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Name of your Organisation: Norwegian Church Aid
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ABOUT THE EVALUATION

Evaluation year: 2006
Conducted by: Malawi Interfaith AIDS Association
Country: Malawi
Region: Southern Africa
Theme/DAC sector: HIV and AIDS

SUMMARY OF THE EVALUATION (maximum 2 pages)

Title of Evaluation Report: HIV and AIDS related Stigma and
Discrimination within the Faith Communities
In Malawi

Background: As the HIV and AIDS pandemic continues in Malawi, three phases could be identified. The first phase of the HIV epidemic which creeps silently into the communities. The second phase of the AIDS epidemic which has given rise to life threatening Infections and lastly the Stigma and Discrimination which has proved to be the biggest challenge. In its bid to fight against Stigma and Discrimination MIAA decided to conduct the research and take steps in addressing it.

Purpose/ Objective: The operational research aimed at unveiling HIV and AIDS related stigma and Discrimination being perpetuated within the faith communities in order to contribute to the prevention of spread of HIV and mitigate the impact of AIDS.

Methodology: The research was qualitative and six operational districts were covered basing on their Religious, cultural and socio-economic diversity. The districts were Mzimba, Dowa, Lilongwe, Ntcheu, Mangochi and Nsanje. Key informant interviews were conducted for the different categories (Religious leaders) focus group discussions (Men, Women, PLWAs, Youth) and individual interviews. Data was collected by use of PRA school of action research. The tools included Semi structured interviews, structured interviews and direct observation. A total of two days were devoted for consultations and discussions with different groups of respondents in each district. A total of 368 people were interviewed, 7 focus groups discussions were held.

Key Findings: The major findings were included:

- The majority of the congregants are not ready to admit that Stigma and Discrimination exists
- Traces of stigma and discrimination could be noted but you needed to go deeper to find the practices and behaviours.
- Stigma and discrimination exist in forms of language and labelling of people living with HIV
- Stigma and Discrimination is perpetuated by lack of information and understanding of the causes and symptoms of HIV and AIDS.
- The faith community has not done much to create a forum for open discussions on HIV and AIDS related Stigma and Discrimination. Thus perpetuating the silence
- Religious leaders are not sufficiently educated on issues of HIV and AIDS within their congregations, even through policies and guidelines
- Theological orientations and practices are laden with judgementalism leading to increase in Stigma and Discrimination.

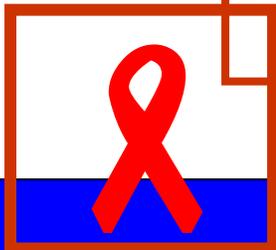
Recommendations:

- The faith communities are best placed to provide accurate, unbiased information, ways should be identified to ensure frequency and regular provision of HIV and AIDS related information to dispel myths, fears and anxiety on issues of Stigma and Discrimination
- Policies should be introduced and implemented to the faith communities in relation to the National AIDS Framework and global principles on PLWAs
- There should be greater empowerment of PLWAs and involvement in activities.
- Faith communities should collaborate and network with other stakeholders in the fight against HIV and AIDS.
- Religious leaders have to be trained for theological transformation and practices so as to enable them to fight HIV and AIDS and assist in the mitigation.
- Faith communities have to protect the rights of women and children so that they are able to decide responsibly on issues of sexuality.
- Faith communities need to produce a set of guidelines for stigma –mitigation interventions.

Comments from Norwegian Church Aid (if any): Stigma and Discrimination is one of the biggest challenges in the face of HIV and AIDS. The research has set a baseline on what issues to deal with in HIV and AIDS. Partners like MANERELA and MIAA will be supported to spearhead Stigma and Discrimination activities, targeting Religious leaders and other Faith Based Organisations.



MALAWI INTERFAITH AIDS ASSOCIATION



HIV and AIDS Related Stigma and Discrimination within the Faith Community in Malawi

AN OPERATIONAL RESEARCH REPORT

**MALAWI INTERFAITH AIDS ASSOCIATION
PRIVATE BAG 385, Capital City, Lilongwe 3**

December 2006

ACKNOWLEDGEMENTS

The Operational Research was undertaken in six districts in Malawi under the consultancy contract agreement with the Malawi Interfaith AIDS Association (MIAA) to unveil HIV and AIDS related stigma and discrimination being perpetrated within the faith community. Our indebtedness and gratitude to numerous individuals who have contributed to this work can not be adequately conveyed in few sentences.

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Finally, the consulting team appreciates sincerely the contribution as well as the dedication of the research assistants (Christopher Tembo, MacLean Gondwe, Madalitso Kaferawanthu and Luke Tembo) who managed to facilitate individual and group interviews within a tight schedule. The team also appreciates the insights and contribution of the data entry expert, Temweka Nyangulu.

Without the cooperation of all these individuals and groups, the assignment would not have been accomplished successfully.

MIAA Operation Research Districts

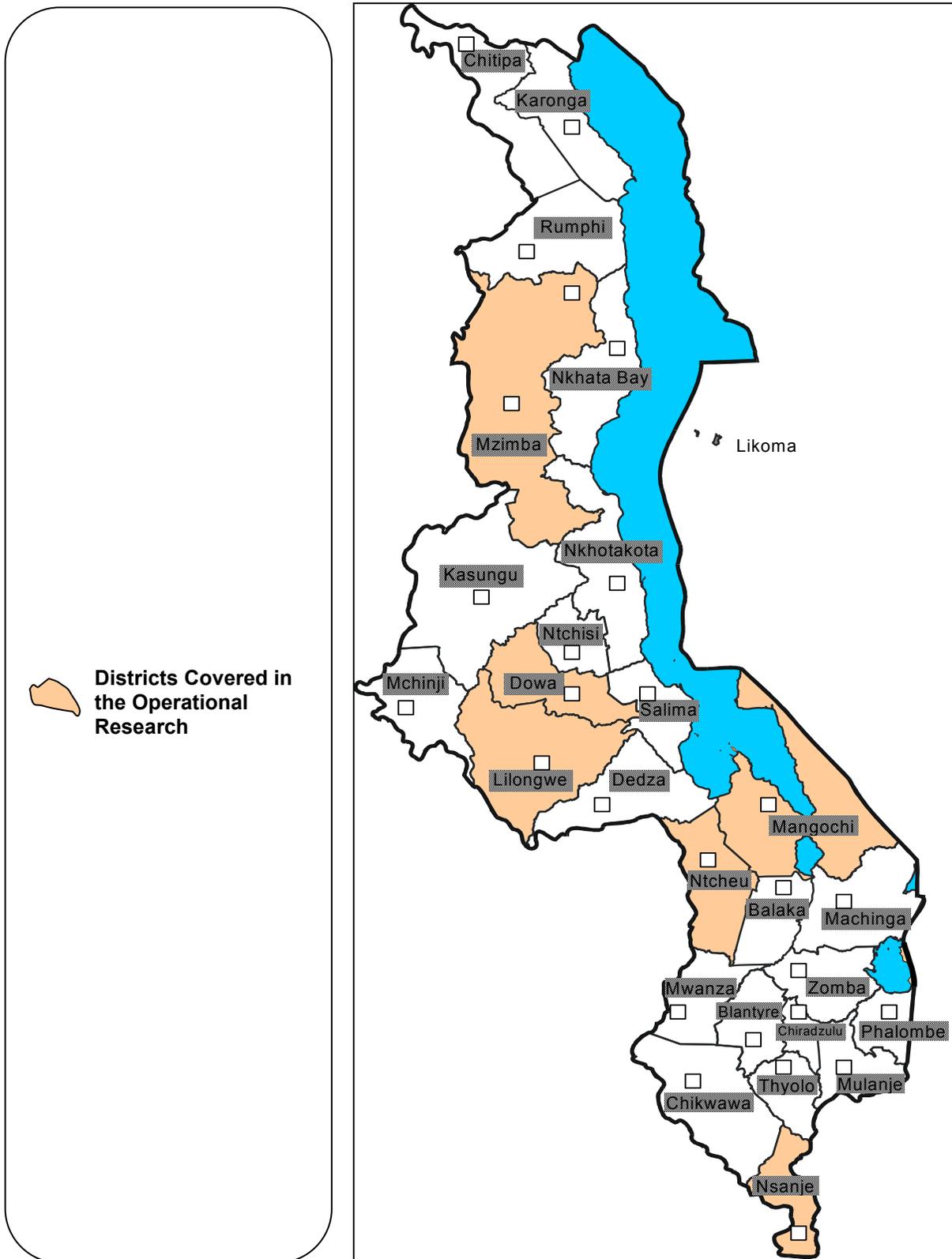


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LIST OF ABBREVIATIONS

ADC	Area Development Committee
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
CBCI	Catholic Bishops' Conference of India
DFID	Department for International Development
FBOs	Faith Based Organisations
FGDs	Focus Group Discussions
GIPA	Greater Involvement of People living with AIDS
HBC	Home Based Care
ICRW	International Centre for Research on Women
KIIs	Key Informant Interviews
MIAA	Malawi Interfaith AIDS Association
NAC	National AIDS Commission
NAF	Malawi HIV and AIDS National Action Framework (2005 – 2009)
NACP	National AIDS Control Programme
NGOs	Non-Governmental Organisation
NSF	National HIV and AIDS Strategic Framework
OVC	Orphans and Vulnerable Children
OPC	Office of President and Cabinet
PMCT	Prevention of mother-to-child transmission
PLHAs	People Living with HIV and AIDS
PRA	Participatory Rural Appraisal
TORs	Terms of reference
UNAIDS	The Joint United Nations Programme on AIDS
UNESCO	United Nations Education Scientific and Cultural Organisation
UNFPA	United Nation Population Fund
UNICEF	United Nations International Children's Fund
VCT	Voluntary Counselling and Testing

EXECUTIVE SUMMARY

There is now a popular opinion that there are *three phases* of HIV/AIDS epidemic. The first phase is characterised by the epidemic of HIV and this creeps in the community silently followed by the second phase shown by the epidemic of AIDS which gives rise to life threatening infections. The third phase, characterised by the epidemic of stigma, discrimination, and denial is said to be the greatest challenge facing the Globe as it thwart concerted action at community, national, and global levels.

The operational research aimed at unveiling HIV and AIDS Related Stigma and Discrimination Being Perpetrated within the Faith Community in Malawi in order to contribute to the prevention of the spread of HIV and mitigate the impact of AIDS.

In its bid to contribute in the fight against HIV and AIDS at national level, MIAA has begun to take bolder and more comprehensive steps to address stigma and discrimination within the faith communities. With funding from Norwegjan Church Aid (NCA), MIAA decided to carry out an operational research on the topic 'HIV and AIDS Related Stigma and Discrimination Being Perpetrated within the Faith Community in Malawi'.

Operational Research Objectives and Methodology

The main purpose of the operational research was to unveil HIV and AIDS related stigma and discrimination being perpetrated within the faith community in Malawi. The research also explores voluntary counselling and testing before marriage from the faith perspective as it relates to stigma and discrimination.

A total of six operational research districts were covered based on their religious, cultural and socio-economic diversity: these include Mzimba, Dowa, Lilongwe, Ntcheu, Mangochi and Nsanje. In all the selected operational research districts, the assessment team consulted different categories of respondents at various levels for key informant interviews, focus groups discussions and individual interviews.

The tools used for the collection of qualitative information were taken from the participatory rural appraisal (PRA) school of action research. The specific tools used by the research team included semi-structured interviews (with focus groups and key informants), structured individual interviews and direct observation.

A total of two days were devoted for consultations and discussions with different groups of respondents in each district. Using questionnaire-based individual interviews, a total of 368 people were involved as respondents in the research. A total of seven focus group discussions in addition to a number of individual key informant interviews were conducted. The team devoted every evening of the field phase for reflection as well as validation of the information captured using questionnaires and analysis of findings as well as planning for next day's activities.

Main Research Findings

The following is a summarised list of major findings and interpretations based on the focus groups discussions, individual interviews using a structured questionnaire and key informant interviews.

- The majority of congregants are not ready to admit that stigma and discrimination against people infected and affected by HIV and AIDS exists within their midst. The majority (two in every three respondents) report that they do not know people living with HIV in their congregations. Disclosure of VCT results within the faith community is not a common phenomenon. On one hand, the majority of respondents (88 percent) paint a picture that those who disclose their HIV status are accepted and shown love within the faith community.
- On the other hand, the results show some traces of the existence of stigma and discrimination within the faith community, and one has to dig deep to lay bare the associated practices and behaviours.
- Incidences of stigma and discrimination are not wide spread on the surface, but existed and manifested in the language and labelling of people living with HIV. PLHAs are also frequently subjected to insults and abusive language and usually pushed to the background and invisible functions within the congregations.
- Generally, lack of information and understanding of the causes and symptoms of HIV and AIDS is one of the factors perpetrating stigma and discrimination within the faith community. The vulnerability to HIV infection by disparities in power that are a product of gender imbalances, age differentials, abuse of authority, physical power and violence, and economic power, which all affect individual agency and thereby influence how and when and with who sex occurs is not given attention.
- The faith community has also not done much to create a forum or take advantage of other activities to allow open discussions on HIV and AIDS related stigma and discrimination, thus perpetrating the culture of silence within the faith community.
- Discussions on such issues as ARVs, VCT, stigma and discrimination are not common and frequent within most congregations.
- Religious leaders are not sufficiently equipped to deal with HIV and AIDS within their congregations through policies and guidelines.
- Theological orientations and practices are laden with 'judgementalism' which give rise to the classification of congregants thereby nurturing stigma and discrimination.

Key Recommendations

- The faith community is best placed to provide accurate, unbiased information about HIV and AIDS which is generally agreed to be the most critical first step in addressing stigma and discrimination. There is need to identify ways to ensure frequent and regular provision of HIV and AIDS related information to dispel myths, fears and anxieties on various issues related to ARVs, VCT, stigma and discrimination.
- There is a need for the faith community to introduce policies to strengthen and reinforce national action frameworks in line with development and processes at global level that embrace the principle of equal rights for PLHAs and oppose all forms of discrimination on the grounds of HIV and AIDS status.
- There is general emphasis on promoting the role of PLHAs themselves in developing and implementing strategies for reducing stigma and discrimination, including self-stigma by PLHAs as one of the best strategies. There is need, therefore, for the faith

community to identify activities which provide a platform for PLHAs to make their voices heard and participate in HIV and AIDS related activities within the faith community.

- In the same light, there is need for the faith community to network and associate with PLHAs to help increase self-confidence and enhance the self-image of PLHAs, both as a group and as individuals.
- In line with the National Action Framework (NAF) in Malawi, there is need to ensure that the faith community accords women and girls regardless of marital status or HIV sero status equal access to appropriate HIV-related information and education, means of prevention and health services. The faith community needs also to take a look and protect the rights of women to take control over and to decide responsibly on their sexuality, including sexual and reproductive health, free of discrimination or coercive violence from theological interpretations.
- Both the NAF and the World Council of Churches are calling for the theological transformation and practices. This to a large extent calls for the training of pastors, priests, lay leaders on the concept of the “Theology of Hope” and counselling using the concept.
- The faith community also needs to produce a set of guidelines for stigma-mitigation interventions. The details on how to develop this are presented in the review of literature as well the recommendations section in the main report.

1 INTRODUCTION

The global fight against HIV and AIDS has taken a new twist in recent times with reports of the escalation of the epidemic accompanied by accusations that the faith community contributes to the spread of the disease rather than its prevention. In November 2001, a group of African church leaders met, in Nairobi, to draw up an ecumenical plan of action for responding to the HIV and AIDS epidemic. Their conclusion was this. *'For the churches,'* they said: *'the most powerful contribution we can make to combating HIV transmission is the eradication of stigma and discrimination'*¹.

It is a historical fact, as noted by some commentator², that faith organisations' health work has generally been conducted, at arm's length, through semi-autonomous organisations run on secular lines by medical or health care professionals. At that level, religious hospitals and clinics can be proud of their record in opening their doors to people whom the world rejected. But stigmatisation and discrimination which operate at the level of human community, local culture, and the way in which the day-to-day life of the worshipping, praying and believing, seem to weaken the position of the faith community in the fight against the HIV and AIDS epidemic.

The operational research aimed at unveiling HIV and AIDS Related Stigma and Discrimination Being Perpetrated within the Faith Community in Malawi in order to contribute to the prevention of the spread of HIV and mitigate the impact of AIDS. The research explores voluntary counselling and testing before marriage from the faith perspective as it relates to stigma and discrimination. The operational research was undertaken in six districts in Malawi from 28th September to 16th October 2006.

The report contains distinct chapters. The first chapter is the introductory part of the report. It presents a brief background of the operational research as well as its objectives and the context in which the research was carried out. This is followed by a summary of the methodology employed in the collection of information. Presented in the second chapter are key findings of the literature review on stigma and discrimination. The discussion in the second chapter outlines gaps, issues, strategies and challenges in relation to stigma and discrimination. Chapter three presents the research findings on stigma and discrimination within the faith community. This is followed by a presentation on HIV and AIDS silence within the faith community in chapter four. Possible strategies to combat stigma and discrimination are summarised in chapter five. Chapter six of the report presents a summary of the conclusions and recommendations. The recommendations are drawn from the findings as well as the literature review.

The report concludes with a list of reference materials including websites used to inform the discussions particularly in the literature review. The annexes contain the terms of reference and consultations schedule of the assessment.

¹ Plan of Action: The Ecumenical Response to HIV and AIDS in Africa World Council of Churches 2001 available on www.wcc-coe.org/wcc/news/press/hiv-aids-plan.html

² Gillian Peterson (undated) in *Church, AIDS and Stigma*.

1.1 Background to the Operational Research

Malawi has one of the highest sero prevalence rates in Africa and currently, AIDS is the leading cause of deaths. According to the Malawi HIV and AIDS National Action Framework (NAF) 2005 – 2009 published in 2005, without AIDS, the number of deaths among adults (15 – 49 years) in Malawi would have remained constant from 1985 until today at about 22,000. However, with AIDS the deaths of adults have more than tripled to nearly 80,000 annually (NAC, 2005). In 2003, more than 900,000 Malawians were estimated to be infected with the HIV virus (NAC 2003). It is estimated that there are about 840,000 orphans, 45 percent of them are due to AIDS (NAC, 2005).

Recognising the severity of the HIV/AIDS problem in the country, the Government of Malawi responded by setting up the National AIDS Control Programme (NACP) and National AIDS Secretariat (NAS) in 1989 to provide technical leadership in HIV and AIDS programmes. The programme, which was transformed into the National AIDS Commission (NAC) in 2001, developed National HIV and AIDS Strategic Framework (NSF): 2000 – 2004 that focused on the provisions of VCT, prevention of mother-to-child transmission (PMCT), treatment of opportunistic infections and use of ARVs (OPC/NAC, 2003). In 2003, the Government developed a National HIV and AIDS Policy to provide technical and administrative guidelines for the design, implementation, and management of HIV and AIDS interventions. Quite recently, the Office of the President and Cabinet through National AIDS Commission developed a new National HIV and AIDS Action Framework (NAF) 2005 – 2009 to guide the national response to the epidemic.

The NAF serves as a point of reference for all Malawians and all stakeholders in planning and implementing and thereby contributing towards the realisation of the national goal which is “to prevent the spread of HIV infection among Malawians, provide access to treatment for people living with HIV and AIDS and mitigate the health, socio-economic and psychosocial impact of HIV and AIDS on individuals, families, communities and the nation” (NAC 2005).

Upon entering into the new Millennium, religious leaders from different religious institutions and organisations have joined hands and established the Malawi Interfaith Aids Association (MIAA) whose purpose (at national level) is to provide an institutional framework for implementing strategies in the fight against and mitigating the impact of HIV and AIDS by the faith based organisations (FBOs). The Membership of MIAA comprises Christians and Moslem institutions and organisations. The Association, through its Secretariat, facilitates and coordinates a united commitment of faith communities in the fight against HIV and AIDS. The Association implements HIV and AIDS programmes in collaboration with various faith based institutions and organisations through various religious structures at various levels.

In its bid to contribute in the fight against HIV and AIDS at national level, MIAA has begun to take bolder and more comprehensive steps to address stigma and discrimination within the faith communities. In 2005, during the MIAA Annual General Conference members resolved to conduct an operational research to unveil ‘**HIV and AIDS Related Stigma and Discrimination Being Perpetrated within the Faith Community in Malawi**’. MIAA received funding from Norwegian Church Aid (NCA) to among others activities, carry out the operational research.

The operational research came soon after a baseline assessment commissioned by MIAA to document Knowledge Levels among Religious Leaders and Households on HIV and AIDS, Gender, Sexuality and Human Rights and Explore the Impact of HIV and AIDS Pandemic on Women, Men, Girls and Boys. The baseline assessment revealed that significant proportions (37 percent) of the respondents in the project impact areas of Machinga, Mchinji and Nkhata Bay perceive HIV and AIDS as a punishment from God. The assessment also revealed that stigma and discrimination is the major factor that prevents people living with HIV and AIDS from receiving treatment and care.

The current research is important with a view of investigating the nature, magnitude and causes among others of HIV and AIDS related stigma and discrimination being perpetrated within the faith community in Malawi. The research is also important in establishing the levels of silence in the faith community associated with HIV and AIDS, the impact of stigma and discrimination on Voluntary Counselling and Testing before marriage from the faith perspective and the impact of stigma and discrimination on discordant couples and children orphaned by AIDS. In addition, the research determines the most effective ways of rooting out stigma and discrimination within the faith community and provides appropriate recommendations based on the findings.

The research further facilitates a common understanding among all players and faith communities as regards HIV and AIDS related stigma and discrimination, creating a base for concerted action. Even more so, project activities to be devised out of the research exercise empower different development faith based organisations (FBOs), the women, men, girls and boys with knowledge and information that can be applied to address stigma and discrimination. The term FBO in this report is used broadly to encompass any religions, religious communities, religious institutions, faiths and denominations.

1.2 Objective of the Assessment

The main purpose of the operational research is to unveil HIV and AIDS related stigma and discrimination being perpetrated within the faith community in Malawi. The research also explores the voluntary counselling and testing before marriage from the faith perspective as it relates to stigma and discrimination. The findings of the operational research are aimed at facilitating the faith communities' response to the HIV and AIDS pandemic in Malawi.

The scope of the assignment and primary responsibilities for the operational research team included the following:

- 1) To conduct literature review of relevant documents on HIV and AIDS related stigma and discrimination
- 2) Design appropriate survey methodology (in a manner that is participatory) and sampling for the survey
- 3) Investigate the nature, magnitude and causes, among others of HIV and AIDS related stigma and discrimination being perpetrated within the faith community in Malawi
- 4) Establish the levels of silence in the faith community associated with HIV and AIDS
- 5) Determine the most effective ways of addressing stigma and discrimination from within the faith community.

- 6) Establish the impact of stigma and discrimination on VCT before marriage from the faith perspective and to establish the impact of stigma and discrimination on the discordant couples and children orphaned by AIDS
- 7) Analyse the data systematically and produce the report on findings
- 8) Provide recommendations based on the findings of the survey
- 9) Present the results of the survey to the project management team and key MIAA stakeholders

Each chapter on the operational research findings ends with specific conclusions. The conclusions are developed based on the responses from various respondents and the analysis by the operational research team. The recommendations propose possible and practical areas of interventions for MIAA and other stakeholders.

1.3 Operational Research Methodology

Different tools and techniques were employed in the evaluation including (i) documentation search and literature review, (ii) key informant interviews (KIIs) - stakeholder consultative meetings, (iii) focus group discussions (FGDs) with various groups and (iv) individual interviews.

These are described in detail below:

- 1.3.1 Literature review/analysis and document search:** Emphasis was on understanding the HIV and AIDS related stigma and discrimination within the faith community.
- 1.3.2 Key Informant Interviews (KIIs):** Key informant interviews with different religious leaders at various levels (including pastors from different denominations, Moslem sheiks, catholic priests, and traditional leaders) were undertaken with a view of generating information and lessons on various areas of the operational research as presented under 1.2 above. Wide ranging group of professionals and religious leaders reflected on the operational research findings during the stakeholders' consultative meeting.
- 1.3.3 Focus group discussions (FGDs):** Focus group discussions were held with different groups of women, men, youth and PLHAs to solicit views and perceptions in relation to stigma and discrimination with the faith community.
- 1.3.4 Individual Interviews:** Individual interviews formed the main instrument designed to capture information on nature, magnitude, causes and impacts of HIV and AIDS related stigma and discrimination among the communities. The main purpose of the questionnaire was to obtain the individual experiences and perceptions on the stigma and discrimination.

1.4 Research Design and Approach

1.4.1 Research Design

The research team started with a thorough examination of the terms of reference (TORs) and the scope of work during the preparatory phase of the exercise to isolate specific areas of focus. The team also took time to reflect on research processes through consultations with the MIAA Secretariat to discover specific areas of interest, priorities and/or questions.

Apart from the preparatory consultations, the research team also examined relevant literature obtained from various sources including websites. After this level of work, an outline of interview guide was prepared and data collection tools were developed. The data collection tools were pre-tested with different groups in Lilongwe for a period of one day. This was done to test whether the tools designed for the research were relevant. The structured questionnaire was adjusted accordingly by the research team during the review of the pre-test exercise. The team also used the pre-testing to translate some of the questions into local language and close some of the questions that were left open-ended at the design stage. The pre-testing was also design as a training process for the research assistants to sharpen further their interviewing skills and approach.

1.4.2 Sampling Criteria

A total of six operational research district were covered based on their religious, cultural and socio-economic diversity: these include Mzimba, Dowa, Lilongwe, Ntcheu, Mangochi and Nsanje. In all the selected operational research districts, the assessment team consulted different categories of respondents at various levels for key informant interviews, focus groups discussions and individual interviews. These are as follows:

A: Key informants

- a) Pastors and Reverends from mainstream churches as well as Pentecostal and Charismatic churches
- b) Moslem Sheikhs
- c) Leaders from other faiths like Hindu and Rastafarianism
- d) Traditional leaders (Group Village Heads)

B: Individual interviews with members of different faith communities

- e) Women
- f) Men
- g) Girls
- h) Boys

D: Focus group discussions with members of different faith communities

- i) Women
- j) Men
- k) Youths
- l) Group of PLHAs

1.4.3 Research Process

The tools used for the collection of qualitative information were taken from the participatory rural appraisal (PRA) school of action research. The specific tools used by the research team included semi-structured interviews (with focus groups and key informants), structured individual interviews and direct observation.

A total of two days were devoted for consultations and discussions with different groups of respondents in each district. Using questionnaire-based individual interviews, a total of 368 people were involved as respondents in the research. The team also conducted a total of seven focus group discussions in addition to a number of individual key informant

interviews. The team devoted every evening of the field phase for reflection as well as validation of the information captured using questionnaires and analysis of findings as well as planning for next day's activities.

Duly completed questionnaires were sent for data entry using the computer-based statistical package for social scientists (SPSS).

1.4.4 Analysis of the Assessment Findings

The research team analysed manually the qualitative information generated from key informant interviews and focus group discussions. The team paid close attention to responses obtained from various respondents on a particular area of investigation across interview groups, individuals, and research areas. The assessment team then developed interpretation of the responses on various topical issues. The responses were also used to compare findings emerging from the quantitative results.

All data collected from the individual interviews using questionnaires was entered into the computer. The primary tool for analysis of quantitative data was the Statistical Package for Social Scientists (SPSS). The statistical package was used to generate analysis tables on specific assessment themes which allow comparison of results across different groups of respondents and also research districts.

1.4.5 Limitations of the Research Exercise

There were a number of challenges that the research team faced during the field phase, while every effort was made to ensure a smooth data collection process in all the research districts. A number of practical factors placed considerable challenges on the research team as follows:

- Within the City of Lilongwe, most of the respondents faced difficulties to grant the research team an opportunity for interview as they were engaged in various economic activities. Most of the respondents were at pains to set aside more than 20 minutes of interview with the research assistants. Most religious leaders within the City faced difficulties when setting appointments with their congregants for focus group discussions, a factor which impinged on desired progress during the field phase of the operational research. To solicit meaningful information from the target groups, the research team had to split periods of interview for the City of Lilongwe which mounted considerable pressure on the logistical arrangements as well.
- Some respondents particularly religious and traditional leaders earmarked for consultations in the districts were reported to be engaged in other activities. Further, despite advancement in modern communication technology, information regarding the research team's visit did not reach some respondents in time to allow adjustment of their programmes.
- A number of national level institutions were approached to set appointments for interviews, but most of the relevant individuals were reportedly busy to the extent that consultations at central level did not cover as many key individuals as desired. However, that the stakeholders' workshop provided the national level institutions an opportunity to file in their input.

2 LITERATURE REVIEW

The popular opinion is that there are *three phases* of HIV/AIDS epidemic. The *first phase* is characterised by the epidemic of HIV and this creeps in the community silently and unnoticed. The *second stage* is shown by the epidemic of AIDS which gives rise to life threatening infections. Finally, the *third phase* is characterised by the epidemic of stigma, discrimination, and denial. The third phase is said to be a global challenge because it perverts concerted action at community, national, and global levels. It makes prevention efforts difficult by forcing the epidemic out of sight and underground.

The popular opinion is that stigma and discrimination both stymie efforts to control the global epidemic and create an ideal climate for further growth. Together, they constitute one of the greatest barriers to preventing further infections, providing adequate care, support and treatment and alleviating the epidemic's impact (UNAIDS, 2003). The terms, 'stigma' and 'discrimination' are often used together and they practically reinforce each other, but they have distinct meanings.

Stigma generally refers to any attribute that marks the bearer as culturally unacceptable or inferior. Stigma can be associated with a physical condition or disfigurement, a moral blemish, membership in a despised social group, or simply being 'different'. The afflicted person is cast out of the social community and is made to feel of little worth. As a result, people who are stigmatised experience guilt, shame and rejection: feelings they may accept with fatalism that stops them seeking help or trying to change things (Gillian Paterson, undated).

Stigma lets people or groups see differences or "others" in a negative light while confirming their own sense of normalcy and decency. According to Gillian Paterson (undated), anthropologists observe that stigma is often interpreted as punishment, visited on a particular individual or group as just retribution for violating community norms. The stigmatised person may also be held responsible for real or imagined ills that afflict the community, which can only be cleansed by the expulsion or isolation of the polluting influence. Their continued presence can become a threat to the survival of the whole group. With this background, exclusion, victimisation and 'scapegoating' follow, further justified by the belief that those who are 'different' are less than human, and do not feel things as 'normal' people do.

On the other hand, discrimination can be defined as any action or measure that results in someone being treated unfairly because they belong or are perceived to belong, to a particular group (National AIDS Trust, undated). Discrimination occurs when a distinction is made against a person that result in his or her being treated unfairly and unjustly on the basis of their belonging, or being perceived to belong, to a particular group. The National HIV and AIDS policy document in Malawi indicates that discrimination against PLHAs violates their rights and makes them less likely to voluntarily disclose their HIV sero status, thus increasing their vulnerability to HIV and AIDS (NAC, 2003).

Stigmatisation reflects an attitude while discrimination is an act or behaviour. The most fundamental concern in this chapter is not to get lost in the myriad ways in which stigma and discrimination are defined. The central focus, however, is placed on the issues, attitudes, gaps and strategies related to stigma and discrimination in relation to the fight against HIV and AIDS within the faith community.

2.1 Stigma and Discrimination within the Faith Community

Literature shows that stigma and discrimination is deep within the faith community. A Global AIDS Interfaith Alliance (2005) document states that clergy and other religious leaders are as susceptible as any to the temptation to exercise power over others. These tendencies are facilitated by structured inequalities (clergy over lay, more spiritual over less spiritual, more morally pure over less so, and the like). Many Christians, Muslims and perhaps other faiths as well, believe that living with HIV and AIDS implies promiscuous or sinful behaviours. A recent baseline assessment study conducted in three districts in Malawi reported that close to 40 percent of religious leaders interviewed felt HIV was a punishment from God/Allah (MIAA, 2006). It is thus not surprising that many PLHAs have been pushed out of religious congregations, or have excluded themselves, because of discriminatory attitudes and behaviours.

2.1.1 Magnitude of Stigma and Discrimination

For people living with HIV, or those assumed to be HIV-positive, no area of life is untouched by stigma and no area of life is invulnerable to discrimination. Examples of discriminatory practices in various sectors of life include:

- Pre-employment HIV testing, denial of employment to people who test positive, harassment in the workplace and pressure to resign.
- Refusal to rent property for no stated reason, harassing a tenant and eviction for no stated reason.
- HIV-positive teachers can be dismissed through irrational fear of transmission to children, and the widespread fear of AIDS has led many adults to take extreme measures in an effort to prevent HIV-positive children from attending school.
- Service providers can also discriminate, especially in relation to access to health care. Examples include general practitioners, surgeons, nurses or dentists refusing to treat patients with HIV or suspected of being HIV-positive, providing discriminatory standards of health care, or adopting unnecessary infection control measures (National AIDS Trust, undated)

The UN Integrated Regional Information Networks (September 21, 2003) reports to a greater length that Christian and Muslim leaders attending the 13th International Conference on AIDS and Sexually Transmitted Infections in Africa held in Kenya, spoke of negative attitudes to the virus that were spread by their churches and mosques. At the conference, Sheikh Al Haj Yussuf Murigu, Vice-Chair of the Muslim Supreme Council of Kenya, remarked that HIV was equated with "a curse", and those who lived with it were viewed as "sinners". At the same conference, Bishop Otsile Osimilwe said the church tended to point a finger at people living with HIV, instead of adopting a caring and compassionate response.

At the same conference, an Anglican priest living with HIV, Rev Jape Heath, linked the stigma and discrimination to what he described as his church's double standards when it came to the concept of 'sin'. Lying and cheating on tax returns were considered "socially acceptable", he said, while being HIV positive was equated with being caught in adultery. "The church has been exceptionally good at judgementalism and the role of the stigma has been to see an increase of the pandemic" because people were too scared to be tested for HIV", Heath said. The Anglican church looked upon those living with HIV as sinners who

could be "written off" and that has been the church's major contribution to the stigma attached to HIV." he concluded.

Lack of gender equality had also contributed to the spread of the virus, the conference heard, by not allowing women to make choices about their lives. "The church has been quite behind in dealing with gender injustice," said Musa Dube, a Christian theologian who also added that "every culture that is patriarchal exposes women to HIV."

The DFID/Futures Group (2005) in the review of the HIV and AIDS, Stigma and Faith-based Organisations reports that the enactment of stigma through discriminatory practices included:

- Physical isolation (for example, separating eating utensils and living quarters).
- Social isolation (for example, isolation from social events, loss of social networks, and diminished standing as a productive member of the community)
- Verbal discrimination and abuse (for example, gossip, taunting, blaming and labelling); and
- Institutional discrimination (for example, loss of employment, customers, housing, financial opportunity/protection, poorer health care, refusal of services, fear-based representation).

On labelling, Chaturvedi K. and Chaturvedi S. K (undated) in their presentation on Stigma and Discrimination related to HIV and AIDS reports that in Africa common terms used for people living with HIV and AIDS include 'moving skeleton', 'walking corpse', and 'keys to the mortuary."

2.1.2 Causes of Stigma and Discrimination

Literature shows that, there are a host of contextual and theological forces and factors constraining the fight against HIV and AIDS. These are nourishing and perpetrating stigma and discrimination within the faith community.

A 2003 review of HIV/AIDS-related stigma in faith-based organisations in South Africa, which included interviews and focus groups with both Christian and Muslim religious leaders, identified a number of practical issues and challenges which remain barriers to reducing stigma and discrimination within religious communities. These included:

- Inadequate training of religious leaders in the basics of HIV transmission;
- Failure to incorporate issues related to HIV and AIDS into theological training and curricula;
- A lack of specially-developed materials and resources for use in addressing HIV/AIDS in religious settings – e.g. interpretations of religious scriptures and readings through an HIV 'lens';
- Problems with confidentiality in relation to individuals' HIV status and lack of guidelines for clergy on how to deal with disclosure; and
- Denial on the part of some religious leaders that AIDS is present within their faith or congregation (DFID/Futures Group, 2005).

Alison Rader and Campbell, in their article on HIV and AIDS Stigma and Religious Responses, observe that religious groups, in general, have a reputation for responding to the issue of HIV in negative terms and this breeds stigma and discrimination. Factors that

influence this perception have included judgmental comment from religious leaders; debate about condoms; and an obstructive stance towards policy development. The religious sector has been largely unwilling to engage in any way that could imply dilution of moral standards. As a result, people with HIV have experienced rejection by religious people, congregations or institutions.

According to Sushil Huidrom (2004) stigma and discrimination comes from the powerful combination of shame and fear - shame because the sex or drug injecting that transmit HIV are surrounded by taboo and moral judgment, and fear because AIDS is relatively new, and considered deadly. Huidrom admits that there is complexity and diversity of stigma and discrimination. HIV and AIDS related stigma and discrimination reinforce with pre-existing stigma and discrimination associated with sexuality, gender, race and poverty. HIV and AIDS related stigma and discrimination also interact with pre-existing fears about infection and disease.

Further, early AIDS 'similes' such as death, horror, punishment, guilt, shame, and otherness have exacerbated these fears, reinforcing and legitimising stigmatisation and discrimination. The stigma is triggered by many forces, including lack of understanding of the disease, myths about how HIV is transmitted, prejudice, lack of treatment, irresponsible media reporting on the epidemic, the fact that AIDS is incurable, fears relating to illness and death, and fear about illicit drugs and injecting drug use (Huidrom, 2004).

Prevention messages suggesting that it is all about "individual's choice and vigilance" to avoid contracting HIV are also blamed for perpetrating stigma and discrimination. The DFID/Futures Group (2005) in their review of the HIV and AIDS, Stigma and Faith-based Organisations compiled for the Christian Aid Programme for the Anglican Church in Southern Africa note that HIV prevention campaigns emphasise individual choice – for example, promoting abstinence, faithfulness and condom use. Such emphases imply that people who become HIV positive have been irresponsible through their own actions and omissions as a product of not adopting appropriate HIV prevention behaviours.

Emphasis on individual agency masks many of the underlying conditions that influence and exacerbate HIV risk – for example, economic conditions (such as labour migration brought about by economic disparity) foster the break-up of families and fragmentation of communities. Additionally, vulnerability to HIV infection is influenced by disparities in power that are a product of gender imbalances, age differentials, abuse of authority, physical power and violence, and economic power, all affect individual agency and thereby influence how and when sex occurs (DFID/Futures Group, 2005).

Literature also shows that the very fact that HIV can be sexually transmitted bestows to it a separate status from other conditions. A research conducted in three countries (Zambia, Tanzania and Ethiopia) by the International Centre for Research on Women (ICRW) reported that, much of the harshest stigmatizing language and discriminatory behaviour canters on the sexual transmission of HIV. When asked why HIV is not considered a "normal disease," an urban woman in Ethiopia replied, "*This is because it is transmitted through sexual contact.*" Another Ethiopian respondent explained how he believed that HIV is different from fatal diseases like cancer: *The other disgusting thing of this disease is that it is related with sexual intercourse.... If someone gets sick (from) cancer, no one would isolate him. It is not considered as stigma* (ICRW, 2003).

2.1.3 Silence on HIV and AIDS

Generally, silence on HIV and AIDS is also included on the list of factors perpetrating HIV and AIDS related stigma and discrimination. To date, the faith community is accused of its silence on HIV and AIDS issues which seriously weakens the fight against the epidemic. Gillian Paterson (undated) argues that ending stigma demands strong, sensitive, truthful and well-informed leadership. He adds that it demands that the Church shatters the conspiracy of silence and admits to the presence of AIDS in its midst; and that churches go out of their way to nurture and encourage those who have HIV, because they are the most valuable potential resource they can have in the struggle against AIDS.

Other commentators give a sweeping view that congregations have colluded in stigmatisation by their silence on sexual matters in general and have thereby exempted themselves from the struggle against HIV and AIDS. For example, a Global AIDS Interfaith Alliance (2005) document states that religious leaders presiding at funeral rites typically do not mention that the deceased died of AIDS-related illnesses, though this is usually out of respect for the fears of the family.

It is also noted that African christian, which could apply to Moslem organisations, under influence from religious interpretations, tout a trite evangelical theological paradigm: (good) referring to creation; (bad) fall; and (good) redemption (for the chosen) - that buttresses tendencies to categorise people as saved or sinner, pure or impure. In its way, this feeds stigma directly by blaming those who are fallen from faith as bad, and it indirectly strengthens the broader social stratifications within which stigmatising flourishes (Global AIDS Interfaith Alliance, 2005).

2.1.4 Impact of Stigma and Discrimination

Literature indicates that stigma and discrimination has severe consequences in the fight against HIV and AIDS. Stigma and discrimination threaten the effectiveness of HIV prevention and care programmes by discouraging individuals from coming forward for testing and seeking information on how to protect themselves and others (National AIDS Trust, undated). The DFID/Futures Group (2005) put it more plainly that stigma and discrimination are identified as primary barriers to effective HIV prevention, as well as the provision of treatment, care and support.

Fear of stigma amongst PLHA, or people who believe they are HIV positive, has been found to be a barrier to accessing voluntary counselling and testing (VCT) and other HIV and AIDS-related support services (DFID/Futures Group, 2005). This may include fears of disclosure, fears of judgmental attitudes of health workers, and fears of confidentiality. It is also noted that fear of stigma intersects with other psychological processes to do with HIV infection, including guilt at potentially having infected others, fear of illness and death, feelings of inadequacy, and denial.

An article appearing in the *Archives of Iranian Medicine* (Vol. 6, No 2, April 2003) states that AIDS-related stigma refers to prejudice, discrediting, and discrimination directed at PLHAs as well as the individuals and groups with which they are associated as secondary targets. This imposes on patients the experiences of guilt, anger, grief, and fear of abandonment due to others' fear of the infection and associated stigma.

This additional suffering has often interfered with and hampered treatment, care and social benefits. It stops patients developing healthy habits and preventing the disease by seeking decent medical care and discontinuing behaviours that transmit HIV. Some patients even behave in a way that jeopardizes healthy individuals in revenge and anger at communities that discount people living with HIV and AIDS.

It is also widely accepted that stigma and discrimination undermines 'self-respect'. The Global AIDS Interfaith Alliance (2005) document states that self-respect is an essential human good, something we need in order to live our lives in an affirmative way. This enables an individual to value the self and to have realistic confidence in the ability to fulfil one's aspirations. Generally, we sustain self-respect by having the acceptance and approval of an individual or a group. Self-respect is undermined by stigma and discrimination - directly by inducing shame and other self-denigrating feelings within the individual, and indirectly by weakening or destroying the social support surrounding the targeted person - including sometimes the community support needed by their family and survivors.

2.1.4.1 The Gender Dimension of Stigma and Discrimination

Literature shows that stigma and discrimination has an entrenched gender dimension. An Avert article on HIV and AIDS discrimination and stigma³ reports the impact of HIV/AIDS on women is particularly acute. The Avert article adds that in many developing countries, women are often economically, culturally and socially disadvantaged and lack equal access to treatment, financial support and education. In a number of societies, women are mistakenly perceived as the main transmitters of sexually transmitted diseases (STDs). Together with traditional beliefs about sex, blood and the transmission of other diseases, these beliefs provide a basis for the further stigmatisation of women within the context of HIV and AIDS not only on the community in general, but also within the faith community.

HIV-positive women are treated very differently from men in many developing countries. Men are likely to be 'excused' for their behaviour that resulted in their infection, whereas women are not. As reported by the Avert article, in India, for example, the husbands who infected them may abandon women living with HIV or AIDS. Rejection by wider family members is also common. In some African countries, women, whose husbands have died from AIDS-related infections, have been blamed for their deaths.

A woman living with HIV may be doubly stigmatised – as a PLHA and as a presumed 'sex worker'. "How otherwise could my wife become HIV positive?" this could be the common question from the husband. A double standard in parts of Africa allows men to be sexually active with several women, or be polygamous, while wives are denied comparable freedoms (Global AIDS Interfaith Alliance, 2005). While this is common in the secular world, it could also apply within the faith community.

2.1.4.2 Strategies for Coping with Stigma

Literature shows that people living with HIV and AIDS, as well as affected families, use many different strategies for coping with the experience and impact of stigma. In this

³ An article on HIV and AIDS discrimination and stigma appearing on AVERT website: <http://www.avert.org>

discussion 'coping' is described as a process where the strategies employed to withstand situations change over time, and vary by short-term versus long-term realities and circumstances.

According to the International Centre for Research on Women (2003), the common strategies for coping with stigma include the following:

- disclosing an HIV-positive status in order to seek support
- denying or not disclosing an HIV-positive status if stigma is anticipated
- participating in PLHA networks or seeking work in the arena of HIV
- directly challenging stigma publicly and in everyday life
- seeking explanations and comfort, for instance in witchcraft or religion

2.2 Strategies to Combat Stigma and Discrimination

A number of factors put the faith community and faith based organisation in an advantageous and powerful position to combat HIV and AIDS related stigma and discrimination. The Faith community and FBOs are influential institutions as a product of:

- the respect and trust they enjoy from the communities in which they operate and their moral authority within society as a whole
- their nature as value-based institutions with direct 'jurisdiction' over issues of personal behaviour, morality, family life and belief;
- their regular involvement with members and followers, including direct contact with people at key life events (birth, coming of age, marriage, death); and
- their position as a spiritual home for members and as a source of strength, support and hope for people who are ill or in need

All these provide an opportunity for the faith community to address HIV and AIDS as well as its related stigma and discrimination. In the next sections, we take a look at areas and issues that need to be addressed within the faith community. In doing this, examples of success stories are presented based on the lot of literature reviewed.

2.2.1 Breaking the Silence on HIV and AIDS

An examination of literature regarding best strategies to combat stigma and discrimination brings into the limelight the Ugandan success story in reducing HIV and AIDS Prevalence. The Global AIDS Interfaith Alliance (2005) document reports that Ugandan President Museveni believed his country's success in prevalence reduction was primarily due to transparency, openness, and in particular, frank discussion about HIV and AIDS and human sexuality. Transparency's opposite, and deadly, condition is silence. Stigma cannot flourish under such circumstances, when silence, shame, secrecy, and denial are weakened or altogether absent.

According to the Global AIDS Interfaith Alliance (2005) document, President Museveni said, "as opposed to other cultures that tend not to appreciate their own problems and keep quiet, enduring suffering silently, Ugandans come out in public using all sorts of forums ...I had to impose it on my people to use forums like political rallies, church congregations, school assemblies, sports festivals to always talk about HIV/AIDS". The importance of the Ugandan President statement cannot be over-emphasized. A prominent International Red Cross

official remarked that it was not a coincidence that Swaziland now had the world's highest HIV prevalence since it is also where there is no public discussion of HIV and AIDS.

Gillian Paterson (undated) argues that churches cannot address HIV and AIDS without first breaking the silence that surrounds issues of sex, drug addiction, sin and death. Paterson adds that HIV is to do with sex, with premature death, with human relationships: all profound and universal human experiences, located at the core of human family and community life. In theory a church should be ideally placed to engage with such matters, intimately involved as it is in the lives of people and communities.

2.2.2 Development of HIV and AIDS Policies

The absence of coherent HIV and AIDS policies within the faith community has given rise to confusion and the implementation of *ad hoc* decisions which in some instances are contradictory and perpetrate stigma and discrimination.

In India, the Catholic Church found it more imperative to develop a policy for the Church to effectively address the challenges posed by the ramifications of HIV and AIDS. The HIV and AIDS Policy of the Catholic Church reaffirms the collaborative endeavour of the community and its commitment to fight against HIV and AIDS. The policy is developed on the foundation of Gospel values, teachings of the Church, scientific facts and research in contemporary realities.

The policy of the Catholic Church in India is presented as a guide to all Catholic health, development, educational, research and spiritual institutions and associations; to all Commissions and ministries of the Catholic Bishops' Conference of India (CBCI); to the dioceses, parishes and congregations; to the religious priests and sisters, to the clergy and the faithful (CBCI, 2005).

The policy document for the Catholic Church in India demonstrates interest to address issues of stigma and discrimination. This is evident in one of the objectives which seek to "effectively address issues related to stigma, discrimination, gender, equity, human rights, and to particularly empower the vulnerable population". The mission statement of the policy document reads as follows:

Inspired by the Divine Mandate to bring health and healing, the Church will make a concerted effort to address the challenges of HIV and AIDS, take care of the infected and affected, help arrest the spread of the virus through awareness and promotion of healthy, positive lifestyles and behaviour, **and create an environment free from stigma, shame and discrimination** (HIV and AIDS Policy of the Catholic Church in India, 2005:9, *emphasis added*)

With respect to orphans, the CBCI's HIV and AIDS Policy stipulates that the Church will contribute to building and strengthening governmental, family and community capacities to provide a supportive environment for OVC; appropriate counselling and psycho-social support; ensure their enrolment in school and access to shelter, good nutrition, health and social services on an equal basis with other children; and protect OVC from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance.

In Malawi, the National HIV and AIDS Policy, in a bid to ensure the protection, participation and empowerment of PLHAs and vulnerable population calls on the government and other stakeholders among others to:

- Ensure that the human rights and dignity of those affected and infected by HIV and AIDS are respected, protected and upheld
- Ensure that HIV and AIDS, whether suspected or actual is not used as a reason for denying access to services
- Ensure that orphans living with HIV are not discriminated against in access to health care, in education, or in access to fostering, adoption and placement in institutions
- Ensure that all women and girls regardless of marital status or HIV sero status have equal access to appropriate sound HIV-related information and education, means of prevention and health services
- Protect the rights of women to have control over and to decide responsibly on their sexuality, including sexual and reproductive health, free of discrimination or coercive violence.

Recognising that they represent a major resource in the effort to prevent the spread of HIV and AIDS the faith community and faith-based organizations (FBOs) are called upon by the wider society to develop guidelines, policies and action plans to address the multi-faceted issues confronting the society in the context of the HIV and AIDS epidemic

2.2.3 Transformation of Theological Orientations and Practice

Other sets of literature are calling for the transformation of theological orientation in a bid to deal with stigma and discrimination in the faith community. The World Council of Churches calls for churches to go through a transformation process, become AIDS competent and be a better home for those directly affected by the pandemic (World Council of Churches, 2005). The World Council of Churches states in the guidelines for partnerships between Churches and PLHA organisations that the worldwide church is one body of Christ, Therefore, for churches, whose theology holds that, “For in one Spirit we were all baptized into one body...If one member suffers, all suffer together with it; if one member is honoured, all rejoice together with it”.

The World Council of Churches guidelines also report that religious leaders in the Arab States, in December 2004, vowed to *“break the silence around HIV/AIDS: We emphasize the need to break the silence, doing so from the pulpits of our mosques, churches, educational institutions, and all the venues in which we may be called to speak. We need to address the ways to deal with the HIV and AIDS epidemic based upon our genuine spiritual principles and our creativity, and armed with scientific knowledge, aiming at the innovation of new approaches to deal with this dangerous challenge. We reject and emphasize the necessity to abolish all forms of discrimination, isolation, marginalization, and stigmatization of people living with HIV and AIDS we insist on defending their basic freedoms and human rights”*.

The Malawi HIV and AIDS National Action Framework (NAF) 2005 – 2009 also takes note of the need to promote transformation of theological orientations and enhance the involvement of FBOs in offering spiritual counselling to PLHA and affected families. The NAF outlines a number of strategies and areas of action. Key strategies include integration of the “Theology

of Hope” in counselling curriculum of FBOs and increasing involvement of FBOs in providing psychosocial care and support to PLHA and affected families. The NAF identifies a number of action areas. These include the following:

- Developing “Theology of Hope” curricula
- Training pastors, priests, lay leaders on the concept of the “Theology of Hope” and counselling using the concept
- Integrating HIV and AIDS education in regular activities of religious organisations
- Funding production and dissemination of IEC based on the “Theology of Hope”
- Conducting workshops to popularise the concept of the “Theology of Hope”

2.2.4 Greater Involvement of people living with AIDS (GIPA)

In Malawi, the need to address stigma and discrimination was recognised at the time the Malawi HIV and AIDS National Action Framework (NAF) 2005 – 2009 was being developed. The NAF, within its guiding principles has identified greater involvement of people living with AIDS (GIPA) and human rights where it stipulates that all Malawians have the right to know their HIV status and to appropriate pre-test education for informed consent.

On human rights, the NAF (NAC 2005) stipulates that people living with HIV and AIDS, orphans, widows, and women have the right to protection against discrimination and stigmatisation with equal access to education, and health including access to treatment, employment and other services. The NAF document adds that non-discrimination, equal protection and equality before the law of Malawi, are key guiding principles for the implementation of the national action framework.

2.3 Guidelines to Address Stigma and Discrimination

Looking at the impact that stigma and discrimination has in the fight against HIV and AIDS within the faith community, the question is no longer whether stigma and discrimination should be addressed or not, but how? On a lighter note though, the question is who spearheads the process? The DFID/Futures Group (2005) report that the Siyam’kela Initiative, led by the Policy Project to explore aspects of HIV and AIDS related stigma in South Africa, produced a set of guidelines for faith based organisations wishing to develop stigma-mitigation interventions. Based in part on focus groups and interviews with faith leaders, faith community members and PLHAs who are part of faith groups, the following recommendations were made:

- Guidelines should be developed to assist faith leaders and religious communities to deal with HIV and AIDS in faith settings, including managing disclosure and protecting the confidentiality of HIV-positive people who have chosen to disclose;
- Anti-discrimination and stigma mitigation approaches should be mainstreamed into various aspects of religious practice through policy
- Faith leaders should be trained to contribute effectively to anti-stigmatisation activities, including greater sensitisation on how stigma develops and is experienced within faith communities
- HIV and AIDS stigma mitigation interventions should be driven and monitored by faith leaders who should also ideally be the ‘face’ of anti-stigma campaigns and be actively and directly involved in interventions

- PLHA should be appointed to positions of leadership within FBOs and should be involved to a greater degree in policy development, programme delivery and monitoring
- Anti-stigma interventions should be built upon local-level stigma assessments that gauge the extent of the problem, identify local barriers to stigma mitigation, and recognise factors contributing to stigma reduction
- Anti-stigma messages should emphasise tolerance and acceptance, should involve non-stereotypical images and concepts of PLHAs (i.e. not focus on images of frail or ill people or high-risk groups only), should employ positive and inclusive language, and should focus on risk behaviours rather than risk groups
- Faith communities need greater sensitisation to HIV/AIDS stigma, but interventions should move beyond simply providing information and attempt to address underlying beliefs or assumptions which can contribute to behaviour change, and
- Partnerships between FBOs and other institutions should be enhanced, including with NGOs, hospices and others, and better use should be made of existing services and referral networks which assist and support PLHAs.

While the importance of addressing stigma and discrimination in relation to HIV and AIDS is recognised, literature also points towards the need for an internal assessment within the faith community. The following areas are relevant for assessing stigma and discrimination within the faith community and FBOs:

- The way that HIV and AIDS and PLHA are spoken about by religious leaders
- The way language is used to talk about HIV and AIDS and how it is used in relation to PLHA and affected persons
- The way religious texts are employed towards PLHAs and affected persons
- The way HIV status is managed in relation to privacy and disclosure
- The way HIV and AIDS has been integrated into religious practices and ceremonies
- The way constructions of sexuality and sexual morality are employed by religious leadership in relation to HIV and AIDS
- The involvement of PLHA in faith-based activities.

3 STIGMA AND DISCRIMINATION WITHIN THE FAITH COMMUNITY

People believed to be living with HIV and AIDS are demoted from their church positions fearing they may die any time... (Males from Nsanje); Perceived as sinful... (Youth from Mangochi); despised as prostitutes...(Women from Dowa); though there are no known cases in the church those who may be found could be perceived as sinful and cursed... (Youth from Mzimba).

The church, mosque or indeed any place and institution of worship is believed and taken to display the sympathy and love and offer comfort to the folks or the faithful. The teachings in these religious institutions centre on the divine love of the almighty God and the honoured prophets. But a look at statements from only a sample of the focus groups discussions comprised of members of the Christian churches and Moslems quoted in the caption above, one sees obvious evidence that those people who are known or believed to be living with HIV and AIDS are heavily stigmatized and discriminated against.

In this chapter, we take a closer look at HIV and AIDS related stigma and discrimination within the faith community. In doing this, we focus our attention on the nature, magnitude and causes of stigma and discrimination within different religions and congregations. We also make an attempt to explore the impact of stigma and discrimination on VCT services before marriage, discordant couples and orphans based on discussions held with individuals as well as key informants, groups of women and men drawn from the operational research districts of Mzimba, Dowa, Lilongwe, Ntcheu, Mangochi and Nsanje districts.

3.1 Nature of stigma and discrimination

The research established that various forms of stigma and discrimination exist within the community in general and the faith-community in particular against those who are affected or infected and living with HIV and AIDS.

3.1.1 Discrimination in the community

In the community, stigma and discrimination takes many forms ranging from excluding those who are HIV positive and orphans from the usual household activities. There are also cases of people deserting their spouses in case where the other partner is found to be HIV positive. Out of the entire sample surveyed in the six districts, about 22 percent (21.5 percent) had knowledge of some person living with HIV and AIDS being excluded by family members from the usual activities due to their HIV status.

The district level picture shows higher discrimination in Nsanje where 35 percent were aware of PLHAs being excluded from household activities. Mangochi and Ntcheu districts reported the lowest incidences of household members excluding the family members that were living with HIV. For Mangochi only 12 percent knew and in Ntcheu only 13 percent had knowledge of some PLHAs excluded from household activities. In Dowa and Lilongwe district about two in every ten people interviewed had knowledge of family members discriminating people with HIV, while in Mzimba one out every four respondents knew such

exclusions taking place in the families. The table below illustrates how those who are living with HIV are excluded from the usual activities of the households.

Table 3.1: Knowledge of Exclusion of PLHA at household Level

Household activity/District	Proportion aware of PLHAs Excluded						
	Dowa	Lilongwe	Mangochi	Mzimba	Nsanje	Ntcheu	All
Not cooking	35.7	46.2	-	18.8	13.6	10.0	22.2
Not sharing of food	37.5	46.2	33.3	50.0	50.0	40.0	44.4
Don't share utensils	21.4	7.7	-	12.5	18.2	44.4	17.5
Don't sleep with others	57.1	15.4	50.0	37.5	40.9	44.4	40.0

Note: Percentages not adding to 100 because of multiple responses.

As can be seen from table 3.1 above, most household members were unwilling to allow the PLHAs to be involved in sharing food as indicated by 44 percent of the respondents who were aware of such exclusions taking place. The other activity which shows that the PLHAs were excluded was from sharing the sleeping rooms (40 percent). Those that are HIV positive are isolated from the rest of the family members and given their own rooms or own house in which they can sleep. It was reported also that they are not assisted or given proper care when they are sick and other community members stop visiting them.

With regard to partner deserting an HIV positive spouse, 18 percent of the total sample reported such knowledge of cases happening in their communities. The highest was reported in Lilongwe 26 percent and then in Mzimba 25 percent followed by Dowa (20 percent). Few people indicated having heard cases where one partner had actually deserted the HIV positive spouse in Nsanje, Ntcheu and Mangochi with 14.5 percent, 14.8 percent and 9 percent respectively.

As regards orphans, the results from interviews with different groups show that they are not excluded nor given different treatment from other children as reported by only 3.3 percent of the total sample and 14.3 percent in Dowa and only 5.6 percent in Ntcheu. But surprisingly, when respondents were asked whether orphans are excluded from some household activities and ill-treated in various ways, higher proportions of respondents confirmed this to be the case. From the total sample, 29 percent of the respondents agreed that orphans are generally excluded from household activities or ill-treated in different ways as we will see in the next paragraphs.

Looking at the results from each district covered in the research, close to half of the respondents in Mzimba (which turns out to be the highest proportion above all districts) agreed that orphans are excluded from household activities or ill-treated at household level followed by Dowa district at 43 percent respectively. In other districts the responses were as follows: Lilongwe (17 percent), Mangochi (15 percent), Nsanje (24.4 percent) and Ntcheu (28 percent).

As can be seen from table 3.2 below, the orphans are seriously denied love from the other household members. The general picture, from those that responded to the question, show that up to 63 percent of the orphans are not shown love. This was most serious in Nsanje where 87.5 percent reported that orphans are not shown love. Further Mzimba reported 58 percent, Ntcheu (55 percent), Dowa (53 percent) and the lowest was in Mangochi (12.5

percent). Orphans are also not allowed to cook food and are not given enough food as compared to other children. Table 3.2 summarises details of the major activities of exclusion and ill-treatment towards orphans at household level.

Table 3.2: Major incidences of ill-treatment towards orphans

Activity	No	Percentage
Not given enough food	6	10.17
Left out in social activities	2	3.39
Not shown love	37	62.71
Not allowed to cook food	10	16.95
Not allowed to wash dishes	2	3.39
Use of abusive language	1	1.69
Sent away from home	1	1.69
Total	59	100

Regarding deserting an HIV partner in marriage, when asked whether they felt it was justified for a person living with HIV to be deserted by their spouse, 19 percent of the total sample said it was justified and 95 percent said the other partner could avoid infection that way. Responses from the districts show that more people in Nsanje felt it is justified for a person living with HIV to be deserted by their partner (33.3 percent) followed by Dowa (22.4 percent), Ntcheu (17 percent), Lilongwe (16.4 percent) and Mzimba (11 percent).

In the districts the most cited reason why they felt it was justified for a person living with HIV and AIDS to be deserted by their partner was fear of infection. Out of all those who thought it was justified, 95 percent of respondents in Nsanje felt the partner could avoid getting infected, in Mzimba 78 percent felt the same way, and 23 percent in Ntcheu. Respondents both in Dowa and Mangochi felt the partner is justified to avoid getting infected. Others and quite on the extreme (about 13 percent in Lilongwe and 11 percent from Mzimba) felt PLHAs should be deserted as a punishment for their sins.

This agrees with the reasons that were given as to why people living with HIV and AIDS are discriminated against. The following table shows why the PLHAs are discriminated in the community.

Table 3.3: Reasons for discrimination

Reason for Discrimination/District	Proportion Responded						
	Dowa	Lilongwe	Mangochi	Mzimba	Nsanje	Ntcheu	All
Seen as sinners	16.9	16.4	16.9	21.5	20.6	21.3	19.7
Fear spreading HIV	46.6	46.7	58.2	37.1	55.6	50.0	48.9
Lack of Love	34.5	30.0	25.5	35.5	30.2	25.9	30.3
Fear discrimination	1.7	3.3	1.8	8.1	4.8	1.8	3.7

Note: Percentages not adding to 100 because of multiple responses.

Most respondents (close to 50 percent) felt that people living with HIV and AIDS are discriminated against because of fear of spreading the virus. The other reason is that PLHAs are discriminated against because of lack of love (30 percent) and because those with the virus are seen as sinners (19.7 percent). There was also a feeling that those who associate with PLHAs run a risk of being discriminated against as well. This was however reported by only 4 percent of the respondents.

3.1.2 Faith Community

Stigma and discrimination doesn't just take place within the community alone but in the congregation as well. It is generally accepted and should be born in mind that the faith communities or groups influence behaviour and the way of life for the 'faithfuls' or followers. Having noted the existence of such stigma and discrimination taking place within the community, it can be argued that the teachings of love compassion and fairness advanced by the faith community and synonymous with religious groups are not being assimilated or at least put into application in the daily life of the congregants.

Against the background of the findings at the community level, when the respondents were asked if they know of anyone who has been excluded from their usual religious congregations because they are HIV positive, only 4 percent of the entire total sample accepted that such exclusions take place. The trend in the districts also showed that people are not aware of any exclusions taking place in the congregation. Out of those who indicated such exclusions taking place, 5 (representing 45 percent) said those who are HIV positive are not allowed to preach or teach in the church. Others reported that they are not allowed to participate in decision making and not allowed to serve meals (18 percent each). It is worthy noting however, that such low reported responses on exclusions in the congregation are hampered by lack of disclosure as most people indicated that they were not aware of any person living with HIV and AIDS in their congregations.

Example of stigma and discrimination taking place in the faith community

“Wodwala sapatsidwa mwayi wolalika mawu chifukwa anatenga matenda mchiwerewere ndiye angadetse malo opatulika – a person living with HIV is not given chance to preach because that person contracted HIV through adultery and she/he may render the pulpit unholy”. A statement by a young person during in a focus group discussion session in Mangochi.

The emphasis and the main message in this statement is that PLHAs cannot be given chances to preach because they believe they may contaminate the holy places. This is also a clear manifestation of 'judgementalism' that prevails within the faith community.

With regard to discriminatory language, although due to lack of disclosure the majority of respondents reported that there was none at all, there were still some respondents who indicated that negative language is used to describe those who are living with HIV within the faith community. Such derogatory language which was reported included *amahang'ala* (looking skinny like a wire-hanger referring to severe loss of weight); *anadya pepala*, *ayamba kudaya* (referring to a symptom of hair which looks pale, as if it has been treated with hair chemicals); *government disease* (meaning a common type disease); *battery*

loyendera kutchajidwa (which literally translate *rechargeable batteries* - referring to those who are now on anti retroviral therapy (ARVs). Further those that are living with HIV and AIDS are said to be prostitutes. All these statements are stigmatising in nature and are usually said in passing during preaching sermons or religious teachings.

Apart from the negative language some practices which are discriminatory in nature include fewer visits by the congregation leaders (the clergy and elders) to the PLHAs as reported by a focus group in Nsanje. In addition, those that are in some church positions are relegated so that they are not conspicuous to the rest of the congregants. Upon further probing the respondents felt that if they are left in such leadership positions the church would be seen to be tolerating or condoning sinful practices (that are related to the transmission of HIV) contrary to the teaching of the law.

The culture of silence in the church may also to some extent be responsible for fomenting the practice of stigma and discrimination. In Mangochi, the youth in a focus group discussion reported that the sheikhs do not freely discuss the issues of stigma and discrimination. These sentiments were echoed by the youth from Mzimba who indicated that silence in the church on issues of HIV and AIDS is itself responsible for stigma and discrimination. On a different note, the women in Dowa felt that frequent talk and excessive concern and compassion for the PLHAs contributes to self stigmatization. The women reported that *“Kuwamvera chisoni mopitilira muyeso nawonso amaona ngati kuti ndiye akudwala kwmbiri – sympathising too much with people living with HIV gives them an impression that their condition is quite bad”*

3.1.3 Extent of disclosure in the congregations

Out of all the seven focus group discussions that were conducted across the six districts, only in two (women group in Mangochi and men group in Ntcheu) did the participants indicate that people are free to disclose their HIV status in the congregations. In Mangochi and Lilongwe the youth and PLHAs reported that people don't disclose their status because their religions or their congregations have not provided an opportunity nor created any fora for disclosure.

The respondents further indicated that it seemed their religion was not even interested whether one discloses their status or not. The focus group discussions with men in Nsanje, the youth group in Mzimba, women group in Dowa and the group of PLHAs in Lilongwe reported that people are not free to disclose their status because of fear of being discriminated against. In Nsanje however, they added that only in cases where disclosure is accompanied by material supplies like food, clothing and only when the churches and NGOs are involved in HIV and AIDS campaigns do some people disclose their status.

3.2 Magnitude of Stigma and discrimination

The research also attempted to explore the magnitude of stigma and discrimination at the community level in general and within faith community in particular. From discussions with various groups of respondents, there was an indication that some form of discrimination takes place at the household level with fear of infection as the main reason. This could imply

that that people do not fully understand how the HIV virus can be transmitted from one person to the other.

On average in all the districts, about one person out of every five was aware of some person living with HIV and AIDS being excluded by family members from the usual activities due to their HIV status. Nsanje ranked higher than the rest of the districts as 35 percent were aware of some person being excluded from household activities. Further, while there is only limited disclosure of HIV status in the faith community, as only 4 percent of the entire total sample reported having knowledge of such exclusions taking place, 45 percent indicated that those who are HIV positive are not allowed to preach or teach in the church. Others indicated that PLHAs are not allowed to participate in decision making neither do they serve meals during religious functions (18 percent each).

The results show that 18 percent of the total sample was aware of some person living with HIV being deserted by their partner, with higher knowledge in Lilongwe, Mzimba and Dowa where at least 20 percent of the respondents were aware. Only few people reported having heard cases where one partner had actually deserted the HIV positive spouse in the other sample districts.

To assess the magnitude of this stigma and discrimination, the research wanted to establish what happens with regard to marriage if one partner has been found to be HIV positive before marriage. The responses are detailed in the table below.

Table 3.4: Whether partners proceed to marry if one partner is HIV Positive

Response/District	Dowa	Lilongwe	Mangochi	Mzimba	Nsanje	Ntcheu	All
Yes	6.7	18.9	23.4	16.1	20.0	16.4	17.0
No	28.9	28.3	42.6	25.0	38.0	30.9	32.0
Its up to them	64.9	52.8	34.0	58.9	42.0	41.8	49.0
Not happened	-	-	-	-	-	10.9	2.0

The findings from the table above show that if one partner is HIV positive it should be left up to the two to decide whether they proceed to marry or not. Others however, about one person in every three felt that it would not be a good idea to allow the two to marry. Those that indicated that they should not marry justified their perceptions by saying that they may end up getting infected right in the family (74 percent).

At the district level, however, there are variations as regards to whether they should marry or not. The majority of the respondents in Dowa (65 percent) felt the decision to proceed to marry or not should be left entirely to the two that are anticipating to get married. In Mangochi 42.6 percent of the respondents (which is the highest record above all the other research districts) felt that they should not get married.

Apart from looking at what is happening or what would happen at congregation level, the individual respondents were also asked to solicit their opinion as to whether they would allow marriage to proceed if a partner of their relative is HIV positive. The responses are summarized in table 3.5 below.

Table 3.5: If partner of relative is HIV positive, would you allow them to marry

Response/District	Dowa	Lilongwe	Mangochi	Mzimba	Nsanje	Ntcheu	All
Yes	8.6	15.5	17.5	15.6	11.3	21.7	15.0
No	41.4	44.8	56.1	35.9	50.0	38.3	44.3
Its up to them	50.0	39.7	26.3	48.4	38.7	40.0	40.7

The results in the table reflect an obvious shift in the feelings of the people as the question seemed to be more personalized. A higher proportion (44 percent) indicated that they would not accept that their relatives get married to an HIV positive partner. Upon finding out why they thought they would not allow such marriage to take place, the general picture was that they were afraid that their relative would die (17.5 percent) or would be infected (77.9 percent) and/or their relative would be discriminated (3.2 percent). The women focus group in Mangochi added that even if the two got married, they would not enjoy sex as they may have to use the condom for the rest of their married life besides having problems to conceive and bear children.

Those however, who felt the two would be allowed to marry had the following reasons to support their views: love (58.9 percent), rely on ARVs (7.1 percent), rely on condoms (14.3), and adequate counselling (17.9). A small proportion of the respondents (1.8 percent) indicated that they would allow them to marry as one way of discouraging discrimination. It was also learned that for a couple that after being stopped, insists to get married, becomes the subject of talk as well as scorn and are they are usually castigated. Such statements as *“Ameneyu akukaziponya bwanji muchitsime – people wonder why is this somebody throwing him/herself voluntary into the deep well where they may drown; ... wakwela galimoto yokuphwa matayala - meaning one is has chosen to ride a vehicle with flat tyres”* as reported by male FGD in Nsanje.

All this point towards a general feeling among people that an HIV negative person who chooses to live in marriage with an HIV positive person may not live long, or s/he will not enjoy married-life either sexually and/or the gift of childbearing.

3.2.1 Incidences of Stigma and discrimination

Within the faith community some incidences that are believed to show that there is stigma and discrimination were reported. Apart from knowledge of incidences of stigma and discrimination among congregants, the respondents indicated that PLHAs are excluded from the usual religious activities due to their HIV status. Due to problems of disclosure however, only 11 representing a small percentage (3.1%) of all the respondents reported having knowledge of some people being excluded from usual religious activities. They reported that they were actually excluded from preaching (70.0 percent) and not allowed to hold influential church positions (30.0 percent). Key informants from Mzimba, Ntcheu, Dowa, Mangochi and Mzimba reported that when preaching the clergy have made reference to those that are positive as receiving due punishment for their prostitution. Sometimes these statements are made out of innocence and concern to persuade people to change their behaviour warning them on incurable diseases if they are not careful. During discussions, some key informants in Christian faith quoted *Deuteronomy 28:20-22* which prophesies the misfortunes which will befall mankind if they departs from the spiritual law or forsake God’s commands.

In all the districts however, the FGDs did not come up with specific incidents of HIV and AIDS related stigma and discrimination in the congregations except in Mangochi where the youth reported that the PLHAs are not allowed to stand and share the word of God in the mosques because the disease is associated with promiscuity.

The captions below highlight some negative statements which depict discrimination made by congregants in reference to people living with HIV and AIDS

- *“Akuyenda wokufa kale – they walk while already dead”* (reported by the youth of Mangochi)
- *“PLHAs are prostitutes”, “watsala ndi mafupa okha okha – only skeletons remains”, “bwenzi la telala - tailors’ friend or customer because they adjust clothes frequently to fit them as they grow thin”* (women in Mangochi);
- In Dowa, people make such statements as *“mwawaona awa atha ngati curtain - they look like worn out curtains”, “ananyamula ma keni - referring to the protrusion of the collar-bone of the shoulders common when one lifts heavy load on both hands ”*; and *“Tsitsi anadaya kapena anajelula – meaning they dyed their hair and have applied gels to their hair”* (reported by women focus group)

Apart from the negative statements which the congregants utter against or with reference to those that are living with HIV, the focus group discussions with the youth in Mzimba, revealed existence of gossip. By this it means the fellow congregants having agreed and visited one of their members suffering from HIV and AIDS, after the visit they go about talking or gossiping how this person has deteriorated looking different from the last time they saw him or her.

It was also reported by the youth in Mzimba that when a person with HIV has developed sores either in their hands or the mouth, such persons are not allowed to share the feeding utensils. These sentiments were corroborated with the results of the discussions with the PLHAs in Likuni, Lilongwe. *They reported that one female PLHA member who belongs to the CCAP had travelled with other members of the church to a church function in Zambia. This woman was stunned when her fellows cautioned their counterparts in Zambia that they should not dare share a cup with this lady.*

In terms of treatment of orphans due to HIV and AIDS with respect to other children, very few, only 3.3 percent of the total sample reported that such children experience discomfort while attending Sunday school in Christian churches or madrassah in the Muslim community. In Dowa it was reported by 3 out of four respondents that these children are discriminated because of fear that they can spread the virus to other children.

In Mangochi one key informant, a pastor of a Pentecostal church around MALDECO area indicated that if one is found positive, they don’t allow them to marry. He gave an example of a failed marriage two days before the wedding day because the female was found positive. The board of the church called off the marriage but did not reveal to the rest of the congregation why they had decided not to officiate the wedding.

3.3 Causes of Stigma and Discrimination

In this section, we present the causes of stigma and discrimination within the faith community as reported by different respondent groups. In the presentation, four distinct issues are discussed as having some link to stigma and discrimination.

It has been highlighted that not many people come out in the open to disclose their status even after testing. The survey wanted to find out if the congregants knew any person living with HIV in their congregations and table 3.6 summarises the responses.

Table 3.6: Are there people living with HIV and AIDS in your Congregation

Response/District	Dowa	Lilongwe	Mangochi	Mzimba	Nsanje	Ntcheu	All
Yes	41.8	33.9	15.5	34.4	28.6	30.5	30.7
No	56.4	62.7	74.1	57.8	61.9	62.7	62.6
Don't know	1.8	3.4	10.3	7.8	9.5	6.8	6.7

The results depicted in the table above show that the majority (63 percent) were not aware of anyone living with HIV in their congregations. One respondent in every three was aware of some people living with HIV. A small proportion, 7.0 percent were not sure. This implies that congregants in all the districts visited are generally not aware of person living with the virus in their congregations. Those that responded that they were aware of such people were further asked to explain how they came to know that: the results are presented in figure 3.1 below.

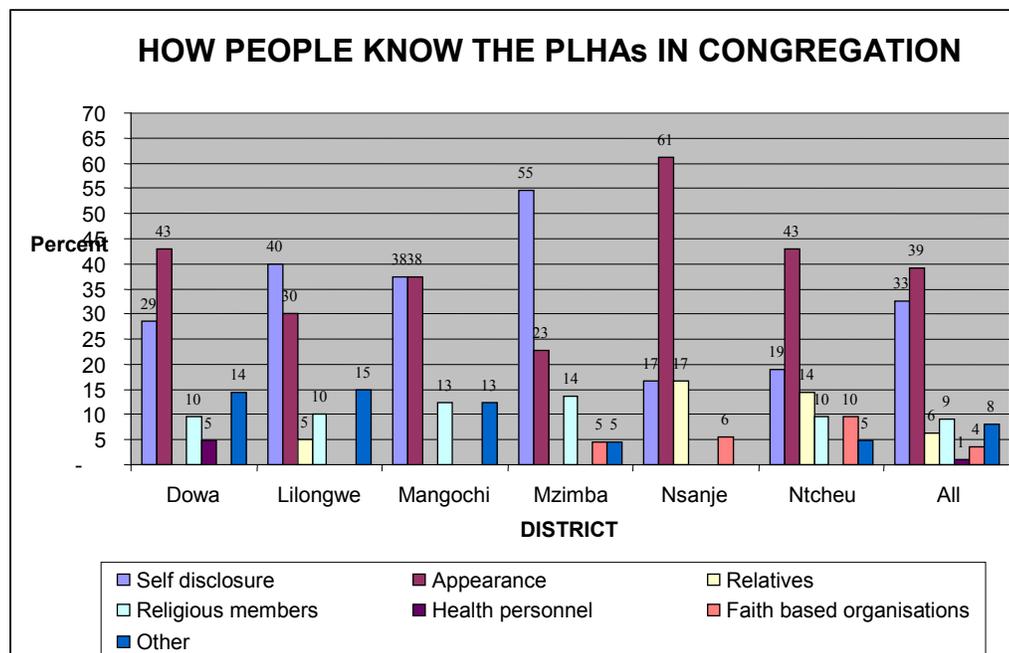


Table 3.7: How did you know that one is living with HIV

Method	Dowa	Lilongwe	Mangochi	Mzimba	Nsanje	Ntcheu	All
Self disclosure	29	40	38	55	17	19	33
Appearance	43	30	38	23	61	43	39
Relatives		5			17	14	6
Religious members	10	10	13	14		10	9
Health personnel	5						1
Faith based organisations				5	6	10	4
Other	14	15	13	5		5	8
	100	100	100	100	100	100	100

The results presented in the graph on the previous page (also presented in the table form above) show that the people who claim to know some people living with HIV only deduce from one's appearance (39 percent). Nsanje had the highest record on this aspect (61 percent). The results also show there are some who disclose voluntarily that they are living with HIV (as reported by 33 percent). This seems to be highest in Mzimba district where 55 percent of the respondents indicated that they know about some people living with HIV in their congregation through self disclosure.

3.3.1 Perception of Stigma and discrimination

There is a popular opinion that when people know that one is infected and is living with HIV within the congregation, the perceptions, comments and reactions of the fellow congregants play a role in fuelling stigma and discrimination. This section looks at how the religious leaders and congregants perceive those people living with HIV in the congregation. Out of the total sample of respondents, 85.6 percent reported that religious leaders accept the PLHAs in their congregations followed by 7.8 percent of the total respondents that indicated that the religious leaders see PLHAs as sinners. A small proportion of 3 percent and 2 percent reported that religious leaders reject them and believe that such people will die shortly.

On how the congregants view those people living with the HIV and AIDS, again the majority (88 percent) of the total sample reported that they accept them. Six percent reported that congregants view such PLHAs as sinners, 3 percent reported that congregants reject them and only 2 percent said congregants think that the PLHAs will not live long.

From the results, one would get the impression that there isn't as serious stigma and discrimination within the faith community. The small proportions reporting that rejection and exclusion exists and a perception that PLHAs will die soon or where they are seen as sinners by both the religious leaders and the congregants may influence the general response in the rest of the faith community and on how the congregation respond to those people who reveal their HIV status. Table 3.8 below summaries responses as regards congregation's response to those who disclose their HIV status.

In the table, it shows that the proportion of those respondents reporting that the congregation accepts those who reveal their HIV status stands at 44 percent. Those that reported that the congregation excludes them are only about 8 percent.

Table 3.8: Congregation's response to those revealing their HIV status

Response	Dowa	Lilongwe	Mangochi	Mzimba	Nsanje	Ntcheu	All
Socialise with them	22.2	15.4		47.8	30.4	18.2	25.2
Love them	18.5	24.0	70.0	34.8	26.1	4.5	20.0
Accept them	55.6	42.3	20.0	30.4	30.4	45.5	43.5
Exclude them		11.5			13.0	9.1	7.7
Pray for them	18.5	11.5		21.7	13.0	9.1	13.7

Note: Percentages not adding to 100 because of multiple responses.

3.3.2 Self Disclosure

It is generally accepted that self disclosure has an effect on stigma and discrimination. It was observed that apart from suspicions and other means discussed earlier (please refer to table 3.7 above), people come to know whether someone has HIV in the congregation through self disclosure as reported by 33 percent of the total sample of respondents. Respondents were asked more directly whether people that go for VCT and their results are found to be positive take a bold step to disclose their status. Only 10 percent of the total respondents accepted that such people disclosed their status.

The lowest results on self disclosure were recorded in Nsanje (3 percent) and Mangochi (4 percent). In the other districts the responses were as follows: Dowa (16.7 percent), Lilongwe (11 percent), Mzimba (18 percent) and Ntcheu (7 percent). Asked why people would not disclose their status, the common reason was fear of discrimination (44 percent) and to protect one's integrity (17.6 percent). Table 3.9 below summarises the rest of the reasons why people don't disclose their HIV status after VCT.

Table 3.9: Reason for not revealing HIV status after VCT

Reason	Dowa	Lilongwe	Mangochi	Mzimba	Nsanje	Ntcheu	All
May break relationship	17.9	11.1	3.6	25.5	11.5	3.5	13.8
One's choice	20.5	25.0	30.4	24.0	32.8	28.1	27.9
Fear dicrimination	30.8	28.6	55.4	32.0	47.5	54.4	43.6
Protect ones integrity	38.5	34.7	8.9	22.0	8.2	19.3	17.6

Note: Percentages not adding to 100 because of multiple responses.

While disclosure of one's HIV status is a human rights issue and that it remains one's choice to disclose their status, this points towards a challenge of tackling silence on issues related to HIV within the faith community. Those that have tested would rather keep the news to themselves than reveal to the congregation and the community. The implication of this is that the few that reveal their HIV status are stigmatised and discriminated. Focus group discussions with men in Nsanje, women in Dowa, PLHAs in Lilongwe and the youth in Mzimba all pointed out to the fact that people in the congregation are not free to disclose their status because of fear of discrimination.

Apart from asking a seemingly distant question where people were supposed to talk about the general situation as to whether people are free to disclose their status, the survey asked respondents directly if they themselves were free to do so. Out of the total sample 58

percent indicated they were free to do so, however, only 40 percent had gone for VCT. Out of these only 7 percent of those who were free to disclose their status revealed that they were HIV positive.

Asked why they had not yet gone for VCT, out of the 60 percent who indicated that they had not gone for VCT, over half of these (56 percent) said they were not ready for the test. It would appear people are freer to talk about their HIV status when the results are non reactive than when the results are positive after VCT.

3.3.3 Policies on HIV and AIDS related Stigma

The research also looked at whether the various faith groups have in place HIV and AIDS related policies to guide the congregants on how to handle issues related stigma and discrimination. Out of the total sample, only 11 percent reported that their religions and the congregations had policies to guide the church on HIV and AIDS issues. The lowest proportion was recorded in Nsanje where only 8 percent indicated that their congregations had a policy.

The situation was not different among the key informants and the focus group discussions who apart from the Holy Books indicated they didn't have any expressly written policies to guide them. A key informant in Dowa indicated that the Holy Quran is clear on how the congregation should interact with people affected by abominable diseases and therefore there is no need to have another policy. All what people need to do instead is to go back to the laws of God as stipulated in the holy books.

Upon probing further, it became apparent that the congregations whose members were covered in the research did not have any policy related to HIV and AIDS. Those who indicated that there is a policy were only concluding from what they see their congregations doing and what they themselves felt should be done so as not to discriminate those living with HIV and AIDS.

Respondents pointed towards the need to associate with people living with HIV, love them, and provide material and social support. Findings from focus group discussions show that to try and protect the PLHAs from being discriminated against, the clergy are preaching messages of love, and inclusion of PLHAs in religious activities. There is however, need for a clear stand of the faith community on VCT and how the faith community can support those disclosing their status especially those that are positive.

3.3.4 Messages within the Faith Community

As noted earlier, different sets of literature are calling for the transformation of theological orientation in a bid to deal with stigma and discrimination in the faith community. The NAF identifies development of "Theology of Hope" curricula as one way of combating stigma and discrimination. At the heart of these theological orientation and 'theology of hope are messages that pass from and within religious leaders and congregants related to HIV and AIDS.

It is generally accepted that messages that pass on to the communities can have a lasting effect on the subjects and especially where they seem to be persuasive. Messages are likely to influence behaviour. In this case messages that the congregants receive from their different faith groups may induce or to the contrary help to contain the problem of stigma and discrimination. The research explored the messages which circulate within the faith community with a view to identify the potential to instigate stigma and discrimination.

Responding to question regarding how they think the religious leaders and elders perpetrate stigma and discrimination against PLHAs, some of the key informants in Mzimba, Dowa, Ntcheu and Mangochi felt that some messages delivered within the faith community while preaching are stigmatising. One of the key informant made reference to such statements as those who are suffering and have HIV as receiving due punishment for their immoral behaviour and prostitution. This presupposes that those who are living with HIV got the virus from promiscuity which is regarded as sinful within the faith community and ignores other ways through which people contract HIV.

Secondly the way the discordant couples are viewed could actually be fuelling stigma and discrimination. When respondents were asked if they are aware of any discordant couples in the congregations, out of the total sample 23.2 percent said they had knowledge of discordant couples. Mzimba reported the highest with 42.9 percent of the respondents agreeing, followed by Dowa (25 percent) and Lilongwe (24 percent), Nsanje (21 percent). Mangochi with only 9 percent had the lowest proportion of the respondents affirming the existence of discordant couples. While the majority, 78 percent of the total sample indicated that such couples are accepted within the faith community, 11 percent of the respondents revealed that these couples are perceived as sinners while a small proportion (2.4 percent) indicated that discordant couples are rejected, and the other 2.4 percent reported that they are excluded. The total for the negative reactions is quite considerable and may have negative effects on the fight against stigma and discrimination.

Silence on issues where the congregation should come out in the open and provide the necessary guidance is believed to be one way of encouraging stigma. This link becomes clearer when questions on what messages the faith community has for discordant couples and on what the church does if one partner wants to leave the other one who is HIV positive are considered.

On what messages the congregations have for discordant couples, 34 percent reported that the congregation does not do anything. Twenty-nine (29) percent reported that the congregation advises them to love one another, 19 percent reported that the congregation preaches against discrimination while 14.4 percent reported that the congregation encourage acceptance of partners and a couple within the wider faith community. Of interest in this case is higher proportion of 34 percent which reported that the congregation does not do anything. This begs the question, why to which no clearer answers were generated.

In a related question of what the congregation does if one partner in discordant couple wants to divorce particularly if the other partner is HIV positive, the responses were quite varied. Table 3.10 below presents a summary of the response across the various districts covered in the research.

Table 3.10: What the congregation does if one wants to divorce an HIV positive partner.

Action	Dowa	Lilongwe	Mangochi	Mzimba	Nsanje	Ntcheu	All
Allow	4	4	3	4	4	5	4
Force to remain	15	8	10	11	6	11	10
Leave it to them	19	27	13	44	38	28	29
Nothing	38	48	54	27	26	45	39
Other	23	13	16	15	26		16
Counselling			5				1
Not happened						11	2
	100	100	100	100	100	100	100

A considerable proportion of respondents (39 percent) reported that the congregation doesn't do anything to intervene in a situation where one partner wants to divorce the HIV positive spouse. The second highest reported option is where the congregation leaves the issue to the two and other family friends to resolve the issue. A small proportion of respondents reported that the congregation allows the two partners to divorce (4 percent). This was also echoed by the key informants from Mzimba and Dowa that the two would be better divorced to avoid spreading the virus to innocent partners. This sends messages to other congregant that if one partner is HIV positive, s/he may be divorced easily, which in itself connotes discrimination.

3.4 Impact of Stigma and Discrimination

The research also looked at the impact of HIV and AIDS related stigma and discrimination on VCT before marriage, discordant couples and orphans. The following sections present the findings from discussions with different groups of respondents.

3.4.1 VCT Before Marriage

During focus group discussions, respondents were also asked what they considered to be the benefits of VCT. Groups of women in Dowa, men in Ntcheu and Nsanje, and youth in Mzimba as well as the boys in Mangochi indicated that VCT is important to know one's HIV status. The youth in Mzimba added that going for VCT helps people to plan their future and how to protect oneself from infection if found negative or how to avoid further infection and multiplying the virus if found to be positive. Similar responses were echoed by different key informants in all the districts visited during the operational research.

Using an individual questionnaire we asked our respondents whether their religions encourage congregants to go for VCT services before marriage or whether VCT before marriage is mandatory.

As shown in the table below, the majority (250 of 358) of the respondents felt their religion encourage their members to seek VCT services before entering into marriage. During focus group discussions in Mzimba, Dowa, Ntcheu and Nsanje respondents indicated that their

various religions and congregations encourage VCT before marriage to know their status and properly plan and approach their future in light of the advice and counsel they receive during testing.

Table 3.11: Whether religions encourage couples to go for VCT before marriage

Religion	Respondents Response			Total
	Yes	No	Don't now	
Christianity	212	77	6	295
Islam	34	13	2	49
Rasta	3	8	-	11
Hindu	1	2	-	3
Total	250	100	8	358

As can be seen from the table 3.11 above, only 100 of 358 people interviewed said their religion does not encourage congregants to go for VCT before marriage. It is possible that some respondents felt that religions do not encourage VCT before marriage because they do not talk about it at all. On the other hand, religions might be silent on VCT before marriage on the understanding that going for VCT is out of one's choice. Further, encouragement only does not make VCT before marriage mandatory, as people are free to make own decisions after receiving word of encouragement from their religions.

In terms of the response to the call to go for VCT before marriage, there were mixed reactions. During focus group discussions the youth in Mzimba and a group of men in Ntcheu indicated that there are some who go for VCT while others don't. In Dowa women reported that the congregants go for VCT while in Nsanje the men just like their women counterparts in Mangochi reported that congregants do not go at all. In Nsanje men explained that the majority of people in the district have sexual relations even before they are married and there is a prevailing feeling that even if they go for VCT, the results will have little impact on their life apart from increasing their chances of worry particularly if found positive. This demonstrates lack of understanding that people infect with HIV can also live positively.

Asked what happens after VCT particularly for those who respond positively to the call to test for HIV before marriage, in Mzimba the youth reported that people do not disclose the results to the rest of the congregation but the clergy. In Dowa, women indicated that after VCT, the partners disclose their results to the pastor/reverend only, while in Ntcheu, men speculated that couples disclose the results to their family members and do not even bother to tell the religious leaders and the congregation. A group of women in Mangochi argued that couple do not disclose once one is found positive, but if found negative they go about bragging that they don't have the virus.

It was also learnt during focus group discussions with various groups of respondents that VCT before marriage is not mandatory in various religions arguing that people have a right or choice to go for VCT services before marriage.

During interviews using individual questionnaires, there were mixed

Response	sex of respondents		Total
	Female	Male	
Yes	98	101	199
No	68	92	160
Total	166	193	359

reactions as regards to whether VCT before marriage should be mandatory within their religion. As can be seen from table 3.12, a total of 199 respondents felt VCT before marriage should be mandatory while a considerable number of respondents (160 out of 359) felt it should not be mandatory at all citing various reasons.

The respondents who felt that VCT should be mandatory argued that before people enter into marriage they should know their status and plan their future accordingly. On the other hand, respondents with contrary views felt making VCT mandatory would lead to breaking relationships and encourage discrimination in an event that one or both are found positive. It was also added that making VCT mandatory would encourage informal marriages as couples intending to marry may not feel free to disclose their intentions for fear of being asked to test for HIV. Others argued that VCT should not be mandatory because one has the right not to go for HIV test.

Respondents were also asked to state whether couples proceed to marry in an event that one of them is found positive (ref Table 3.13). Again on the understanding that many respondents were not aware of couples who had gone for VCT services before marriage, the research team gave chance to such respondents to

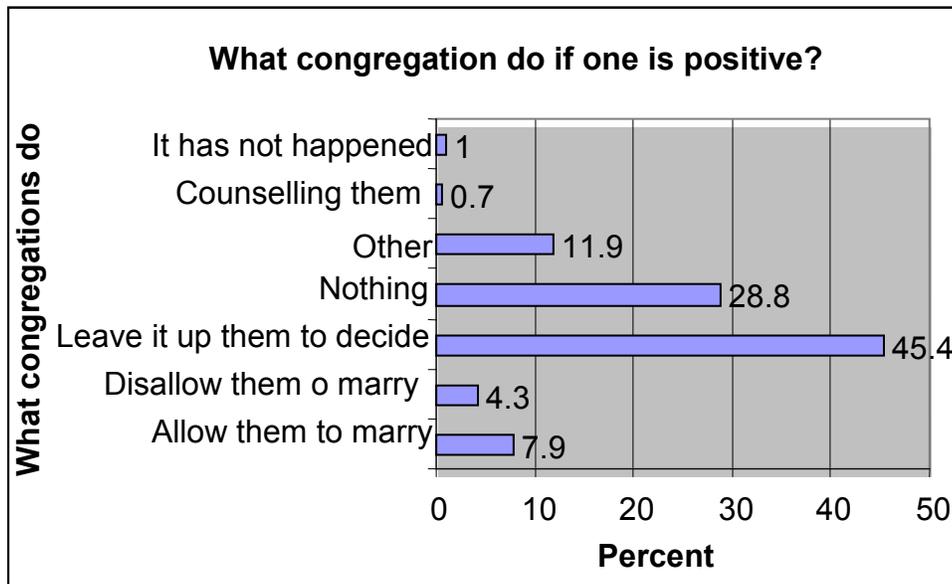
Table 3.13: If one partner tests positive, do they marry?

Do they marry?	Valid Percent (%)
Yes	17.0
No	32.0
Leave it up to them	49.0
Not sure of such scenario	2.0

speculate what they think could happen is one is found positive. Only 17 percent indicated that such couples would proceed to marriage. The majority, close to 50 percent of the respondents, indicated that the decision to marry would rather be left up to them, while 32 percent of the respondents were inclined to say no to marriage if one is found positive.

A key informant in a leadership position in Mangochi reported that within their faith community, couples are discouraged to marry if one of them is found HIV positive. He narrated that *“there is a case where a marriage failed two days to the wedding day because the bride was found positive. We as elders called off the wedding and congregants were on my neck to know why the wedding was called off but we did not disclose the reason”*.

During individual interviews respondents were also asked to describe what the congregations do if one partner is found positive before marriage. The graph below presents a summary of the responses from all the research sites. It is apparent that congregations would either leave it up to them to decide whether to marry or do nothing at all.



During focus group discussions, there were mixed reactions as regards to whether couples should marry if one is found positive after VCT. In Mangochi, the youth felt that if the two are committed and love one another, they may get married. There were some, however, in the same group who felt they should not proceed to marry because this may encourage the spread of the virus. Women participating in focus group discussions reported that they can not get married because the one that is negative would be afraid of infection and give up on such marriage. As indicated earlier, women in Mangochi felt that even if they got married, such couples would not enjoy sex as they may have to use the condom for the rest of their marriage and if they decide to conceive, their children are likely to be infected and not live long.

In Mzimba, a group of youths, just like women respondents in Dowa reported that the partners may proceed to marry if they seriously love each other and insist to do so. In Ntcheu, men reported that the partners may proceed to marry if they seriously love each other although a small segment of the respondents felt it would not be good to marry for fear of infecting one partner.

The respondents were also asked if they knew some couples that had gone for VCT services before entering into marriage within the past twelve (12) months at the time of the research. As can be seen from the table below close to 70 percent⁴ of the respondents did not have knowledge of any couple that had gone for VCT before their wedding.

⁴ The results here need to be interpreted cautiously as this could also be attributed to the fact that people do not just disclose their VCT results anyhow.

Table 3.14: How many couples went for VCT in past 12 months?

No. of Couples who went for VCT	Valid Percent (%)
None (0)	69.8
Between 1 – 5	28.2
Between 6 - 10	1.5
Between 11 - 20	0.8

Different respondents were asked to state what they considered to be reasons why many couples intending to marry do not go for VCT in their various religions. In Mzimba youths reported some couples have perceptions that they already have the virus and therefore it is not necessary to go for VCT while others don't go for VCT because they are confident that they are negative judging from their past lifestyle. Some don't go for VCT because they are afraid of the outcomes especially if they turn out to be positive.

In Dowa, women reported that many people largely fear the outcome – to be tested HIV positive, while others do not go for VCT for fear of discrimination. One of the respondents said *“once you get the virus you become a public shame because of status occupied in society”*. In Ntcheu, men reported that those who have lived a clean past don't find it difficult to go for VCT while those who have lived recklessly in their past life fear that VCT would only confirm their HIV positive status.

In Nsanje, men reported that people are not willing because it is only voluntary while other people are not interested to know their status. They also added that some fear that they will be found positive. One of the men respondents in Nsanje also added that *“others don't go for VCT because of their belief in Christ and the healing power such that if they were converted while positive the virus will disappear with the power of Christ”*.

An interview with a key informant in Mangochi also revealed that others do not go for VCT services because of ignorance of the benefits of VCT while others fear that the results may weaken their faith in some divine healing power.

There was also mention of fear and discrimination as one of the reasons. Some respondents argued that couples do not go for VCT for fear of discrimination and that if found positive, their partner might desert them. This also came out during focus group discussions with PLHAs in Lilongwe who emphasized that people do not go for VCT before marriage for fear of being discriminated against whenever others know about their HIV sero status. All key informants consulted in Mzimba, Dowa, Ntcheu and Mangochi mentioned fear of discrimination as one of the reasons why people do not go for VCT services. This implies that VCT services do not assure some people of confidentiality of the results.

3.4.2 Discordant couples

There is popular opinion that HIV related stigma and discrimination has devastating impact upon discordant couples. In this research, the team explored respondents' knowledge of any discordant couples and how such people are perceived and supported within various religions.

The majority of respondents (76.8 percent) indicated that they did not have knowledge of any discordant couples while 23.2 percent knew some couples within their congregations where one is positive and the other negative. PLHAs interviewed in Lilongwe also indicated that because of lack of self disclosure, they did not know any discordant couples in their respective congregations.

During focus groups discussions, most of the respondents confirmed the findings from individual interviews that many people did not know any discordant couples in their midst. The youth in Mangochi indicated that they had no idea of any discordant couples and they had not seen any such partners in their congregation. A group of men in Ntcheu admitted that it is difficult to tell how the congregation perceives such couples because discordant couples have not come forward to disclose their status.

In Mangochi, however, women indicated that the congregants accept discordant couples like any other members of the congregation. In Nsanje, those that are suspected to be living discordant are accepted. In Mzimba, respondents indicated those suspected to be positive are accepted although some respondents reported that such couples are stigmatized and discriminated against through gossip. In Dowa, women informed the research team that only when the couples disclose that they are in that state, they will be accepted, but when they don't congregants just suspect and continue to talk about their situation which connotes discrimination.

One of the key informants however indicated that the partner who is positive in a discordant marriage is perceived by the faith community as a prostitute and unfaithful to the other partner.

When asked how the respondents themselves perceived discordant couples, there were no traces of discrimination in their answers. In Mangochi, the youth group felt there was nothing strange about such couples; they are just like any other member of their congregation. The women also reported that there was nothing wrong with such couples; all they can do is to stick to the counsel provided during testing. In Mzimba and Dowa, the youth and men respectively indicated that they are seen as any couple without the virus or AIDS.

As regards messages for discordant couples, in Mangochi women reported that they are encouraged not to discriminate against each other. They are also advised to use condoms in their sexual relations. In Mzimba, the faith community offers spiritual encouragement while respondents in Dowa indicated that the faith community preaches messages of acceptance and reconciliation.

Discussions with individuals confirmed the findings from focus group discussions. As can be seen from the table below, the faith community preaches messages of love (29.3 percent), preach against discrimination and encourage acceptance among discordant couples. However, the results also revealed that the faith community in some cases does nothing (34.2 percent).

Table 3.15: Message that faith community give discordant couples

What faith community do	Valid Percent (%)
Preach message of love	29.3
Preach against discrimination	19.4
Encourage acceptance	14.4
Nothing	34.2
Other	2.7

Asked what the faith community does if one of the discordant couples want to divorce, in Mzimba, the youth reported that the church tries to reconcile the two to stay together while in Dowa, women reported that the church provide counselling and stand with this couple in prayers while in Ntcheu, they encourage them to continue loving each other despite their situation.

During individual interviews respondents indicated that the faith community would rather do nothing (38.7 percent) or leave it up to them to decide (29.2 percent) while a small percentage of respondents (4 percent) felt the faith community allows them to divorce if one of the

Table 3.16: If a partner wants to divorce because the other is positive

What the faith community do?	Valid Percent (%)
Allow them to divorce	4.0
Force them to remain in marriage	10.2
Leave it up to them	29.2
Nothing	38.7
Other	15.7
Counselling	0.7
No knowledge	1.5

partners is HIV positive. Slightly above 10 percent felt of the respondents felt the faith community would force them to remain in marriage.

On the question of whether an HIV partner had ever been deserted, the results show that only 14.4 percent of the respondents who answered this question were aware of at least a partner who deserted their HIV positive spouse. Major reasons for deserting partners included fear of infection (74.5 percent), fear of death (19.6 percent) and to a small extent fear discrimination (2.0 percent) and other reasons (3.9 percent).

3.4.3 Orphans

Literature shows that HIV and AIDS has devastating impact on orphans. Joseph Tumushabe (2005) writes extensively that the advent of HIV and AIDS epidemic has seen increased child labour and exposure of AIDS affected children to exploitation and the worst forms of child labour including commercial sexual exploitation. This is also combined with the underlying vulnerabilities in mostly rural African communities to impoverishment which is marked by the danger that destitution and coping strategies will themselves increase social susceptibility to HIV (e.g. through young women resorting to commercial sex work as a survival strategy and many orphans and young adults from AIDS afflicted household migrating in search of elusive jobs in cities where vice and crime are rampant)⁵.

⁵ Tumushabe J., (2005) *HIV and AIDS Epidemic and Emergencies in Africa: Policy Issues Paper and State of the Art Review* Action by Churches Together (ACT) International.

In this section, we turn our focus on the impact of HIV and AIDS related stigma and discrimination on orphans by looking at how orphans due to HIV and AIDS are perceived and the messages that the faith community has for such orphans.

To begin with, respondents in all the districts were asked if they knew any orphans due to HIV and AIDS within their various congregations. The results in the table 3.17 below show that the majority in two districts only (i.e. Dowa and Mzimba, 65.5 and 56.8 percent of all respondents respectively) were aware of orphans due to HIV and AIDS in their congregation. In Ntcheu, only 21.6 percent of respondents interviewed were aware of orphans due to HIV and AIDS while in Lilongwe urban, only 27 percent of the respondents indicated that there were orphans due to HIV and AIDS. In Mangochi and Nsanje, only 31.4 percent and 38.9 percent respectively indicated that they were aware of some orphans due to HIV and AIDS in their congregations.

3.17: Are there any orphans in your congregation due to HIV and AIDS

District	Response	Valid Percent
Dowa	Yes	65.5
	No	34.5
Lilongwe	Yes	27.0
	No	64.9
	Don't know	8.1
Mangochi	Yes	31.4
	No	45.7
	Don't know	22.9
Mzimba	Yes	56.8
	No	34.1
	Don't know	9.1
Nsanje	Yes	38.9
	No	61.1
Ntcheu	Yes	21.6
	No	68.6
	Don't know	9.8

The results shown in the table 3.17 above show that not many people in the faith community know about the existence of orphans due to HIV and AIDS in their midst. A considerable proportion of respondents in Mangochi (22.9) did not know whether orphans due to HIV and AIDS existed within their faith community.

When asked how they knew that some orphans in their congregation were due to HIV and AIDS, most of the respondents indicated that they know through guardians or appearance, self disclosure and rumours. In only one case in Mangochi, a respondent indicated that a religious leaders was the one who disclosed the information.

Having established that people are aware of orphans due to HIV and AIDS, the research team turned its focus on how such orphans are perceived with the faith community. The results, as can be seen from the table below, show that orphans due to HIV and AIDS are accepted and treated just like other orphans. Only few respondents reported that orphans

due to AIDS are perceived as if they will die soon (7 respondents) and are rejected (only 2 respondents).

Table 3.18: How are orphans due to HIV and AIDS perceived in their religions?

How orphans due to HIV and AIDS are perceived	Religion of the respondent and No.				Total
	Christianity	Islam	Rasta	Hindu	
They will die soon	7				7
They are accepted	82	13	3	1	99
They are rejected	2				2

During interview, key informants in Mangochi indicated that orphans due HIV and AIDS are accepted and given material and spiritual support by the faith community. During focus group discussions most of the respondents participating in the discussions indicated that orphans due to HIV and AIDS do not face any discrimination with the faith community.

The respondents however noted that orphans due to HIV and AIDS are ill-treated in the households and at community level. In Mangochi, the youths participating in a focus group indicated that some families treat the orphans well while others ill-treat them by not eating together with them. Women in the same district indicated that some families ill-treat orphans by harsh remarks and shouts like; *“ndinapha makolo ako ndine? – Am I the one who killed your parents?”* In Lilongwe, PLHAs revealed that orphans due to HIV and AIDS are showered with all sorts of accusations and when they grumble, their guardians remarks: *“Ukawadzutse amako kapena atate wako ku manda – you should raise your dead mother or father from the graveyard”*.

In Mzimba, respondents indicated that other orphans face discrimination at household level by not buying them clothes or giving them harder tasks (jobs). In Dowa, respondents reported that orphans due to AIDS are ill-treated by not giving them food. In worst scenarios, they are stopped from attending schools while in Ntcheu it was reported that orphans are generally despised.

Looking at the impact of the ill-treatment that orphans receive at household and community levels, the youths in Mangochi stated that orphans due to HIV ad AIDS start engaging in prostitutions and are also involved in stealing household items in a bid to meet their needs in life. The youth also added that the orphans are psychologically affected as they always live their lives in fear of being reprimanded by their guardians. Women in Mangochi also indicated that orphans due to AIDS end up stealing while young boys start beer drinking and alcohol abuse at a tender age.

In Mzimba, respondents reported that orphans due to HIV and AIDS may engage in prostitution to fend for themselves while others grow thin because of lack of nutritious foods. Other orphans do not look decent because of the lack of clothes. In Dowa, a group of women indicated that orphans grow with evil thoughts (as they scheme ways of retaliating when they grow up). The women also added that the orphans end up deserting their homes and run to urban centres while young girls enter into marriage quite early. In Nsanje respondents added that orphaned children school performance deteriorates as they get occupied with their experiences at household and community level.

From discussions with various groups of respondents the research learned that the faith community preaches messages of love and encouragement. In Mangochi, a group of

women indicated that orphans are encouraged not to lose hope. They are also advised that they should not be interacting with youth with immoral behaviour. The youth indicated that the orphans due to AIDS are encouraged and offered spiritual support. In Nsanje, men indicated that they are encouraged not to lose heart in everything that they do. In Ntcheu, a group of men interviewed indicated that orphans are encouraged to work harder and attend prayers.

4 Silence on HIV and AIDS within Faith Community

The conspiracy of silence is a powerful thing. The first challenge that faith communities face is in naming the truth. Where bishops or clergy have died of AIDS, the faith community has fought to conceal it. Everybody may know that a family member has AIDS, but it still requires courage to admit it in public. Priests and pastors and other religious leaders may fail to face the challenge because they do not know the facts. Above all, the faith community is afraid that in becoming more open and accepting about sexual matters, they will be undermining their commitment to faithful, permanent and trusting human relationships (adapted from Gillian Paterson: undated, *emphasis added*).

There is a popular opinion that the faith community cannot address HIV and AIDS without first breaking the silence on various issues surrounding the epidemic including sex, drug addiction, sin and death. Until this day, lack of knowledge on HIV and AIDS has made people associate AIDS with sin. This association has caused undue suffering to the PLHAs as well as members of their family and friends.

In this chapter, we explore the levels of silence on HIV and AIDS among religious leaders and indeed during religious activities. In doing this, the operational research looks at the sources of information and also examines the frequency of messages concerning HIV and AIDS related condom use, ARVs and VCTs within the faith communities.

4.1 Sources of HIV and AIDS Information

During questionnaire-based individual interviews, the research sought to get respondents views on the prime sources of information on HIV and AIDS issues within the faith community. The questionnaire allowed for multiple responses and table 4.1 presents the findings.

Table 4.1: Sources of HIV and AIDS Information

Source/District	Dowa	Lilongwe	Mangochi	Mzimba	Nsanje	Ntcheu	All
Hospital	46.6	39.3	45.8	41.5	41.3	31.1	40.9
Parents	8.6	4.9	5.1	1.5	9.5	8.2	6.3
Radio	70.2	63.9	78.0	64.6	65.1	59.0	66.8
Teacher	14.0	14.8	15.3	20.0	17.5	14.8	16.1
Peers	12.1	23.0	6.8	18.5	7.9	13.1	13.6
Newspaper	14.0	18.0	5.1	16.9	12.7	10.0	12.1
Church	34.5	14.8	16.9	44.6	39.7	34.4	31.1
Mosque	3.4	1.6	23.7	3.1	-	1.6	5.4
NGOs	15.5	27.9	10.2	26.2	22.2	13.1	19.3

Note: Percentages not adding to 100 because of multiple responses.

The study results show that radio is the most frequently mentioned source of information (66.8 percent) followed by hospital, 40.9 percent. Of the two major religious blocks, the Christian churches seem to be ahead of their Muslim counterpart in providing HIV and AIDS related information to their congregants. The table above shows that 31.1 percent of the respondents mentioned the church as the source of information on HIV and AIDS while only

5.4 percent mentioned the mosques⁶. Other important sources of information as reported by respondents include NGOs (19.3 percent), teachers (16.1 percent), peers (13.6 percent) and newspapers (12.9 percent).

Looking at the results at the district level, the findings for Dowa, Lilongwe, Mangochi and Nsanje reflect the pattern described above where radio tops the list followed by the hospital. In Mzimba and Ntcheu on the other hand, the church takes the second place after radio (44.6 and 39.4 percent respectively) after radio as a main source of HIV and AIDS information.

Among all the districts, the results show that respondents in Lilongwe frequently mentioned peers (23 percent) as sources of HIV and AIDS information more than any other district covered in this research. In Mangochi, a predominantly Moslem district mentioned mosques (23 percent) more than any other district.

Newspapers were also mentioned more in Lilongwe (18 percent) than any other research district. This could be attributed to the fact that the respondents in Lilongwe were drawn mainly from the urban areas.

It is apparent from the results that radio is the number one means of passing on HIV and AIDS information. From the findings, one would easily conclude that the faith community is not doing much to inform people about HIV and AIDS although the majority of the Malawians belong to different religious groups. These findings suggest that there is no sufficient transparency, openness, and in particular, frank discussions about HIV and AIDS within different faith groups.

During focus group discussions, different groups of respondents identified a number of ways through which the faith community can disseminate HIV and AIDS information. These included the following:

- Preaching sermons during prayers where HIV and AIDS can be addressed
- Sensitising and mobilising congregants to abstain from sexual activity to avoid contracting the virus
- Preaching and encourage messages of love
- Visiting those infected and affected by HIV and AIDS
- Providing material and spiritual support
- Establishing HBCs and groups to specifically address HIV and AIDS

4.2 Frequency of HIV and AIDS related Messages

To establish the level of silence, respondents were also asked to mention how frequently issues related to HIV and AIDS, condom use, ARVs, VCT as well as stigma and discrimination had been addressed within the faith community. The respondents were asked to recall the frequency of HIV and AIDS related messages during the past six months in their faith communities and religious gatherings. Respondents were asked to rate on the scale of

⁶ Please note that the responses on the faith community as the sources of information could be biased towards churches as only 50 of the respondents were Moslems against 301 Christians.

frequency as follows; every day, once a week, once a month, less than once a month to never talked about the issue in question.

4.2.1 Messages on HIV and AIDS

Close to third of the respondents (32.4 percent) recalled that there were discussions around the facts of HIV and AIDS less than once a month while 30.2 percent of respondents recalled that HIV and AIDS was mentioned within their faith community once a month. Slightly close to 24 percent revealed that there was not a single moment when HIV and AIDS was discussed in their congregations.

Quite small proportions of respondents (12.6 percent and 1.1 percent) recalled that HIV and AIDS were mentioned that once a week and every day respectively in the past six months. If these findings are anything to go by, it can be concluded that facts about HIV and AIDS are not being discussed adequately within the faith community.

The results at district levels are equally unimpressive. In Dowa 27.6 percent of the respondents recalled that HIV and AIDS was being mentioned once a month, while in Mzimba 38.5 percent recalled that there were discussions within their faith community once a month. In Nsanje, 34.9 percent of the respondents interviewed indicated that talking HIV and AIDS was also mentioned at least once a month. In Lilongwe 35 percent of respondents reported that HIV and AIDS were mentioned less than once a month while in Mangochi, 32.2 percent of the respondents recalled discussions on HIV and AIDS in just under a month. In Ntcheu, a total of 42.4 percent of respondents indicated that HIV and AIDS were mentioned less than once a month.

Overall results show that 32.8 of all the respondents reported that HIV and AIDS facts are never discussed in their respective congregations. This is followed by a relatively small proportion (28.4 percent) of respondents who indicated that HIV and AIDS is mentioned once a month in their congregation while 25.6 recalled that HIV and AIDS was mentioned less than once a month. Only 12.4 percent of respondents indicated that HIV and AIDS facts are discussed once a week.

The findings at district level show that in each district very small proportions of respondents (ranging between 0 to 3.4 percent) recalled that there was mention of HIV and AIDS every day while between 6.8 to 23.1 percent indicated that there are HIV and AIDS discussions once a week. Between 25.4 to 33.3 percent indicated that they get HIV and AIDS related facts once a month. Between 22.4 and 40.7 percent of the respondents revealed that HIV and AIDS was never talked about within their faith community.

4.2.2 Messages on condom use

The majority of respondents (72.3 percent) in all the districts visited indicated that condom use was never discussed within their faith community. Only a small proportion of 13.2 percent indicated that there were discussions on condom use in less than once a month, while 9.6 percent indicated condom use was mentioned once a month. An even small proportion (4.1 percent) of the respondents reported that there was mention of condom use

at least once a week. One person only out of 368 respondents said that condom use is discussed every day.

While all other districts had higher proportions of respondents who felt condom use is never discussed, Mzimba had the highest proportion of respondents (75.4 percent). This confirms the popular opinion that condom use is the most shunned topic when it comes to HIV and AIDS discussions.

4.2.3 Messages on ARVs

The proportion of the respondents who reported that ARVs are generally not discussed within the faith community is still higher (39 percent). A total of 26.8 percent of the respondents had a contrary opinion. They recalled that ARVs are discussed at least less than once a month while 24 percent indicated that ARVs are mentioned once a month. An even smaller proportion of respondents (9.9 percent) indicated that ARVs are discussed once a week within their faith community.

There are indications that ARVs are never mentioned in the religious gatherings, the findings as shown by 44.4 percent of the total respondents. The highest proportion of respondents (62.7 percent) in Lilongwe reported that ARVs are never discussed followed by Ntcheu 52.5 percent. Considerable proportions in Nsanje (39.7 percent), Mangochi (39 percent) and in Dowa (37.9 percent) reported that ARVs are never discussed.

A closer look at the findings shows that proportion of respondents who reported that ARVs are never discussed in religious gatherings is more than the total of those who reported that ARVs are discussed either every day or once a week and once a month.

4.2.4 Messages on VCT

Close to a third of respondents (32.2 percent) of all respondents reported that VCT is never mentioned within the faith communities while 29.5 percent reported that VCT is discussed less than once a month followed by 27 percent of respondents who indicated that VCT issues are discussed once a month. An even small proportion of respondents (10.7 percent) reported that it is mentioned at least once a week.

At the district level, the results in Mzimba and Nsanje (32.3 and 38.1 respectively) show that VCT is mentioned at least once a month. In religious gatherings, only 10.8 percent recalled that VCT is discussed once a week while an equally larger proportion 44.4 percent felt VCT is never discussed. The results also show all the districts except Nsanje had the proportion of respondents' percentages reporting that VCT is never discussed within religious gatherings. For example Dowa, the never category pulled the highest proportion of respondents 33.3 percent while Lilongwe had 50.8 percent of the respondent saying VCT is never discussed.

4.3 Levels of Silence among Religious Leaders

Respondents were also asked to list down different groups within the faith community who take part the dissemination of HIV and AIDS information. The predetermined lists included the clergy, elders, group leaders, congregants, peers and other visiting speakers or preachers. Table 4.2 below presents the findings.

Table 4.2: Involvement of Different groups in HIV and AIDS Information Dissemination

Group/District	Dowa	Lilongwe	Mangochi	Mzimba	Nsanje	Ntcheu	All
Clergy	46.9	39.7	68.5	70.8	75.9	57.1	60.1
Elders	42.9	29.8	27.8	23.1	31.5	39.3	31.9
Group leaders	40.8	19.0	22.2	24.6	29.6	33.9	28.0
Congregants	28.6	8.6	3.7	4.6	1.9	16.1	10.1
Peers	24.5	22.4	7.4	9.2	5.6	19.6	14.6
Visiting Speakers	12.2	10.3	3.7	1.5	-	-	4.5

Note: Percentages not adding to 100 because of multiple responses.

From the table above it can be seen that the clergy were mentioned frequently (60 percent) as the ones who are involved most in the talk about HIV and AIDS issues within the faith community. The religious elders (31.9 percent) were also recognised by respondents as the group which tackles issues of HIV and AIDS within the faith community. Group leaders (for example chairperson of the youth or men and women groups) were also mentioned by a considerable proportion of respondents. The results also show that visiting speakers were not fond of tackling HIV and AIDS as only 4.5 percent mentioned them.

Looking at the data at district level, the results show that the clergy were more frequently mentioned in Nsanje (75.9 percent), Mzimba (70.8 percent) and Mangochi (68.5 percent). The least mentioned groups in all the districts are the visiting speakers, peers and congregants who are perceived to be relatively quite as regards dissemination of HIV and AIDS related information within the faith community.

When senior clergy make visits to congregants at grassroots it offers them an opportunity to address HIV and AIDS related issues even from an advantageous position. The influential position of the senior clergy can have a tremendous impact upon the faith community to start opening and discuss issues around the HIV and AIDS epidemic. Respondents in the study were asked to state if senior clergy visited them in the last six months specifically to address issues of HIV and AIDS.

Only 31.2 percent of the respondents accepted that their senior clergy made visits in the last six months to talk about HIV and AIDS while 68.8 denied having been visited. The visits were made mainly by pastors/reverends (46.6 percent of the respondents), sheiks as mentioned by 13.7 of the respondents and bishops (9.2 percent).

During their visits, respondents indicated that that the senior visiting clergy addressed issues related to abstinence, VCT, support to PLWHA, condom use, ARVs and mutual faithfulness.

When asked whether they felt religious leaders were sufficiently addressing HIV and AIDS issues, 54.3 percent of respondents felt religious leaders are sufficiently talking about HIV and AIDS. Religious leaders were reported to be addressing HIV and AIDS issues as they talk about the issues frequently. Key informants reported that they were satisfied because of the establishment of home based care initiatives and various HIV and AIDS programmes run by the faith community such as Livingstonia Synod Aids Program [LISAP].

The respondents who felt religious leaders are not adequately talking about HIV and AIDS said that the leaders do not address the issues sufficiently (43.4 percent) and they do not talk about the issues at all (31.3 percent). The dissatisfaction also came because other respondents noted that leaders talk about the HIV and AIDS only during special occasions (12.6 percent) and that the religious leaders do not know the seriousness of the problem (6.1 percent).

On the contrary though, various focus group discussions revealed that religious leaders do not sufficiently address the HIV and AIDS issues. Many reasons were cited. In Mangochi the youth noted that the message for worship service is in Arabic and it is difficult for the clergy to divert to address issues of AIDS. In Dowa, the respondents felt the messages of HIV and AIDS are mentioned in passing by the clergy. In Ntcheu, only Sheikhs were reported to be talking about such issues while the rest of the congregation do not. In Nsanje, respondents felt religious leaders do not sufficiently address issues because the religious leaders are not free to talk about HIV and AIDS in a mixed age groups congregation.

As regards the members of various congregations, the findings show that 49.7 percent reported that the congregants talk sufficiently while 50.3 percent were not satisfied. The respondents who were satisfied felt congregants address HIV and AIDS issues (46.4 percent), 45.6 percent of respondents felt congregants talking frequently, while 31.9 percent or respondents were happy that congregants talk about HIV and AIDS in every gathering.

Respondents with contrary opinion stated that congregants do not talk about HIV and AIDS at all (40.2), while others felt congregants do not address HIV and AIDS issues (29.3 percent) but speak only during special occasions.

4.4 Levels of Silence in Religious Activities

The respondents were asked to mention the religious activities which are used to provide space for discussions on HIV and AIDS issues. The results of the findings are presented in the table 4.3 below.

Table 4.3: Religious fora to provide space for HIV and AIDS Discussions

Religious activity/District	Dowa	Lilongwe	Mangochi	Mzimba	Nsanje	Ntcheu	All
Prayer Service	65.3	50.9	65.3	47.7	85.4	67.9	62.6
Group Meetings	56.3	35.1	55.1	56.3	45.8	44.2	48.7
Community prayers	12.2	10.5	10.2	3.1	8.3	9.6	8.8
Wedding functions	6.1	5.3	-	4.7	2.1	1.9	3.4
Funerals	4.1	1.8	-	4.6	-	-	1.9
Initiation ceremonies	-	3.5	-	1.5	-	1.9	1.3
Sunday school/madrassah	6.1	3.6	4.1	1.5	-	5.9	3.5

Note: Percentages not adding to 100 because of multiple responses.

Prayer services were the most frequently mentioned forum (62.6 percent) followed by groups' meetings (48.7percent) such as women, men or youth groups meetings. There were no indications that small community prayers, wedding functions, funeral services, initiation ceremonies and Maddrassah/Sunday schools were being utilised for discussion on HIV and AIDS issues.

For example, none of the respondents interviewed mentioned any of the following religious activities: initiation ceremonies in Dowa, weddings, funerals and initiation ceremonies in Mangochi and funerals as well as initiation ceremonies and Sunday school in Nsanje. This implies that while there are many religious activities that could potentially provide space for discussing HIV and AIDS issues; prayer sessions are the only ones that are used by the faith community at the moment. There may be need to explore use of such other church gatherings and activities to ensure information sharing among the religious peers.

During focus group discussions, respondents also added the following religious activities were being used for disseminating HIV and AIDS related information:

- Prayer services or during worship sermons(mentioned in Mangochi, Ntcheu, and Nsanje)
- Group (youth, men, women) meetings mentioned in all districts visited except Lilongwe
- In Home Based Care (HBCs) mentioned in Nsanje
- In Lilongwe, the PLHAs reported there are no fora created by the religions to talk about HIV and AIDS issues.

4.4.1 Disclosure of HIV and AIDS Status

During focus group discussions, respondents were also asked if people within their congregants are free to disclose their sero status. The following presents a summary of findings from different districts visited.

- In Mangochi, the Youth indicated that people are not free because there is no opportunity / fora for disclosure. The youth felt the religious groups are not even interested whether one discloses or not. The women, however, contradicted the youth and indicated that the people are free to disclose their status.
- In Nsanje, respondents indicated that people are not free to disclose because of fear of discrimination. However, it was noted that people are only free to disclose their status if there are immediate benefits for disclosure like material supplies (food, clothing etc). This usually happens when NGOs and the faith community are on promotional campaigns.
- In Ntcheu, respondents indicated that congregants are free to disclose their status
- In Dowa, respondents indicated that people are not free to disclose especially if they are positive because they are afraid of being discriminated against. This was also echoed in Mzimba, where respondents indicated that people are not free to disclose especially if they are positive because they are afraid of being discriminated against.
- In Lilongwe, respondents felt people are not free to disclose because they are not given an opportunity to do so in their congregations.

5 Strategies to Combat Stigma and Discrimination

A wide range of actors have come together to take up the challenge of confronting the HIV and AIDS crisis head on. However, the biggest challenge that remains to be overcome is that of HIV and AIDS related stigma and discrimination. As indicated earlier in this report, stigma is of urgent concern because it is both the cause and effect of secrecy and denial, which in turn are the primary preconditions for rapid HIV transmission. Moreover, it adversely affects care for people living with HIV and AIDS (PLHAs), who frequently become isolated in their communities.

By 2000 the urgency of dealing with stigma was re-stated by Peter Piot, Executive Director of UNAIDS, when he remarked that it was the most important task in fighting the global HIV and epidemic. Piot's insistence on this point bore fruit in the theme of the 2002-2003 World AIDS Campaign: the reduction of HIV/AIDS-related stigma and discrimination (Global AIDS Interfaith Alliance, 2005).

Having considered the issues of stigma and discrimination as well as silence on HIV and AIDS within the faith community, the operational research looked at strategies involving different groups within the faith community to combat stigma and discrimination. The following sections outline a summary of responses from different groups regarding strategies to combat stigma and discrimination within the faith community.

5.1 Religious Leaders

Literature shows that in the fight against stigma and discrimination, it is beneficial to involve religious leaders for a number of reasons: religious leaders (at various levels within the faith community) are recognised by the community and can give encouragement to members of their congregations; they often have links to other faith communities, organisations and people in positions of responsibility in the community, and links to networks at the national level; and more directly, religious leaders are responsible for preaching sermons on worship days and have an important role in teaching about issues related to HIV and AIDS.

The discussions with various respondents validate the importance of religious leaders' participation in the fight against HIV and AIDS related stigma and discrimination. In this section, we provide a summary of findings that need to be considered when developing strategies to combat stigma and discrimination at leadership level.

Table 5.1: What religious leaders should do

District	What religious leaders should do to Curb Stigma and Discrimination	Valid Percent (%)
Lilongwe	Speak about discrimination frequently	14.6
	Encourage participation of those infected	8.3
	Promoting message of love	39.6
	Promote acceptance	14.6
	Discourage discrimination	14.6
	Civic education	6.3
	Desist from immoral behaviour	2.1

The results in the table above show that most of the respondents were in favour of religious leaders promoting messages of love (39.6 percent). Speaking about discrimination

frequently, promoting general acceptance of PLHAs and discrimination were equally considered appropriate strategies for combating stigma and discrimination. From the results shown in the table above, encouraging people to desist from immoral behaviour was not considered as one of the best strategies to combat stigma and discrimination among the respondents within the urban setting.

During focus group discussions with PLHAs, the respondents felt that senior religious leaders need to encourage VCT, promote messages of love and emphasise on awareness campaign in issues related to stigma and discrimination. The group of PLHAs interviewed also noted that most senior Reverends and Pastors from different churches do not attend AIDS related meeting organised by PLHAs. They usually send their representatives which deny the religious leaders relevant information on how to combat HIV and related stigma and discrimination.

Just like in Lilongwe, most of the respondents in Dowa were in favour of religious leaders promoting messages of love and speaking about discrimination frequently (45.1 percent) as a strategy to curb the spread of HIV and AIDS. From the results in the table below, speaking about discrimination frequently was also considered as the second best strategy (31.4 percent) in Dowa.

Table 5.2: What religious leaders should do – Results from Dowa

District	What religious leaders should do to Curb Stigma and Discrimination	Valid Percent (%)
Dowa	Speak about discrimination frequently	31.4
	Encourage participation of those infected	2.0
	Promoting message of love	45.1
	Promote acceptance	7.8
	Civic education	13.7

The results for Dowa show that encouraging the participation of those infected is not one of the strongest strategies amongst the respondents interviewed during the operational research.

The results in Mangochi were quite contrary to the findings in Dowa. In Mangochi, respondents (32.1 percent) felt religious leaders need to encourage the participation of those infected with HIV. Civic education in issues related to stigma and discrimination came second (23.2 percent).

Table 5.3: What religious leaders should do – Results from Mangochi

District	What religious leaders should do to Curb Stigma and Discrimination	Valid Percent (%)
Mangochi	Speak about discrimination frequently	12.5
	Encourage participation of those infected	32.1
	Promote acceptance	7.1
	Discourage discrimination	17.9
	Civic education	23.2
	Associate with PLHAs	7.1

During focus group discussions, the youth in Mangochi said as a strategy, senior sheiks should be involved in preaching against stigma and discrimination. They also added that

sheiks should also be exemplary by visiting PLHAS and orphans due to HIV and AIDS while women indicated that sheiks should preach messages of love and should always give talks to discourage stigma and discrimination at places of worships. Women also indicated that sheiks should encourage VCT and disclosure of HIV status as some of the strategies to curb stigma and discrimination.

In Mzimba, close to half of the respondents interviewed prioritised the promotion of messages as the best strategy to combat stigma and discrimination. Quite contrary to the findings in Mangochi, in Mzimba the respondents did not find encouraging the participation of those infected with HIV and AIDS to be a relevant strategy.

Table 5.4: What religious leaders should do – Results from Mzimba

District	What religious leaders should do to Curb Stigma and Discrimination	Valid Percent (%)
Mzimba	Speak about discrimination frequently	12.7
	Encourage participation of those infected	1.6
	Promoting message of love	49.2
	Promote acceptance	7.9
	Discourage discrimination	14.3
	Civic education	14.3

During focus groups discussions in Mzimba, respondents recommend that religious leaders should lead by example by living together with PLHAs and also involve PLHAs in religious activities.

In Nsanje, the respondents interviewed felt religious leaders need to encourage participation of those infected (38.3 percent) and speak about discrimination frequently (36.7 percent).

Table 5.5: What religious leaders should do – Results from Dowa

District	What religious leaders should do to Curb Stigma and Discrimination	Valid Percent (%)
Nsanje	Speak about discrimination frequently	36.7
	Encourage participation of those infected	38.3
	Promote acceptance	11.7
	Civic education	13.3

During focus group discussions, the respondents corroborated the findings from the individual interviews in Nsanje. During focus group discussions, respondents recommended that religious leaders should preach against discrimination.

In Ntcheu, half of the respondents interviewed felt promoting messages of love was the best strategy for religious leaders to combat HIV and AIDS related stigma and discrimination. They also felt discouraging stigma was one of the best strategies to curb stigma and discrimination. The results also show that speaking about stigma frequently and civic education were not considered as best strategies among the respondents interviewed. During focus group discussions, respondents in Ntcheu recommend that religious leaders should encourage PLHAs not to lose heart and visit them regularly.

Table 5.6: What religious leaders should do – Results from Ntcheu

District	What religious leaders should do to Curb Stigma and Discrimination	Valid Percent (%)
Ntcheu	Speak about discrimination frequently	1.7
	Encourage participation of those infected	3.4
	Promoting message of love	50.0
	Promote acceptance	8.6
	Discourage discrimination	34.5
	Civic education	1.7

5.2 People Living with HIV and AIDS

There is a popular opinion that any effective HIV and AIDS intervention requires mainstreaming stigma eradication strategies into all interventions – something that cannot be achieved without forming partnerships with PLHAs and greater participation of people living with AIDS (GIPA). Further, the pervasiveness of HIV-related stigma underlines the fact that all groups and organisations responding to the epidemic need to be in partnership with PLHA organisations.

During focus group discussions respondents indicated that PLHAs should be encouraged to avoid self discrimination and participate in various activities. In Mzimba, the respondents emphasised that PLHAs should associate with others. In Dowa, respondents also indicated that PLHAs should associate with others and also recommend that PLHAs should involve themselves in counselling of their colleagues so that are not isolated.

In Nsanje, the group of men interviewed felt that PLHAs should involve themselves in activities taking place in their communities and that they should associate with others. In Ntcheu, respondents also emphasised that PLHAs should socialise with others while in Mangochi the youth group recommended that PLHAs should not discriminate themselves. In the same district, a group of women interviewed felt that the PLHAs should participate in all activities in their faith communities. The women group in Mangochi also added that PLHAs should also be free to disclose their HIV status.

The tabulation of results (as shown in the table below) regarding what PLHAs should do to curb stigma and discrimination corroborate the main findings from focus group discussions which indicate that PLHAs should avoid self discrimination.

Table 5.7: What PLHAs should do

What PLHAs should do to Curb Stigma and Discrimination	Percent of
Avoid self discrimination	51.4
Involve themselves in counselling activities	23.9
Participate in religious activities	18.5
Promote messages of love	21.3
Encourage VCT and voluntary disclosure of HIV status	12.1

Please note: The percentage recorded in the table reflects the proportion of respondents who responded positively on the listed strategy and does not necessary add up to 100.

As can be seen from the table above, results from the individual interviews show that respondents did not find encouraging VCT and self disclosure of HIV status as one of the best strategies to be adopted by PLHAs to curb stigma and discrimination.

5.3 Congregants

Turning to congregants, most of the respondents interviewed during focus group discussions made various recommendations as regards to what needs to be done by congregants to curb the spread of HIV and AIDS related stigma and discrimination within their faith community.

In Mangochi, the youth group interviewed recommended that congregants should come up with groups which should teach the rest of the faith community on the disadvantages of stigma and discrimination. They also added that congregants should be involved in counselling the PLHAs apart from accepting and socialising with the PLHAs. In the same district, a group of women felt that the congregants should be involved in home based care (HBC) to reduce the suffering of those affected by the disease. Women in Mangochi also indicated that congregants should also involve PLHAs in religious activities.

In Dowa, respondents recommended that congregants should be involved in visitation of the people infected and affected by HIV. They also added that congregants should be trained in home based care (HBC) to ensure proper treatment and support for PLHAs. In Mzimba, respondents felt that congregants should be encouraged to visit the PLHAs apart from involving them in church and other usual activities in their communities.

In Nsanje, however, a group of men observed that congregants cannot do anything on their own as decisions on what the congregation can do are dictated by senior religious leaders. In line with this observation, the group of men interviewed recommended that religious leaders to provide guidance to their congregants on what they can do to curb HIV and AIDS related stigma and discrimination.

6 Key findings, Recommendations and Conclusion

This chapter presents a summary of the main findings of the research and recommendations based on the analysis of the research findings, impressions from the discussions held with different groups of people in six districts in Malawi and the review of literature.

6.1 Main Findings

6.1.1 Manifestation of stigma and discrimination within faith community

Discussions with various groups of respondent create an impression that the majority of congregants are not ready to admit that stigma and discrimination against people infected and affected by HIV and AIDS exists within their midst. To begin with, the majority (two in every three respondents) report that they do not know people living with HIV in their congregations. Secondly, people who go for VCT, closely guard their results and disclosure of the HIV tests results within the faith community is not a common phenomenon, while a considerable number of respondents felt they could easily disclose their HIV status, against the background that less than half of the respondents had gone for VCT. Further, an overwhelming majority of respondents (88 percent) paint a picture that those who disclose their HIV status are accepted and shown love within faith community.

On the contrary, though, the results show some traces of the existence of stigma and discrimination within the faith community, which prompts the research to conclude that stigma and discriminations is practiced in the background and one has to dig deep to lay bare the associated practices and behaviours.

- There were reports that those perceived to be HIV positive are relegated to less visible functions in the faith community. They are not allowed to preach and even serve food.
- Incidences of stigma and discrimination are not wide spread on the surface, but existed and manifested in the language and labelling of people living with HIV. PLHAs are also frequently subjected to insults and abusive language

6.1.2 Causes of stigma and discrimination within faith community

A number of factors are also identified to be perpetrating stigma and discrimination within the faith community.

- Generally, lack of information and understanding of the causes and symptoms of HIV and AIDS can not be divorced from the factors perpetrating stigma and discrimination within the faith community. Within the faith community, HIV and AIDS is seen from a narrow perspective of immorality and being sinful, thus divorcing from the debate of HIV and AIDS the vulnerability to HIV infection by disparities in power that are a product of gender imbalances, age differentials, abuse of authority, physical power and violence, and economic power, which all affect individual agency and thereby influence how and when sex occurs.

- The faith community has also not done much to create a forum or take advantage of other activities to allow open discussions on HIV and AIDS related stigma and discrimination, thus perpetrating the culture of silence with the faith community. This gives rise to an environment where myths and stereotypes that surround the disease and these flourish and in turn, incite irrational fears and anxieties linked to association and contact with people who are or thought to be infected.
- Associated to the observation made above is the failure of the faith community to involve PLHAs in the religious activities. The faith community has forced PLHAs into the background and the community sees nothing good coming out of PLHAs. Discussions on such issues as ARVs, VCT, stigma and discrimination are not common and frequent within most congregations.
- Religious leaders are not sufficiently equipped to deal with HIV and AIDS within their congregations. There were no clear policies to guide the religious leaders on how to address HIV and AIDS within their midst thus giving rise to confusion and the implementation of *ad hoc* decisions which in some instances are contradictory and perpetrate stigma and discrimination particularly in dealing with issues of VCT before marriage, self disclosure and supporting discordant couples as well as orphans due to HIV and AIDS.
- Theological orientations and practices which give rise to messages that understanding that HIV and AIDS is a punishment to those with immoral behaviours places the faith community on the path of 'judgementalism' which give rise to the classification of congregants thereby nurturing stigma and discrimination. While religion and spirituality usually provide a source of comfort and solace for PLHAs, religious theological orientations and teachings often contribute to the culture of 'blaming' PLHAs by the association made between sex and immorality. In some cases, messages referring to people with HIV are known to have carried demeaning and negative expressions and sentiments.

6.2 Recommendations⁷

The recommendations that follow are cast in light of the literature review as well as the findings and place emphasis is placed on what MIAA together with its key stakeholders should do to address stigma and discrimination within the faith community.

- The provision of accurate, unbiased information about HIV and AIDS is generally agreed to be the most critical first step in addressing stigma and discrimination. The faith community is best placed to fulfil this function because of the respect and trust religions enjoy from the communities in which they operate and their moral authority within society as a whole. There is need to identify ways to ensure frequent and regular provision of HIV and AIDS related information to the congregants in a manner that dispels myths, fears and anxieties on various issues related to ARVs, VCT, stigma and discrimination.

⁷ Please note that in order not to overburden this section, recommendations made by the respondents for religious leaders, congregants and people living with HIV, to combat stigma and discrimination, are presented in the preceding chapter.

- Religious leaders have enormous influence on how people think. There is need therefore for sensitisation and training, including guidance on acceptable terms for referring to PLHAs that specifically target religious leaders. There is also need to train religious leaders in general on the theology of sickness so that people have an understanding on how to relate with sick people. This would also help in relating religious teachings to sickness in general in a manner that is positive and not discriminatory as well as stigmatising.
- Despite development and processes at global level that embrace the principle of equal rights for PLHAs and oppose all forms of discrimination on the grounds of HIV and AIDS status, in practice the faith community in Malawi seems to be lagging behind to introduce relevant policies and mechanisms for countering forms of stigma and discrimination. Thus, there is a need for the faith community to introduce such policies within the faith community to strengthen and reinforce national action frameworks.
- Literature indicates that promoting the role of PLHAs themselves in developing and implementing strategies for reducing stigma and discrimination, including self-stigma by PLHAs is one of the best strategies. PLHAs have played a significant role in educating the public on what it means to live with HIV and AIDS, and the need for people to be compassionate towards PLHAs. They have also helped to give HIV and AIDS a human face, bringing it closer to the minds of people. There is need, therefore, for the faith community to identify activities which provide a platform for PLHAs to make their voices heard.
- The NAF in Malawi identifies the importance of greater involvement of people living with AIDS. There is need for the faith community to network and associate with PLHAs to help to increase the self-confidence and enhance the self-image of PLHAs, both as a group and as individuals.
- In developing the strategies to combat HIV and AIDS related stigma and discrimination, there is need to address the gender dimension, which has been covered to some extent in the review of literature (which has not come out clearly in the main findings). In line with the NAF in Malawi, there is need ensure that faith community accord women and girls regardless of marital status or HIV sero status equal access to appropriate sound HIV-related information and education, means of prevention and health services. The faith community need also to take a look and protect the rights of women to have control over and to decide responsibly on their sexuality, including sexual and reproductive health, free of discrimination or coercive violence from theological interpretations.
- Both the NAF and the World Council of Churches are calling for the theological transformation and practices. For purposes of emphasis this is repeated here. The World Council of Churches *emphasize the need to break the silence, doing so from the pulpits of mosques, churches, educational institutions, and all the venues in which the faith community may be called to speak. The council rejects and emphasize the necessity to abolish all forms of discrimination, isolation, marginalization, and stigmatization of people living with HIV and AIDS and insist on defending their basic freedoms and human rights*". This to a large extent call for the training pastors, priests, lay leaders on the concept of the "Theology of Hope" and counselling using the concept.
- This list of recommendations would not be complete without placing emphasis for the faith community to produce a set of guidelines for stigma-mitigation interventions. As

reported in the review of literature, the DFID/Futures Group (2005) indicates that the Siyam'kela Initiative, led by the Policy Project to explore aspects of HIV and AIDS related stigma in South Africa, produced a set of guidelines for faith based organisations wishing to develop stigma-mitigation interventions based in part on focus groups and interviews with faith leaders, faith community members and PLHAs. We reproduce here a selection of the recommendations:

- Guidelines should be developed to assist faith leaders and religious communities to deal with HIV and AIDS in faith settings, including managing disclosure and protecting the confidentiality of HIV-positive people who have chosen to disclose;
- Anti-discrimination and stigma mitigation approaches should be mainstreamed into various aspects of religious practice through policy
- Religious leaders should be trained to contribute effectively to anti-stigmatisation activities, including greater sensitisation to how stigma develops and is experienced within faith communities
- HIV and AIDS stigma mitigation interventions should be driven and monitored by religious leaders who should also ideally be the 'face' of anti-stigma campaigns and be actively and directly involved in interventions
- Anti-stigma interventions should be built upon local-level stigma assessments that gauge the extent of the problem, identify local barriers to stigma mitigation, and recognise factors contributing to stigma reduction
- Anti-stigma messages should emphasise tolerance and should employ positive and inclusive language, and should focus on risk behaviours rather than risk groups

6.3 Conclusion

The review of literature in this research has highlighted the fact that overcoming HIV and AIDS is challenged by the epidemic of stigma, discrimination, and denial as it perverts concerted action at community, national, and global levels. It makes prevention difficult by forcing the epidemic out of sight and underground.

The findings reveal contradictions in the understanding of respondents both in relation to the existence of stigma and discrimination and practices of the religious groups with respect to HIV and AIDS related stigma and discrimination. There is an apparent tendency among respondent to sweep under the carpet the manifestation of stigma and discrimination within the faith community with very few exceptions in the districts visited. Stigma and discrimination within the faith community is perpetrated by fear and ignorance, compounded by religious norms and values, which give no room for discussions and self-disclosure of HIV status.

The current research has not endeavoured to unpack the gender dimension of stigma and discrimination, but this is something that needs to be looked at in detail in the analyses at individual faith community level, particularly as part of formulating the stigma and discrimination interventions. From discussions with various respondents, a number of strategies are proposed for tackling the problem, ranging from promoting messages of acceptance, providing counselling to PLWHA, discouraging discrimination, preaching messages of love and encouraging VCT and voluntary disclosure of HIV status.

A number of recommendations have been developed, but they do not address all the problems associated to stigma and discrimination and much still remains to be done, particularly at individual and faith community level. The current research provides some answers and some form of framework for subsequent activities in the fight against stigma and discrimination within the faith community.

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Annexes

Terms of Reference for Conducting the Operational Research

1.0 Background

The Malawi Interfaith AIDS Association (MIAA) is an inter-religious umbrella body whose overall objective is to facilitate and coordinate a united commitment of faith communities in the fight against HIV and AIDS. MIAA has received funding from Norwegian Church Aid to among other activities, carry out an operational research. The operational/action research is aimed at facilitating the faith communities' response to the HIV and AIDS pandemic in the country.

MIAA would like, therefore to commission an operational research on the topic 'HIV/AIDS related stigma and discrimination being perpetrated within the faith community in Malawi'.

1.1 Objective of the Consultancy Work

To conduct an operational research that will unveil HIV/AIDS related stigma and discrimination being perpetrated within the faith community in Malawi. The research will also explore voluntary counselling and testing before marriage from the faith perspective as it relates to stigma and discrimination.

1.2 Scope of the assignment and responsibilities

The consultant(s) will visit 6 districts, Mzimba, Lilongwe, Dowa, Ntcheu, Mangochi and Nsanje. The primary responsibilities will include the following:

- 1.2.1 Conduct literature review of relevant documents
- 1.2.2 Design appropriate survey methodology (in a manner that is participatory) and sampling for the survey
- 1.2.3 Present the survey methodology and sample to the MIAA programme management team
- 1.2.4 Investigate the nature, magnitude and causes, among others of HIV and AIDS related stigma and discrimination being perpetrated within the faith community in Malawi
- 1.2.5 Establish the levels of silence in the faith community associated with HIV and AIDS
- 1.2.6 Determine the most effective ways of rooting out/dealing with stigma and discrimination from within the faith community
- 1.2.7 Establish the impact of the stigma and discrimination on voluntary counselling and testing before marriage from the faith perspective
- 1.2.8 Establish the impact of stigma and discrimination on discordant couples and children orphaned by AIDS
- 1.2.9 Analyse the data systematically and produce draft report on findings
- 1.2.10 Provide appropriate recommendations based on the findings of the survey
- 1.2.11 Presenting the results of the survey to the programme management team and key MIAA stakeholders.
- 1.2.12 Incorporate comments from the programme management team on draft report to produce final report

1.3 Expected output

A report on the findings is expected within 30 calendar days from the commencement of the assignment. The consultants shall submit a hard and electronic copy of the report to MIAA.

Research sites

The management team proposes the following sites:

- Mzimba district
- Dowa
- Mangochi
- Nsanje
- Lilongwe
- Ntcheu

This selection has taken into consideration a diversity of socio-cultural beliefs and practices, geographical representation, and religious dominance i.e (Moslems, Christians)

Respondents

At national level

Top religious leaders as key informants

- ✓ 1 from each mother body
- ✓ 1 from seventh day
- ✓ 1 from CHAPEL

In each district the following respondents should be reached

1. Key informants

- ✓ 1 church Pastor (from mainline churches eg CCAP, Anglican, Zambezi etc)
- ✓ 1 Moslem Sheikh
- ✓ 1 Catholic Priest
- ✓ 1 leader from other faiths eg Hindu, Rastas, Traditional church etc
- ✓ 1 pastor from Pentecoastal and Charismatic churches
- ✓ 2 marriage counsellors (1 from the Moslem and 1 from the Christian side)
- ✓ 2 traditional leaders(Group village heads)

2. Questionnaires

For congregants in each district

- ✓ 15 men
- ✓ 15 women
- ✓ 15 boys
- ✓ 15 girls

3. Focus group discussions

- ✓ 1 women group from the Christian sect
- ✓ 1 women group from the Moslem sect
- ✓ 1 men group from the Christian sect
- ✓ 1 men group from the Moslem sect
- ✓ 1 youth group from the Christian sect
- ✓ 1 youth group from the Moslem sect
- ✓ 1 group of PLWAs

Schedule for the Operational Research

	Tasks and Activities	Provisional Dates/Days	Requirements	Outputs
1.	- Finalise contract agreement with assessment goals, objectives and results clearly spelt out - Collect relevant documents	Fri. 8 Sep		Signed contract agreement
2.	Literature review	Sat. – Wed. 9 - 13 Sep	- Program. Docs. - Working space (MIAA)	Themes & key research questions generated
3.	Identify Research Assistants (RAs)	Mon. – Wed. 11 - 13 Sep	- CVs for potential RAs	RAs identified & briefed on work plan
4.	Communication with Pre-testing site in Lilongwe	Thu. 14 Sep		Messages sent
5.	Develop data collection instruments	Wed – Sat 13 – 16 Sep	- Relevant Docs. - Working space (MIAA)	- Interview guide - Questionnaires
6.	Submit data collection instrument	Mon. 18 Sep	-	-
7.	Discuss data collection tools with MIAA	Tue. 19 Sep	-	-
8.	Refine data collection instruments	Wed. 20 Sep	- Working space (MIAA)	Refined data collection tools
9.	Communication to Survey Sites	Wed. 20 Sep		Messages sent
10.	Orient and train RAs on operational research tools	Thu. 21 Sep	- Stationery - Working space (MIAA) - Data collection tools	-
11.	Pre-test (Lilongwe District) and review of instruments	Fri. 22 Sep	- Data Collection tools - Transport - Stationery	Revised data collection tools
12.	Production of final data collection tools	Sun 01 Oct	- Stationery	Copies of Data collection tools
13.	Consultations with key stakeholders & partners	Mon. 25 Sep - Wed. 06 Oct		Data sets
14.	Bookings of accommodation (where possible)	Fri. 22 Sep		
15.	Data Collection in Lilongwe	Mon – Tue 02 –03 Oct.	- Transport	- Completed questionnaires
16.	Depart for Dowa	Wed 04 Oct.	- Transport	

17.	Data entry	Wed. 04 Oct.	- Completed questionnaires - Computer	
18.	Data Collection in Dowa	Wed – Thu 04 – 05 Oct.	- Transport - Accommodation	- Completed questionnaires
19.	Depart for Mzimba	Fri. 06 Oct.	- Transport	
20.	Data Collection in Mzimba	Fri. – Sun. 06 Oct – 08 Oct	- Transport - Accommodation	Completed questionnaires
21.	Depart for Ntcheu	Sun. 08 Oct	- Transport	
22.	Data Collection in Ntcheu	Mon - Tue. 09 – 10 Oct	- Transport - Accommodation	Completed questionnaires
23.	Depart for Mangochi	Tue 10 Oct	- Transport	
24.	Data Collection in Mangochi	Wed - Thu. 11 – 12 Oct	- Transport - Accommodation	Completed questionnaires
25.	Depart for Nsanje	Fri – 13 Oct	- Transport	
26.	Data Collection in Nsanje	Sat – Sun. 14 – 15 Oct	- Transport - Accommodation	Completed questionnaires
27.	Return from Nsanje	Mon – 16 Oct	- Transport	
28.	Data entry	Tue – Wed 17 – 18 Oct	- Data sets	
29.	Data analysis,	Thu. – Fri 19 – 20 Oct	- Working space (MIAA)	Analysis tables and key conclusions
30.	Report writing and development of recommendations	Sat – Thu 21 – 25 Oct	- Working space (MIAA)	Draft report
31.	Submit draft report	Fri. 25 Oct	-	-
32.	Review of draft report by MIAA	Fri. - Sun 25 – 27 Oct	Copies of the draft report	-
33.	Discuss draft report with MIAA	Mon. 28 Oct	-	-
34.	Incorporate preliminary comments from MIAA	Tue. 29 Oct	-	Revised draft
35.	Circulate & review draft report by partners	Wed. – Thu. 30 – 31 Oct	Copies of the revised draft report	-
36.	Present & discuss draft report with partners	Fri. 01 Nov.	Workshop arranged	-
37.	Incorporate workshop comments	Sat – Sun 02 – 03 Nov.	Working space (MIAA)	-
38.	Submit Final Report to MIAA	Mon. 04 Nov.	-	Final Report