried	20	35%
Don't know	6	11%		Don't know	16	28%

From the above, (Table 6 and Table 7) it is evident that there is some correlation between respondents' own and the perceived beliefs about sharing the communion cup. There is an increase in predicted

worry in *others*, compared to the respondents' own reported views, as people are more likely to attribute socially unacceptable attitudes and behaviours to others than to themselves. This is because reports regarding other people's concerns about transmission, for example, are less subject to social desirability bias than reports of personal concerns (Ogden & Nyblade, 2005). It is therefore clear that even when knowledge about HIV/AIDS transmission is internalised, it does not always reduce worry.

4.5.   SHAMING, BLAMING OR JUDGEMENTAL ATTITUDES ASSOCIATED WITH HIV/AIDS

Stigma is characterised by shaming and blaming those associated with HIV/AIDS (Deacon & Simbayi, 2006). Respondents were asked: "Do you personally agree or disagree with the following statements?" The results are given in percentages in Figure 19 and Table 8 reflects the means. A high percentage (44% (n=58)) of respondents would feel ashamed if they were infected. They would not feel so ashamed if someone else in their family had HIV (28%, n=37). Respondents also indicated that HIV-infected people need not be ashamed (74% (n=98)). A large percentage of respondents (87% (n=116)) disagreed that people with HIV *were being punished by God*, or were *poor Christians*, or that they were *getting what they deserved* and were *not part of the congregation*.

I would be ashamed if I were infected with HIV.
Agree 44 | Partly Agree 20 | Disagree 26 | Don't know 10

I would be ashamed if someone in my family had HIV or AIDS
Agree 28 | Partly Agree 17 | Disagree 50 | Don't know 5

People who have HIV or AIDS should be ashamed of themselves
Agree 12 | Partly Agree 8 | Disagree 74 | Don't know 6

People living with HIV and AIDS are being punished by God
Agree 2 | Partly Agree 2 | Disagree 87 | Don't know 8

People living with HIV and AIDS are not good Christians
Agree 2 | Partly Agree 3 | Disagree 93 | Don't know 2

People living with HIV and AIDS have nothing to feel guilty about
Agree 39 | Partly Agree 20 | Disagree 30 | Don't know 11

"People who get HIV and AIDS through sex or drugs get what they deserve
Agree 11 | Partly Agree 17 | Disagree 65 | Don't know 8

Those people living with HIV or AIDS are not part of our congregation
Agree 5 | Partly Agree 2 | Disagree 92 | Don't know 2

■ Agree ■ Partly Agree ■ Disagree ■ Don't know

Figure 19: Shaming and Blaming

Please refer to Table 8 below for further descriptive statistics including median and standard deviations.

Table 8: "Do you personally agree or disagree with the following statements?" (*n*=133)

	"I would be ashamed if I were infected with HIV."	"I would be ashamed if someone in my family had HIV or AIDS"	"People who have HIV or AIDS should be ashamed of themselves"	"People living with HIV and AIDS are being punished by God:	"People living with HIV and AIDS are not good Christians"	"People living with HIV and AIDS have nothing to feel guilty about"	"People who get HIV and AIDS through sex or drugs get what they deserve"	"Those people living with HIV or AIDS are not part of our congregation"
Mean	2.81	2.23	1.59	1.20	1.14	2.68	1.74	1.19
Median	3.00	1.00	1.00	1.00	1.00	3.00	1.00	1.00
Std. Deviation	1.250	1.324	1.067	.583	.566	1.271	1.099	.676
Variance	1.563	1.752	1.138	.340	.320	1.614	1.207	.457

Table 9: Correlations for shaming and blaming (*n*=133)

	"I would be ashamed if I were infected with HIV."	"I would be ashamed if someone in my family had HIV or AIDS"	"People who have HIV or AIDS should be ashamed of themselves"	"People living with HIV and AIDS are being punished by God:	"People living with HIV and AIDS are not good Christians"	"People living with HIV and AIDS have nothing to feel guilty about"	"People who get HIV and AIDS through sex or drugs get what they deserve"	"Those people living with HIV or AIDS are not part of our congregation"
"I would be ashamed if I were infected with HIV."	——							
"I would be ashamed if someone in my family had HIV or AIDS"	.610**	——						
"People who have HIV or AIDS should be ashamed of themselves"	.375**	.579**	——					
"People living with HIV and AIDS are being punished by God:	.004	.025	-.048	——				
"People living with HIV and AIDS are not good Christians"	-.055	.090	.085	.251**	——			
"People living with HIV and AIDS have nothing to feel guilty about"	-.173*	-.078	-.211*	-.036	-.169	——		
"People who get HIV and AIDS through sex or drugs get what they deserve"	.185*	.197*	.232**	.009	.266**	-.112	——	
"Those people living with HIV or AIDS are not part of our congregation"	.203*	.265**	.217*	-.030	.228**	.148	.173*	——

** *p* <0.01 level (2-tailed).

* *p* < 0.05 level (2-tailed).

The Spearman's rho revealed a statistically significant positive relationship between the respondents who agreed with the statement that they would be ashamed if they were infected and if someone in their family are infected by the HIV virus $(r_s(133) = .610, p < .01)$. The effect size of this relationship was large (Cohen, 1992). Squaring the correlation coefficients indicated that 37% of the variance in the number of people who would be ashamed if they are infected would also be ashamed if someone in

their family had HIV/AIDS (Table 9). A Kruskal-Wallis test was conducted and found to be significant when evaluating the differences among respondents who would be ashamed if they were infected with HIV and if someone in their family had HIV/AIDS, PLWHA should be ashamed of themselves, PLWHA get what they deserve and PLWHA are not part of their congregation.

In Table 10, the current results of Figure 19 are compared to those obtained by Deacon and Simbayi (2006), and the study done by Nyblade and colleagues (2003) in Tanzania. From the comparison in Table 10, personal shame as well as feelings of shame towards family who are infected is much higher among the aspiring religious leaders when compared to the other studies. However, when asked if others who are infected should be ashamed of themselves, the stigmatising responses are more infrequent than those from the earlier studies are. Respondents' own, personal views are low on whether people with HIV/AIDS are being punished by God and comparable to the study conducted by Deacon and Simbayi, 2006. However, the responses to the Tanzanian study were much higher.

Table 10: Shaming and Blaming Across Three Studies

	Current study[2]	Deacon and Simbayi (2006)	Nyblade and colleagues (2003)
I would be ashamed if I were infected with HIV.	63.90%	46.50%	38.90%
I would be ashamed if someone in my family had HIV or AIDS	45.10%	34.70%	29.40%
People who have HIV or AIDS should be ashamed of themselves	20.30%	22.30%	35.20%
People living with HIV and AIDS are being punished by God	4.60%	9.20%	44.4%
(Others say) People living with HIV and AIDS are being punished by God	26.30%	23%	64.2%

Feelings of shame (internalised stigma) were much more prevalent among the aspiring faith-based leaders in the current study, and blaming attitudes were much less common than among the respondents from Tanzania (Nyblade et al., 2003). One would expect that shaming would be much lower, as the current study was done several years after the other studies. Continued self-shame

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[2] These results are the sum of percentages from the "agree" and "partly agree" responses. This is also true for the study done by Deacon and Simbayi (2006).

associated with HIV infection in spite of low reported blaming discourse suggests that moral judgements are still being made regarding sexual behaviour and that this is linked to HIV status. These feeling of personal shame can be an indicator of the prevalence of stigma and discrimination among these aspiring faith-based leaders.

The belief that HIV/AIDS is a punishment from God was much more prevalent among the respondents from Tanzania than those from South Africa. It also transpired that respondents reported a much less judgemental stance in personal beliefs, than they would expect from other members of FBOs (Figure 20).

Respondents were asked several questions about what people say about PLWHA. Firstly, they were asked if they knew whether other people in the congregation had in the last twelve months gossiped about PLWHA. The responses suggested that there was a high level of gossip among people in the congregation (41%, n=54). The respondents reported that any observable behaviour towards those who are infected with the virus was low (23%, n=30) but that it does occur within FBOs, as Deacon and Simbayi (2006) also found. Quite a few respondents were not aware of what had happened to HIV-infected people in the congregation in the previous twelve months with regard to their being blamed or gossiped about.
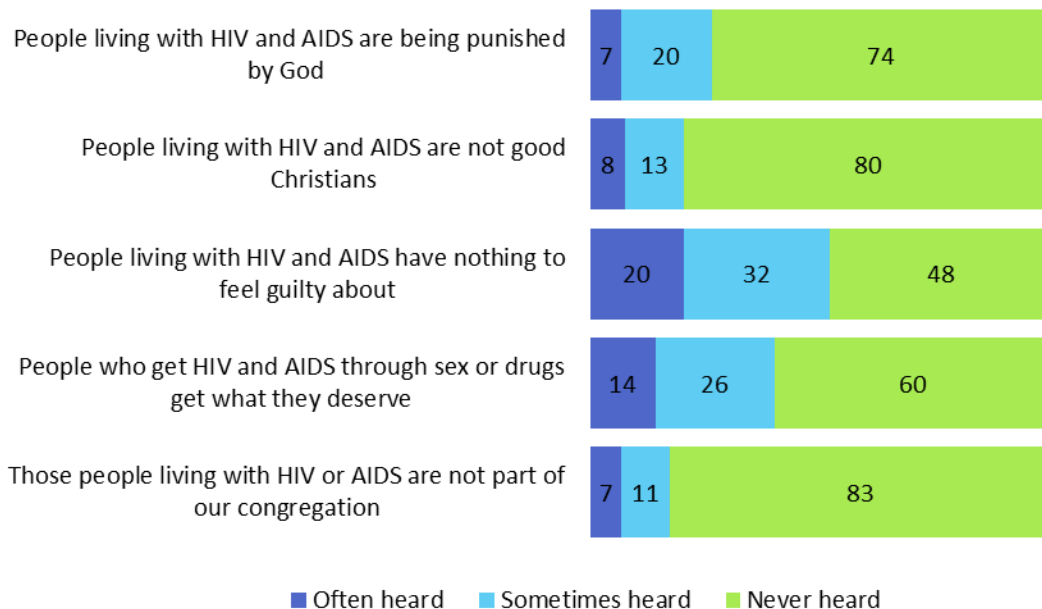
Figure 20: What people say about PLWHA

Table 11: Statistics for: In the last 12 months how often have you heard people in you congregation say something like the following in sermons, bible studies or prayers? (n=133)

	People living with HIV and AIDS are being punished by God:	"People living with HIV and AIDS are not good Christians"	"People living with HIV and AIDS have nothing to feel guilty about"	"People who get HIV and AIDS through sex or drugs get what they deserve"	"Those people living with HIV or AIDS are not part of our congregation"
Mean	1.33	1.28	1.72	1.54	1.24
Median	1.00	1.00	2.00	1.00	1.00
Std. Deviation	.600	.595	.782	.734	.566
Variance	.359	.354	.611	.538	.320

Table 12: Correlations for what people have said about PLWHA in the past 12 months in sermons, bible studies or prayers.

	People living with HIV and AIDS are being punished by God	People living with HIV and AIDS are not good Christians	People living with HIV and AIDS have nothing to feel guilty about	People who get HIV and AIDS through sex or drugs get what they deserve	Those people living with HIV or AIDS are not part of our congregation
People living with HIV and AIDS are being punished by God	——				
People living with HIV and AIDS are not good Christians	.601**	——			
People living with HIV and AIDS have nothing to feel guilty about	.229**	.261**	——		
People who get HIV and AIDS through sex or drugs get what they deserve	.507**	.562**	.338**	——	
Those people living with HIV or AIDS are not part of our congregation	.504**	.429**	.263**	.390**	——

** $p < 0.01$ level (2-tailed).

Respondents were asked how often they have heard people in their congregation say something negative or excluding about PLWHIV during sermons, bible studies or prayers during the last twelve months (Figure 20).

Respondents indicated a high degree of never having heard anyone in the congregation saying that people are being punished by God (74%, n=98)), not good Christians (80%, n=106)) or not part of the congregation (83%, n=110)). These overall sentiments seem to match the responses in Figure 19. In general, people tended to report more blame by others than they reported about themselves. As shown in Table 12 there are significant correlations between negative statements that have been made in by others in the previous 12 months as was heard by the respondents. Overall, the scores indicate more leniency than intolerance. A Mann-Whitney test indicated that respondents' perceptions that people who get HIV/AIDS get what they deserve was greater for respondents who report that they 'sometimes heard' that children or family members have been insulted or humiliated because of the person's HIV status compared to having heard it 'often', U (53)= 192.5, p = .01, $z=-2.571$, r = -.35. So even if respondents feel that those infected get what they deserve it is not a belief that would be made public as it is only 'often heard'. However this confirm that stigma and discrimination does exist.

4.6.   THE NATURE AND EXTENT OF DISCRIMINATORY OR EXCLUSIONARY PRACTICES OR BEHAVIOURS TOWARDS PEOPLE INFECTED AND AFFECTED BY HIV/AIDS

The questionnaire explores the effects of enacted stigma, including discrimination, by asking respondents: "What happened in the last 12 months to anyone you know living with HIV or AIDS"? Figure 21 reports the findings on reported and/or experienced discriminatory practices in the church. These findings represent participants' reflections on what they observed had happened in their congregation and do not constitute a direct report on what PLWHA have actually experienced.
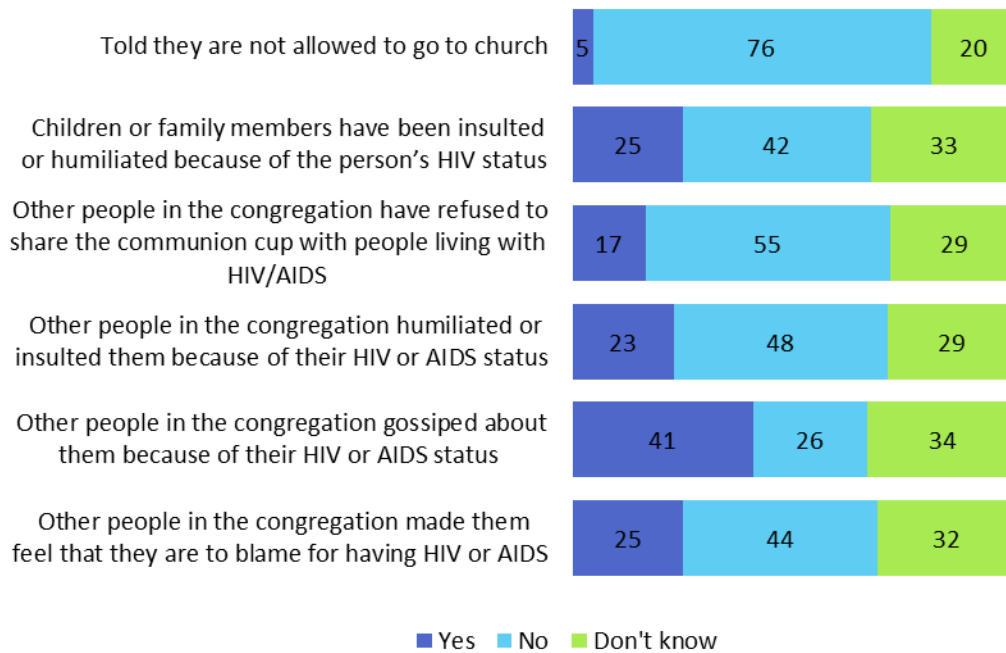
Figure 21: Perceived Discriminatory Behaviour

Table 13: Which of the following has happened in the last 12 months to anyone you know living with HIV or AIDS? (*n*=133)

	Other people in the congregation made them feel that they are to blame for having HIV or AIDS	Other people in the congregation gossiped about them because of their HIV or AIDS status	Other people in the congregation humiliated or insulted them because of their HIV or AIDS status	Other people in the congregation have refused to share the communion cup with people living with HIV/AIDS	Children or family members have been insulted or humiliated because of the person's HIV status	Told they are not allowed to go to church
Mean	1.81	2.15	1.74	1.62	1.83	1.29
Median	2.00	2.00	2.00	1.00	2.00	1.00
Std. Deviation	.809	.802	.804	.756	.803	.545
Variance	.654	.644	.646	.572	.644	.297

Table 14: Correlations for: Which of the following has happened in the last 12 months to anyone you know living with HIV or AIDS? (*n*=133)

	Other people in the congregation made them feel that they are to blame for having HIV or AIDS	Other people in the congregation gossiped about them because of their HIV or AIDS status	Other people in the congregation humiliated or insulted them because of their HIV or AIDS status	Other people in the congregation have refused to share the communion cup with people living with HIV/AIDS	Children or family members have been insulted or humiliated because of the person's HIV status	Told they are not allowed to go to church
Other people in the congregation made them feel that they are to blame for having HIV or AIDS	____					
Other people in the congregation gossiped about them because of their HIV or AIDS status	.518**	____				
Other people in the congregation humiliated or insulted them because of their HIV or AIDS status	.504**	.551**	____			
Other people in the congregation have refused to share the communion cup with people living with HIV/AIDS	.475**	.460**	.687**	____		
Children or family members have been insulted or humiliated because of the person's HIV status	.292**	.457**	.528**	.479**	____	
Told they are not allowed to go to church	.287**	.095	.359**	.405**	.368**	____

**$p < 0.01$ level (2-tailed).

Of the respondents, 41% (n=54) indicated that gossiping is a problem in their congregation. All together 23% (n=30) of respondents had observed others in the congregation insulting or humiliating PLWHA because of their status. In addition, approximately 17% (n=22) reported others refusing to share the communion cup with those affected.

More than half of the respondents (57%, n=76)) said that their congregation was very welcoming and caring towards people living with HIV/AIDS, and another 27% (n=36) said their congregation was quite welcoming and caring (Figure 22). There is thus some covert but not open discrimination against those who are infected or suspected to be infected.
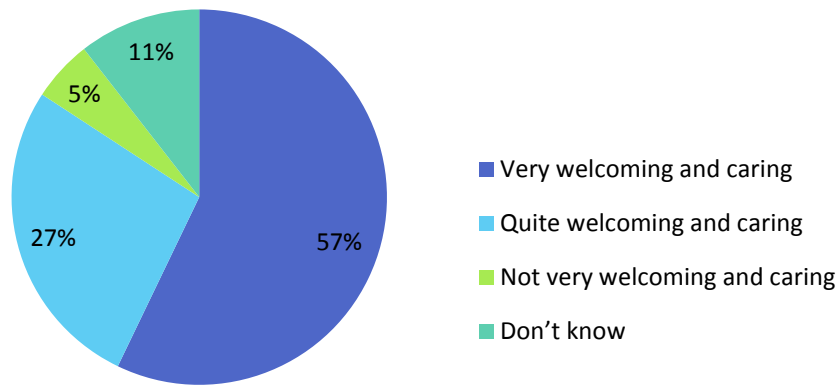
Figure 22: Is Congregation Welcoming and Caring Towards PLWHIV?

Highly significant correlations have been found between the perceived practices of other people in the congregation against those who are infected by the virus. Others have made those who are infected feel that they are to blame for having HIV/AIDS by gossiping (r_s = .518 (*BCa 95% =.320-.660)),* humiliating or insulting them (r_s = .504(*BCa 95% =.446-.735)), by* refusing to share the communion cup with PLWHA (r_s = .475 (*BCa 95% =.401-.688))* (Table 14)*.*

There is a significant positive correlation between those who perceived others to gossip about the PLWHA and the humiliation and insulting of PLWHA (r_s = .457 (*BCa 95% = .399-.682))* (Table 14).

There is also a significant positive correlation between the perceived humiliation and insulting of PLWHA by others as reported by the aspiring religious leaders and the refusal to share the communion cup with PLWHA (r_s = .687 (*BCa 95% =.455-.762))* (Table 14).

There is a small positive correlation between some members of the congregation who have made PLWHA feel that they are to blame for having HIV/AIDS by telling them they are not allowed to attend church (r_s = .287 (*BCa 95% =.085-.487)).* These correlations can be the result of the respondents' own stigma or a generalised perception of others stigma they may experience (Table 14).

Approximately 20% (n=26) of respondents said that HIV/AIDS was never discussed in sermons in their congregation. This suggests that in a few areas, the priests are not taking the problem seriously enough. Approximately 47% (n=63) of the respondents indicated that HIV/AIDS was never discussed at funerals, which may say more about families' willingness to disclose (about what actually happened to the

deceased) at these occasions than about priests' willingness to discuss the issue (Deacon & Simbayi, 2006). Most people (60%, n=80) said it was good to discuss the issue in sermons or prayers, but many (27%, n=36) did not know what others thought, which suggests that too little discussion was actually taking place among people.

In an open question, respondents were asked what they think the church should do about HIV/AIDS? Some responses included:

> *Should teach people; educate people about dangers of HIV and to find a way to stop the stigma.*

> *They should be more open to talk and discuss about it do workshop in all people coming to church so that it can be easily accepted in the church. In the prayer meetings, we should always pray for people living with HIV/AIDS. Allow children to teach older people about it, give them more knowledge. Let them know that it is not a shame to talk about it.*

From the responses, it is clear that much still needs to be done in the fight against stigma and discrimination.

4.7. CONCLUSION

The analysis shows a high degree of overall knowledge about HIV/AIDS prevention and contracting the disease. The respondents did not reflect judgemental discourses about PLWHIV. However, respondents reflected some personal shame associated with the disease. Respondents reported that other people in their congregation were much more likely than themselves to have judgemental beliefs about PLWHA. They reported observed incidents of covert discrimination in their congregation in the form of blaming, insulting people and gossiping. The respondents reported low levels of discussion of HIV in the church. More than half the respondents think, it is good to discuss HIV/AIDS in sermons or prayers, and that their congregation is welcoming and caring towards people living with HIV/AIDS. There is, however, unnecessary anxiety about HIV-positive congregants partaking in religious ceremonies.

CHAPTER 5: DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1. INTRODUCTION

The main purpose of this study was to explore the nature and extent of HIV/AIDS-related stigma reported by aspiring faith-based leaders. This objective was approached from a quantitative perspective. To establish whether this objective has been met, this chapter will begin by providing a synopsis of the major findings of the study. This is done in relation to the literature reviewed and the theoretical frameworks that could explain current findings. The study was evaluated by exploring the limitations and considering the implications of the findings. It also offers some recommendations for future research. The chapter ends with the researcher's conclusions.

5.2. SYNOPSIS OF THE LITERATURE REVIEW

Over the past 30 years, the struggle against HIV/AIDS has faced several challenges. These include increased infections in sub-Saharan Africa and the uncertainty of continued funding by donor organisations. The literature emphasises the importance of addressing societal factors such as stigma and discrimination to promote HIV prevention strategies. Recognising, categorising and measuring stigma present a unique set of challenges, though.

FBOs have always been active in caring for those who are sick and it is no different in the case of HIV/AIDS. FBOs are also playing an integral role in HIV prevention in their congregations, although a predominant focus on morals may result in an unwillingness on the part of FBOs to confront drivers of HIV in societies that do not respond to the moral messages. This may contribute to an uneasy relationship between FBOs and their secular colleagues in the struggle against HIV/AIDS questions of the relevance of the messages of FBOs. Moreover, the risk exists that the moral messages of FBOs may contribute to enhancing stigma in communities. To investigate this issue, the insights and attitudes of aspiring faith-based leaders towards HIV and PLWHA were assessed under the assumption that they are in a position to present more insight into the existing situation regarding stigma in their respective FBOs and that their own views may eventually influence those in their congregation and those they serve.

5.3. DISCUSSION

This study was undertaken to help inform social scientists and faith-based leaders at a local level in making informed decisions towards implementing more effective anti-stigma strategies, in an effort to help reduce stigma and discrimination. Previous research has addressed the issue of stigma and discrimination, yet the problem persists 30 years after the HIV/AIDS was identified (UNAIDS, 2011a).

The discussion focused on results related to knowledge about the nature and extent of transmission methods; feelings of shame, blame or judgemental attitudes, nature and extent of exposure and discriminatory or exclusionary practices or behaviours associated with the disease as reported by aspiring faith-based leaders. This is followed by a discussion of stigma and discrimination using PEN-3 and FINIS as a frame of reference.

5.3.1. What are the Nature and Extent of Knowledge of Transmission Methods for Contracting HIV?

The results showed that HIV-knowledge is very high among aspiring faith-based leaders who were part of the research. Respondents across all educational levels are knowledgeable about the methods of transmission. They knew HIV could not be contracted by sharing cups and plates (97%), having sex with a condom (94%) or kissing (81%). This did not come as a surprise as many of the respondents have attended previous courses or seminars on the subject of HIV/AIDS. The high knowledge levels may be indicative of the positive effect of previous training sessions, exposure to discourses in church as well as general media campaigns. Peltzer, Mngqundaniso and Petros (2006), who investigated the knowledge, beliefs and practices of traditional healers in KwaZulu-Natal, found similar results on high levels of knowledge on the modes of HIV transmission. Visser, Makin, Vandormael, Sikkema, and Forsyth (2009) reported that more than 90% of respondents from the general population in the Tshwane region knew the major transmission routes and that the virus could not be transmitted through casual contact. These aspirant faith-based leaders' knowledge is thus similar to that of other community groups.

It is interesting to note that 94% of the respondents knew that sex without a condom could result in the transmission of HIV. Yet, when asked if two young people who are having sex before marriage and who are both HIV-negative could get HIV, 24% said yes and 5% did not know. The data may then reveal a lack of in-depth knowledge in some (29%) of the respondents. It can also show how a moral perspective can influence knowledge. These perspectives may perpetuate the misconceptions associated with the

disease. Additionally, knowing that condoms can prevent the disease may not translate to the effective use of condoms, as people may be influenced by contextual factors, attitudes, and cultural meanings (Peltzer et al., 2006). The use of condoms may be influenced by a congregation's overall position on condom use. Almost halve of the respondents (43%) indicated that their congregation does not advocate the use of condoms, while the other half believed their congregation advocated the use of condoms. In some FBOs, the use of condoms is thus a debated issue. In some FBOs, prevention of HIV is still limited to the promotion of abstinence outside marriage.

Respondents' attitudes and practices were in some cases inconsistent with their HIV knowledge. When an individual worries about the potential risks of contracting HIV/AIDS, there is an increase in mental attempts to find ways of avoiding the potential threats. This indicates that many people dwell on and worry about HIV transmission through casual encounters in daily life (Ogden & Nyblade, 2005). Respondents were aware that casual contact does not result in transmission. Yet, when asked how worried they are of getting HIV from sharing the communion cup with someone living with HIV/AIDS, 8% of the respondents were worried. Sharing a cup with a person who is visibly sick due to suspected HIV/AIDS, 40% respondents indicated that they would be worried. This is comparable with results from the general population (Visser et al., 2009) where 20% of respondents would not drink from a tap if a person with HIV had just drunk from it. Worry is dominated by negative and intrusive thoughts about negative events we are afraid will occur in the future and are the cognitive component of anxiety (Borkovec, Ray & Stober, 1998). Worry is activated under conditions of uncertainty and persistent fears about HIV transmission. It consists of a series of *what if?* statements that people create in the face of these fears. This indicates the presence of instrumental stigma due to ungrounded fear of casual transmission (Deacon & Simbayi, 2006). Additionally, respondents were asked how worried *other people* would be about getting HIV/AIDS from sharing the communion cup with someone who have AIDS. Most respondents attributed higher levels of worries to others than to themselves.

Instrumental stigma, which arises from the perception that interacting with PLWHA, poses a direct threat to one's own physical wellbeing. A person might *know* how HIV is transmitted and therefore be aware that one cannot become infected via casual contact, but might nevertheless refrain from sharing the communion cup with PLWHA. According to Stein (2003), people may doubt, disregard or disagree with public health information regarding low-risk or non-risk contacts provided by health professionals. That knowledge alone is insufficient to eliminate incorrect beliefs about transmission or, for that matter, to

eradicate stigma. This indicates that knowledge does not automatically translate to actions or attitudes that reduce stigma.

Several studies have established that the basis of HIV/AIDS-related stigma in Africa is fear of contagion, particularly through casual contact, and thus it is powered by inaccurate understandings of HIV transmission (Nyblade et al., 2003). According to Ogden and Nyblade (2005, p.15), "fear of and preoccupation with transmission through everyday casual contact leads directly to stigma in the form of isolation of persons living with HIV and AIDS in all aspects of daily life." Fears of casual contact are deeply rooted, even among people who presumably know better (Rankin, Brennan, Schell, Laviwa, & Rankin, 2005). A significant number of respondents reported fears of being infected through ordinary body fluids, drinking from the same communion cup or using the same utensils with PLWHA who are visibly sick due to HIV/AIDS.

Worry about sharing the communion cup seems to be associated with active discrimination against PLWHA. Exclusion of PLWHA from the communion ritual entails a degree of exclusion and discrimination. About 17% (n=22) of people observed others refusing to share the communion cup with PLWHA. The issue of shared communion therefore has to be addressed, but it cannot be addressed simply by providing people with information as unrealistic fear of HIV transmission is one of the building blocks of HIV-related stigma (Ogden & Nyblade, 2005; Visser et al., 2008).

5.3.2. What are the Nature and Extent of Feelings of Shame, Blame or Judgemental Attitudes Associated with HIV/AIDS?

Previous research found that shame, blame, and judgment are key underlying causes of HIV-related stigma (Nyblade et al., 2003; Ogden & Nyblade, 2005). These findings are consistent with Zou, Yamanaka, John, Watt, Ostermann and Thielman's (2009) findings that religious beliefs about HIV are strongly associated with shame. Shame can be associated with internalised stigma. Religion can therefore be a significant source of negative perceptions of PLHWA. According to Zou et al. (2009), knowledge of HIV does not contribute significantly to a decrease in stigmatising values. It is noteworthy that self-shame among the aspiring faith-based leaders is very common and they may feel ashamed should the virus (44%) infect them or someone in their family (28%). However, judgement of others seems to be low as when asked if respondents agreed with the statement "People who have HIV or AIDS

should be ashamed of themselves" 74% disagreed with the statement indicating that people who are infected by the disease do not need to be ashamed of themselves (12%).

The results of the survey indicated that the aspiring religious leaders only mention HIV/AIDS sometimes (56.4%) in sermons and some respondents have never heard HIV/AIDS mentioned in sermons (19.5%). The largest single proportion of respondents stated that they have never heard HIV/AIDS to be discussed at funerals (47.4%). Nearly a third (27%) of respondents do not know how people in their congregation feel about discussing the issue of HIV/AIDS in sermons, while most respondents (60.2%) think it is a good idea to discuss HIV/AIDS. Most of the respondents (77.4%) also did not know what the congregation say about the stigma linked to HIV/AIDS. Therefore, the findings of the survey established that dissemination of HIV-related stigma information in the church is lacking. The lack of information gives rise to an environment where myths and stereotypes that surround the disease may flourish and in turn, incite irrational fears and anxieties linked to association and contact with people who are or thought to be infected (Malawi Interfaith AIDS Association, 2006).

5.3.3. What are the Nature and Extent of Exposure to HIV/AIDS within FBOs?

Almost all of the respondents (80%) knew someone affected by the disease. This finding is similar to the findings of Deacon and Simbayi (2006) for the faith-based community. It is also comparable with the general population, although slightly higher, as would be expected from people enrolling for the Choose Life courses in particular. In a similar study done among the general population in the Tshwane metropolitan area, 73% reported to know someone with HIV (Visser et al., 2009). HIV is a familiar disease that influences the lives of many people. The finding indicates that faith-based leaders are familiar with issues relating to HIV and that their opinions might be a reliable expression of people's attitudes towards HIV. As many as 80% of respondents indicated that they knew people who are living with HIV/AIDS, 70 % have a close relationships with those PLWHA, which could be a family member or friend. Only a tenth (9.8%) of the respondents identified the people who they knew to be infected to be from their community. Respondents also indicated that PLWHA mostly disclose selectively and not openly to everyone in the congregation. Respondents were generally unaware of people living with the virus in their congregation. This demonstrates that disclosure of HIV status is relatively low. It may be a fear of stigma that represents a barrier to disclosure (Stein, 2003; UNAIDS, 2005). When intense feelings of shame are internalised, it may result in individuals' withdrawal from support networks such as these FBOs, fear of testing and disclosure, and most dangerously, the disregard of adequate prevention

measures (Haddad, 2005). Stigma often feeds on silence and denial (UNAIDS, 2005). All together 19.5% of the aspiring faith-based leaders stated that HIV/AIDS is never mentioned in the church or only sometimes (56.4%). There is thus not adequate discussion on HIV in these congregations to have an influence on people's behaviour. The culture of silence surrounding disclosure of HIV infection is one factor that fuels HIV/AIDS stigma.

5.3.4. What are the Nature and Extent of Discriminatory or Exclusionary Practices or Behaviours Towards People Infected and Affected by HIV/AIDS?

The respondents report that they perceive some enacted stigma in their congregations such as gossiping, insulting and refusal to share the communal cup. **Enacted stigma** refers to the discrimination and violation of human rights that PLWHA experience (Nyblade & MacQuarrie, 2006). According to Nyblade and Ogden (2005), the enactment of stigma through discriminatory practices includes physical isolation, social isolation; verbal abuse; and institutional discrimination. It might result in loss of friendship, gossip, keeping a distance from PLWHA or loss of respect for PLWHA. Stigma and discrimination can be perpetuated by lack of information (Malawi Interfaith AIDS Association, 2006). Some (25%) respondents have reported that children or family members have been insulted or humiliated because of a family members HIV status.

Litman and Pezzo (2005, p. 963) define gossip as "unverified news about the personal affairs of others, which is shared informally between individuals." Gossip was found to be common practice and a covert manifestation of stigma (Maman et al., 2009; Visser et al., 2009). Gossip was usually triggered by visible signs and symptoms of AIDS. This resulted in community members speculating about who were infected with HIV and how they had contracted the virus.

PLWHA might opt to withdraw from social situations in which stigma may be apparent in order to avoid rejection and blame for their HIV status. Under such circumstances, it becomes difficult to get an accurate assessment of the existence of actual experiences of stigma and discrimination as perceived by respondents.

Faith-based leaders may report that PLWHA do not need to feel ashamed. However, when questions are asked about perceived discriminatory behaviour by others, they report more stigmatising attitudes and practices. The respondents perceive other people in the community as more stigmatising than

themselves. This discrepancy can be the result of the respondents' own stigma or a generalised perception of others' stigma they may observe.

FBOs are amongst the many institutions in society that shape the values and attitudes that guide responses to illness and vulnerability and that support appropriate and compassionate responses to social challenges (Green, 2003). Religious groups and organisations have provided psychological support and comfort to PLWHA and their families. Religious values have been used to encourage non-stigmatising behaviours. The principle of not judging the behaviour of others is based on the premise that it is the role of God to pass judgment. Judging others is not the task of people. The spiritual comfort provided by FBOs has helped to reduce the guilt that PLWHA may feel. It is however important to note that religious beliefs may also underlie social norms that can contribute to stigma. FBOs thus have a significant role in promoting religious beliefs that confront stigma and encouraging dialogue on those beliefs that do not (Watt, Maman, Jacobson, Laiser & John, 2009).

5.3.5. Explaining Stigma and Discrimination According to PEN-3 and FINIS

Behavioural analysis and intervention points of entry into a community should focus on culture rather than on individual behaviours, as is commonly found in HIV/AIDS interventions. The PEN-3 model and Framework Integrating Normative Influences on Stigma (FINIS) equip researchers to study stigma and discrimination in communities. This model and framework were therefore applied in this study.

The results of this study have shown that knowledge alone does not lead to behavioural change, because faith based leaders are knowledgeable however, stigma and discrimination persists. Behaviour is influenced by various cultural factors and complementary forces from within and outside the specific community (Airhihenbuwa, et al., 2009) and should therefore be considered in any discussion pertaining to stigma and discrimination.

The way people 'make sense' of their health and illness will also impact on the kind of help they seek and will result in differential patterns of 'help-seeking behaviour' that are socially and culturally represented (Gilbert & Walker, 2010). Much of the literature on stigma is on the 'micro' or individual level. However, there is a need to move beyond such analyses to more 'macro' analyses. Parker & Aggleton (2003) reject the individualism underlying conventional approaches to stigma and its alleviation. Instead they insist that 'stigma and stigmatisation function, quite literally, at the point of intersection between culture, power and difference – and it is only by exploring these different categories that it becomes possible to

understand stigma and stigmatisation not merely as an isolated phenomenon, or expression of individual attitudes or of cultural values, but as central to the constitution of the prevailing social order' (p. 6).

In the existential perception of the PEN-3, words may remain the same, but their meanings change across different cultural boundaries. Western-based programmes will therefore not succeed in reducing stigma and discrimination in the South African context. Those who have not been tested, are viewed as outsiders looking in and this contributes to the fear of HIV/AIDS that is partially responsible for creating stigma. The culture within a faith organisation should also be considered and acknowledge as a potential factor that can contribute to stigma and discrimination.

Although it is necessary to have an understanding of the culture and characteristics of the community, people should not be stereotyped. In some cultures, religious prohibitions affect all discourse. As sex outside marriage is viewed as a sin, it is difficult to discuss the issue in church groups. Women may not feel that they can discuss their husbands' infidelity or strategies to reduce the risk that results, even with other women. In this study, the aspiring faith-based leaders' views are aligned with those of the church. The faith-based leaders and congregations' perceived views on issues of sex outside of marriage and multiple concurrent partners are similar. The negative attributes of having multiple concurrent partners and practicing sex outside the marriage must be considered within the context of the FBO that nurtures the individual and his community. The congregation is a strong support system for the congregation members.

Culture could be seen as reinforcing inequality of gender relations by justifying male superiority and the subordination of women. Gender is viewed as socially constructed differences between men and women and the beliefs and identities that support difference and inequality. Men often have the power to decide what behaviour would be regarded as normal and what is regarded as deviant (Acker, 2006, Ridgeway & Smith-Lovin, 1999). Many women are blamed for their partners contracting the disease. HIV stigma-related stereotypes add to the pre-existing stigmas in the community and marginalised groups, such as women, resulting in the experience of multiple stigmas when they are HIV positive. Women who seek treatment may be regarded as having admitted that they have indulged in immoral behaviour, such as sleeping with someone other than their partner.

The FINIS framework considers factors from the micro-, meso- and macro levels that may influence persons who are affected by the disease (Pescosolido et al., 2008).

Stigma results in the labelling of the individual, which often triggers stereotyping. This could potentially lead to acts of discrimination, but this may not always be the case. However, when stigma and discrimination do occur, it can result in loss of status and reduction of the possible options of an afflicted person. FINIS recognises that all social interaction takes place in a specific context, resulting in complex interactions. Therefore, the framework could provide a starting point for understanding how stigma is created. Assessing problems from the grassroots level may help to inform subsequent theories for understanding stigma.

The micro level relates to the social and illness characteristics at play. These characteristics combine to shape a person's behaviour. The macro Level states that stigma is embedded in the cultural context, and that it shapes the extent to which stereotyping exists and the different groups accept or reject popular cultural beliefs. At the meso level, any contact with a person who is infected or affected by the virus may influence people's responses to those affected. FINIS provides a conceptual map for understanding stigma and discrimination, considering all possible influences.

FINIS may help with creating an understanding of why stigma and discrimination remain pervasive in our society, and it could therefore help to unravel the reasons why attempts to reduce stigma have failed previously. Internal as well as external factors affecting the situation may contribute to impede the intended effects of stigma-reducing interventions, but there will always be an *us* and *them* dynamic in interaction. This only increases the complexity of stigmatisation.

The problem with attempting to reduce stigma is that it could result in some individuals being more stigmatised, because they are in a stigmatised group. Stigma prevention interventions are amplified, magnified and generalised to include all members of the stigmatised group. This is why consideration of the macro level is so important. The way in which stigma and discrimination are referred to in HIV/AIDS is crucial.

However, if the greater group does not endorse this behaviour, stigma and discrimination as well as their effects will diminish. The portrayal of the disease by FBOs is therefore important. It must be considered how the message of FBOs could be rendered more consistent, without stigmatising and without suggesting the wrath of God resting on PLWHA.

In an attempt to understand stigma using FINIS, it is noted that in its most basic sense, stigma lies at the border of community and individual factors (Pescosolido et al., 2008). While there may be many ways to

document the multiplicity of forces at work in establishing and maintaining stigma, the FINIS framework focuses on the central theorem that several different levels of social life – psychological and socio-cultural level social network or organisational level factors; and societal-wide factors – set the normative expectations that play out in the process of stigmatisation. The factors toward the centre of the model represent those best understood and most studied. Those on the periphery represent newer areas to be considered for investigation. The framework sensitises researchers to the possibility of other influences. FINIS may help to unravel why attempts at stigma reduction may fail. Respondents' experience with stigma, being stigmatised or being the stigmatiser, can affect the reaction to a stimulus due to the disease. This results in stigmatising behaviour or the reduction of stigmatising behaviour. If the overall impact of social interactions is troubling, harmful or otherwise disturbing, then contact will likely have a negative impact. If interactions are rewarding and enriching, the effect of contact will be to reduce stigma.

FBOs can use the data from this research to inform future interventions tailored towards the reduction of stigma in their organisations. Managing the fear and worry that persist towards HIV/AIDS will help programme managers to focus on interventions that would result in changing attitudes. Continued self-shame associated with HIV infection in spite of low reported blaming discourse suggests that moral judgements are still being made regarding sexual behaviour and that this is linked to HIV status.

Religious leaders inform the debate about HIV and AIDS, whether HIV infection is a result of sin or due to individual or social factors. On the other hand, should PLWHA be accepted unconditionally into the church? If they have contracted HIV because of sins such as adultery or promiscuity, they should repent of their sin. This could be partly because the church is giving mixed messages on the link between HIV-infection and sin in its prevention and anti-stigma campaigns. ABC prevention messages represent sexual behaviour as a matter of individual choice and focus on certain kinds of high-risk sexual behaviour that are also morally censured by the church (premarital sex and adultery).

To conclude, feelings of personal shame can be an indicator of the prevalence of self-stigma among aspiring faith-based leaders. Stigmatising of others by faith-based leaders is low. Faith-based leaders are accepting of those who are affected by the disease. This may be a result of their training or roles as caregivers.

5.4. LIMITATIONS OF THE RESEARCH

The scope of and resources for this study were dictated by the requirements for a mini-dissertation. It must therefore be acknowledge that the study has commensurate limitations.

One of the major limitations of this study was the non-representative sample used and the results cannot be generalised. The study used a purposive sample of aspiring faith-based leaders who attended an HIV training session. They were mainly Christians and were already interested in HIV. The results of this study can therefore not be generalised to include other groups of people. The roles of these course attendees within their home FBOs were difficult to determine. A larger sample would have allowed for better representation. A larger sample could also have made more robust statistical analysis possible. Factors, like changes in the funding structures of HospiVision, resulted in some uncertainty regarding the future of programmes, which caused the period for data collection to be limited to three months.

The differences between respondents' own attitudes and perceived attitudes made it difficult to interpret the data. Much of the data is perceived or observed data, which correlates with the respondents' own perceptions. It is thus difficult to conclude what the real level of stigma in these communities is. A weakness that became more apparent during the analysis of results, is that not enough additional qualitative data had been gathered. This limited the conclusions drawn from the study.

A more comprehensive stigma measure that was statistically valid, could have contributed to more reliable results on stigma in die FBOs.

5.5. RECOMMENDATIONS FOR FUTURE RESEARCH

The negative impact of stigma and discrimination should be clearly understood. A number of recommendations detailed below are made based on the findings of this study.

The study has established that although faith-based leaders are knowledgeable about HIV/AIDS, further research is needed to better understand why people are so worried about casual transmission of HIV/AIDS and why they still exhibit stigmatising perceptions, beliefs and attitudes. Faith-based leaders should be sensitised regarding HIV-stigma, discrimination and the consequences they have on PLWHA.

As has been highlighted by the FINIS framework, the effects of stigma should be further explored by studying individual experiences in different contexts.

Disclosure should be encouraged as one strategy to diffuse AIDS stigma in FBOs. PLWHA should be encouraged to give testimonies and share their experiences in dealing with the disease during religious gatherings. Disclosure and open communication may reduce the associated shame that accompanies the disease and can help others to understand the risk of HIV/AIDS. Disclosure can increase visibility of PLWHA, resulting in acceptance and support for those who are infected. However, this may not be possible as it could result in a major stressor for PLWHA and exacerbate the problem of stigma and discrimination. Alternatively, faith based leaders should focus on Inclusivity of all, regardless of health or illness to create a safe and caring environment to all community members whether they are infected or not.

Faith-based leaders should be encouraged to speak openly, compassionately and non-judgmentally about HIV/AIDS, thereby dispelling the culture of silence and acknowledging the presence of the disease in the FBOs. The influence of religious leaders cannot be underestimated as they command moral authority and can therefore act as agents of change in reducing HIV stigma (Haddad, 2005).

The study recommends the provision of information and good role model behaviour that can bring changes in values, attitudes and perceptions. The provision of accurate and timely information to dispel the doubts and fears, myths and misconceptions associated with the disease will help to reduce stigma. If more people have direct contact with friends and family members who have died or are ill with AIDS, a greater openness will be possible.

5.6. CONCLUSION

This study describes the nature and extent of HIV/AIDS-related stigma reported by aspiring faith-based leaders. It highlights the complexity of the subject. The findings of the study highlighted knowledge, attitudes and practices about HIV/AIDS that were perceived to contribute to stigmatisation in FBOs. PLWHA do not disclose to everyone in their congregations or seek support from the congregation because they may fear the shame associated with such a highly stigmatised disease. Despite the relatively extensive knowledge of HIV/AIDS, stigma was evident in the inconsistencies in respondents'

responses reflecting worry and self-blame. It is evident that personal attitudes, beliefs and practices could have an impact on stigma in FBOs.

Findings of the study show that stigma and discrimination are still present 30 years after the first diagnosis of HIV/AIDS. However, stigma and discrimination is not as high as expected. The respondents were accepting of other people's status and observed an accepting atmosphere in the faith-based community. They reported high levels of self-stigma nevertheless. They wish to provide a specific message and becoming infected by the virus might be tantamount to letting the community down by not practicing what they are preaching. It is also evident that fear of infection is prevalent as can be seen in the reluctance to share drinking utensils with someone who is visibly infected. It has also been noted that discussions regarding the disease are not done openly in FBOs.

The research highlights the disparity between various approaches and the fact that there is no consensus on how to address the issue of stigmatisation. The researcher hopes these results will encourage improved practices in FBOs.

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APPENDIX A: QUESTIONNAIRE

Anonymous questionnaire for church members and clergy and faith-based leaders

SECTION A: QUESTIONS ABOUT YOURSELF

1. Are you male or female? Tick the correct box.

Male ☐   Female ☐

2. What language(s) do you speak at home?

English	
Sepedi	
Setswana	
Afrikaans	
IsiXhosa	
IsiZulu	
Sesotho	
Tshivenda	
Zitsonga	
Isindebele	
Siswati	

3. Indicate your religious or denominational orientation

Anglican	
Apostolic	
Bahai	
Catholic	
Christian	
Dutch Reformed	
Hindu	
Muslim	
Zionist	
Other, specify:	

4. What is your role in the church? Tick all the boxes you need to.

Member of a congregation	
Lay minister	
Minister	
Ordained member of the clergy	
Bishop	
HIV and AIDS co-ordinator in the church (at parish or diocesan level)	
Church group member (women's group, youth group, prayer group or another group)	
I have another role in the church, which is:	

5. How often do you attend church services, e.g. on Sundays? Tick all the boxes you need to.

Once a week or more	
Once a month	
Once a year or less	
I do not attend church services	

6. Have you attend a workshop related to HIV/AIDS before?

Yes [ ]   No [ ]

If yes, when did you attend and where?

7. What age group are you in? Tick the correct box.

18-24 [ ]   25-34 [ ]   35-49 [ ]   50+ [ ]

8. What is your marital status? Tick the correct box.

Never married	
Cohabiting (living together)	
Married	
Other	

9. How far did you go in formal education? Tick the correct box

Primary school [ ]   Secondary school [ ]   Tertiary degree or Diploma [ ]

10. What is your employment situation? Tick the correct box.

Employed (paid)	
Volunteer (unpaid work)	
Student	
Self employed	
Unemployed	
Retired	

SECTION B: QUESTIONS ABOUT KNOWLEDGE, ATTITUDES AND BEHAVIOURS TOWARDS PEOPLE INFECTED AND AFFECTED BY HIV AND AIDS

11. How many people do you know who are living with HIV or AIDS? Tick the correct box.

None

1

2

3

4 to 9

10 or more

12. What is your relationship with the people you know who are living with HIV or AIDS? Tick all the boxes you need to.

Husband, wife or other sexual partner	
Family member	
Household member (not a partner or family member)	
Friend, neighbour, or colleague	
Myself	
I do not know anyone who has HIV or AIDS	
Other (please specify):	

13. In your congregation what are the congragations position on condom use ?

Does not advocte the use of condoms	
Encourage the use of condoms	

Give reasons for either of these points of view

_____

_____

_____

_____

14. In your own congregation, how many people do you know who are living with HIV or AIDS? Write the estimated number of people you know about, in the boxes.

a. Estimated number of people who have told everyone they are living with HIV or AIDS?

None	1-10 people	11-20 people	21-30 people	31-40 people	41-50 people	More than 50 people

b. Estimated number of people who have told someone (but not everyone) that they are living with HIV or AIDS?

None	1-10 people	11-20 people	21-30 people	31-40 people	41-50 people	More than 50 people

c. Estimated number of people who have not told anyone about their HIV status, but everyone thinks they have HIV or AIDS?

None	1-10 people	11-20 people	21-30 people	31-40 people	41-50 people	More than 50 people

15. How do you take communion in your congregation? Tick all the boxes you need to.

We drink from a shared cup	
We use individual cups	
We dip the communion wafer in a shared cup	
Other	

16. How worried are you about getting HIV or AIDS from sharing the communion cup with someone living with HIV or AIDS:

a. Are you:

Worried	A bit worried	Not at all worried	Don't know

b. And if the person with HIV or AIDS was visibly sick? Would you be:

Worried	A bit worried	Not at all worried	Don't know

17. How worried do you think OTHER PEOPLE are about getting HIV from sharing the communion cup with someone living with HIV or AIDS?

a. Would most people in your congregation be:

Worried	A bit worried	Not at all worried	Don't know

b. And if the person with HIV or AIDS was visibly sick? Would most people in your congregation be:

Worried	A bit worried	Not at all worried	Don't know

18. In which of the following ways do you think people can get HIV or AIDS? Tick the boxes you choose.

   a. From sharing cups and plates with someone with HIV or AIDS

Yes	No	Don't know

   b. From having sex without a condom with someone with HIV or AIDS

Yes	No	Don't know

   c. From kissing someone with HIV or AIDS

Yes	No	Don't know

   Another way (please say how)

   _____

   _____

   _____

19. If two young people are having sex before marriage, and they are both HIV-negative, will they get HIV or AIDS? Tick the box you choose and explain why.

Yes	No	Don't know

   Please explain why

   _____

   _____

20. Do you personally agree or disagree with the following statements? Tick the box you choose.

   a. "I would be ashamed if I were infected with HIV."

Agree	Partly agree	Disagree	Don't know

   b. "I would be ashamed if someone in my family had HIV or AIDS"

Agree	Partly agree	Disagree	Don't know

c. "People who have HIV or AIDS should be ashamed of themselves"

Agree	Partly agree	Disagree	Don't know

21. Do you personally agree or disagree with the following statements? Tick the box you choose.

a. "People living with HIV and AIDS are being punished by God:

Agree	Partly agree	Disagree	Don't know

b. "People living with HIV and AIDS are not good Christians"

Agree	Partly agree	Disagree	Don't know

c. "People living with HIV and AIDS have nothing to feel guilty about"

Agree	Partly agree	Disagree	Don't know

d. "People who get HIV and AIDS through sex or drugs get what they deserve"

Agree	Partly agree	Disagree	Don't know

e. "Those people living with HIV or AIDS are not part of our congregation"

Agree	Partly agree	Disagree	Don't know

22. In the last 12 months how often have you heard people in your congregation say something like the following in sermons, bible studies or prayers? Tick the box you choose.

a. "People living with HIV and AIDS are being punished by God:

Often heard	Sometimes heard	Never heard

b. "People living with HIV and AIDS are not good Christians"

Often heard	Sometimes heard	Never heard

c. "People living with HIV and AIDS have nothing to feel guilty about"

Often heard

Sometimes heard

Never heard

d. "People who get HIV and AIDS through sex or drugs get what they deserve"

Often heard

Sometimes heard

Never heard

e. "Those people living with HIV or AIDS are not part of our congregation"

Often heard

Sometimes heard

Never heard

23. Which of the following has happened in the last 12 months to anyone you know living with HIV or AIDS? Tick the boxes you choose.

a. Other people in the congregation made them feel that they are to blame for having HIV or AIDS

Yes

No

Don't know

b. Other people in the congregation gossiped about them because of their HIV or AIDS status

Yes

No

Don't know

c. Other people in the congregation humiliated or insulted them because of their HIV or AIDS status

Yes

No

Don't know

d. Other people in the congregation have refused to share the communion cup with people living with HIV/AIDS

Yes

No

Don't know

e. Children or family members have been insulted or humiliated because of the person's HIV status

Yes

No

Don't know

f. Told they are not allowed to go to church

Yes	No	Don't know

24. How often is HIV or AIDS talked about in your congregation? Tick the boxes you choose.

a. The priest (or other religious leader) mentions HIV and AIDS in sermons

often	Sometimes	Never

b. HIV and AIDS is discussed openly at funerals

often	Sometimes	Never

25. How do people in your congregation feel when HIV or AIDS is discussed in sermons or prayers?

They think it's good to discuss it	
They don't think it's good to discuss it	
Don't know	

26. Do you think that your congregation is welcoming and caring towards people living with HIV/AIDS? Tick the box you choose.

Very welcoming and caring	
Quite welcoming and caring	
Not very welcoming and caring	
Not at all welcoming and caring	
Don't know	

27. What do you think the church should do about HIV and AIDS?

_____

_____

_____

_____

_____

28. Do you know what the congregation say about stigma linked to HIV and AIDS? Tick the box you choose.

Yes	
No	

If yes , please say briefly what the congregation has said

_____

_____

_____

_____

29. How do you feel about sex outside marriage?

It is acceptable	
It is not tolerated	

30. How does your congregation feel about sex outside marriage?

It is acceptable	
It is not tolerated	

31. What is your view on multiple sexual partners ?

It is not tolerated	
It is acceptable	

32. What is the congreagation you work with, view on multiple sexual partners?

It is not tolerated	
It is acceptable	

THANK YOU VERY MUCH FOR AGREEING TO PARTICIPATE AND ASSIST US IN THIS IMPORTANT RESEARCH PROJECT.

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Psychology

ONLY COMPLETE THE QUESTIONNAIRE IF YOU HAVE READ THE INFORMATION SHEET AND AGREE WITH THE STATEMENT BELOW.

By completing and returning the questionnaire, I agree to participate in the above research on knowledge, attitudes and behaviours towards people infected and affected by HIV and AIDS in faith based organisations. I understand that I am participating freely and without being forced in any way to do so. I also understand that I can stop being involved at any point and that this decision will not affect me negatively, in any way. I know I may feel uncomfortable thinking about some of the questions. I understand that this is a research project whose purpose is not necessarily to benefit me personally. I have received an information sheet containing the telephone number of a person to contact should I need to speak about any issues, which may arise because of completing the questionnaire.

I hereby confirm that I have read the information sheet regarding the study regarding knowledge about HIV and AIDS, and about attitudes and behaviours towards people infected and affected by HIV and AIDS in Faith Based Organisations (FBO), and understand the nature of the anticipated activities. My participation in the study is voluntary and I can withdraw at any time without offering any explanation or suffering any consequences

Participant's signature..

Date...

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UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Psychology

2009-03-05

The aim of this study is to collect information concerning knowledge about HIV and AIDS, and about attitudes and behaviours towards people infected and affected by HIV and AIDS in Faith Based Organisations (FBO), in Tshwane, South Africa. The information gained will be used for the researcher's Masters Dissertation in Research Psychology

This questionnaire will ask you some questions about your views and experiences in the church or faith based organisations you are involved with. There are no right or wrong answers because we are asking about what you and other people think. Therefore, please answer as honestly as possible. In this questionnaire we ask about your experiences in the organisation you are involved in. If you are involved in several faith based organisations or congregations, choose one of them to describe your experiences.

You will be required to complete the questionnaire. This will take approximately 15 minutes to complete. This questionnaire is designed to be anonymous, so please don't write your name on it. General feedback based on the results of the completed research will be available from the University of Pretoria in the form of a report, it will not identify individuals. The survey will only be used for research purposes; to improve the programmes of faith based organisations around HIV and AIDS issues and in sharing the findings with others working in HIV and AIDS, both in the organisations and beyond.

If you want to speak to a counsellor on the telephone about HIV or AIDS-related issues, please contact your local AIDS helpline. In South Africa the free National AIDS helpline is on 0800 012 322 or you can call Lifeline on 0861 322 322.

I understand that my answers will remain confidential and will only be seen by the researcher, who will report back to faith based organisations without identifying individuals.

If you have any questions or concerns arising out of your participation in this research, please contact

Cornelia van Huyssteen (Principal Investigator)

072 720 2015

cvh.cornelia@gmail.com

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13 May 2009

University of Pretoria
Faculty of Humanities
Research proposal and ethics committee

TO WHOM IT MAY CONCERN

This serves to confirm that the HospiVision management committee has granted permission to Cornelia van Huyssteen to conduct research on the Choose Life value based HIV prevention programme. Permission is granted to administer a questionnaire before the start of a course, with a follow up questionnaire three months after attending a course (postal or telephonically).

Please note:

1. Hospivision retains the right to utilize the data and outcome of the research for reporting purposes. This will be done with acknowledgement of the research program.
2. Hospivision and the funder (USAID) must be acknowledged in all publications which may result from this study.
3. HospiVision will provide logistical support, but all costs associated with the research are for the account of the researcher.

Yours truly

Dr. André de la Porte
(Managing Director)

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