

**THE ROLE OF FAITH-BASED ORGANISATIONS IN HIV/AIDS  
PREVENTION, CARE AND SUPPORT IN UGANDA:  
A CASE STUDY OF KAMWOKYA CHRISTIAN  
CARING COMMUNITY (KCCC).**

**BY**

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## DECLARATION

I Namukose Esther Isabirye hereby declare that the work presented in this book is original unless otherwise stated. It has never been presented before in any institution of learning either in part or full, for any academic award, publication or otherwise.

The report is hence submitted for the award of the Master of Arts Degree in Social Sector Planning and Management of Makerere University, Kampala, Uganda.

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## **DEDICATION**

This book is dedicated to parents, David Livingstone and Anne Baidhye Isabirye,

My children, Joshua and Hannah,

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Many thanks to God Almighty, for the knowledge, wisdom, and understanding, that has enabled me to complete this book; for bringing me this far, it has not been easy but God has seen me through ups and downs-stress, financial constraints, even when I thought of giving up, He gave me the courage to move on.

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## ACRONYMS

|               |  |
|---------------|--|
| <b>ABC</b>    | Abstinence, Being Faithful, and Condom use |
| <b>AIDS</b>   | Acquired Immune Deficiency Syndrome        |
| <b>ART</b>    | Anti-Retroviral Therapy                    |
| <b>CBHW</b>   | Community Based Health Worker              |
| <b>CDC</b>    | Centre for Disease Control                 |
| <b>FBOs</b>   | Faith-Based Organisations                  |
| <b>FGD</b>    | Focus Group Discussion                     |
| <b>HIV</b>    | Human Immuno Deficiency Virus              |
| <b>KCCC</b>   | Kamwokya Christian Caring Community        |
| <b>PLWHAs</b> | People Living with HIV/AIDS                |
| <b>WHO</b>    | World Health Organisation                  |

### Operational definitions

**Care and support** refers to any form of help (emotional, medical, physical or even spiritual) given to people who are infected and affected by HIV/AIDS to help them cope with the challenges caused by the disease.

**Faith-based Organisations** are Non-governmental, non-profit making organisations with a religious foundation and are therefore guided by the values and principles of that particular religion. In relation to the study, this applied to fbos whose main objective is to respond to the challenges posed HIV/AIDS

**Prevention** refers to efforts to stop the spread of HIV/AIDS or HIV/AIDS related conditions from progressing at the onset at the individual, family and communities, and the general environment in which people live.

## **ABSTRACT**

The now over two decades of the existence of the HIV/AIDS pandemic have brought into play a number of actors undertaking numerous interventions to combat its effect. Among the actors have been faith based organizations, local and international, big and small, who have been working patiently, compassionately, and effectively for years in HIV/AIDS prevention, care and support. To some players in the field of HIV/AIDS, FBOs have done more harm than good, and criticisms over their work have for years overshadowed their potential and achievements. This study set out to examine the role of FBOs in HIV/AIDS prevention, care and support taking a case study of Kamwokya Christian Caring Community (KCCC).

A descriptive cross sectional study was undertaken based on quantitative and qualitative research designs; Various research methods and tools for data collection were used respectively; exit interviews with semi-structured questionnaires, key informant interviews with interview guides; focus group discussions with the help of focus group guide; and observation with an observation checklist; internet surfing; and document analysis.

Study findings revealed that KCCC uses a comprehensive multi-sectoral approach in providing a wide range of HIV/AIDS prevention, care and support services; by tackling other factors surrounding the individual other than the individual alone.

As far as prevention is concerned, emphasis is on premarital abstinence and marital fidelity hence targeting the youth and the married. Information on condoms and partnerships with organizations that provide condoms are ways in which KCCC helps those in need of them.

There is more emphasis on primary prevention- prevention before acquiring the HIV virus; and care and support to people living with HIV/AIDS (PLWAs) with little emphasis on secondary prevention-prevention after acquiring the HIV virus. All Services are utilised with ease by people from various denominations and are easily accessible to all in terms of distance, cost, and availability.

Conclusions were thus drawn; that KCCC is specialising in what they can do best i.e. the AB strategy, just like any other organisation, and even if they had not succeeded in their AB strategy, they have other areas other than prevention where they have triumphed exceedingly well- specifically in care and support.

Various recommendations were made many players in the field of HIV/AIDS response, and among them is the need for KCCC to established links with organizations in both the health sector, as well as others outside the health sector like the National Agricultural Advisory services (NAADS), prosperity for all programs among others, to help cover the gaps.

## **CHAPTER ONE: INTRODUCTION**

### **1.0 Background to the problem**

Faith plays a critical role in the lives of many people throughout the world; faith in God, in humanity, in science, in love. It is our undying faith in whatever form it takes that brings us hope and gives us energy to carry on, and to believe that however dire our circumstances may be, the future can bring brighter times, healthier times, and happier times. Seventy per cent of the world's population identify themselves as members of one faith community or another and such faith communities play a significant role in influencing people's behaviours and attitudes (UNAIDS, 2008).

Faith or religious leadership has great influence in the lives of many people, and leaders speaking out responsibly about HIV/AIDS can and have made a powerful impact at both community and international levels. The Pope and the Archbishop of South Africa, Desmond Tutu made calls for increased funding into the fight against the AIDS epidemic during the G8 Summit in 2008 (UNAIDS, 2008).

During the early years of the HIV/AIDS pandemic many people who worked in HIV/AIDS prevention believed that religious leaders and organisations were intrinsically antagonistic to what they were trying to accomplish. In the minds of many people the stereotypic religious leaders and or organisations were morally conservative, disapproving of any form of sexual behaviour outside of marriage, condom use (considered the best way to prevent HIV/AIDS infection) and sex education in schools(UNAIDS,2008).

Such generalisations ignored the fact that many FBOs in the field of HIV/AIDS have been working patiently, compassionately, and effectively for years in HIV/AIDS prevention and mitigation, and this is true of large internationally recognised religious groups and smaller ones as well.

Specifically FBOs in the field of HIV/AIDS have been providing care, support, and counselling for people living with HIV/AIDS including care for orphans, income generating activities for people living with HIV/AIDS and their dependants and a variety of HIV prevention activities. (Green, 2003)

FBOs the field of HIV/AIDS play a major role in HIV/AIDS care and treatment in sub-Saharan Africa than previously recognised and greater collaboration coordination and better communication between them and public health agencies is needed if progress is to be made towards the goal of universal access to HIV prevention, treatment, care and support (WHO, 2007). The Catholic Medical Mission Board (CMMB) based in New York in the United States of America is a good example that has not only helped to deliver quality healthcare to the most vulnerable worldwide for 75 years but The organization has been a catalyst in bringing quality healthcare to the most vulnerable worldwide, but has also successfully implemented HIV/AIDS programs in South Africa, Botswana, Namibia, Swaziland, and Lesotho in Africa (Mathai and Galbraith, 2004).

Previous research has suggested linkages between the involvement of FBOs in campaigns to prevent and mitigate HIV/AIDS and the success of countries in reducing or mitigating the HIV/AIDS epidemic in Africa (Green, 2003; Muhangi, 2004; Lom, 2001). In some cases the success of specific faith-based programs has been documented and their effects on particular communities measured, as in the case of the Islamic Medical Association of Uganda (IMAU) and the Church Human Services AIDS Prevention Program (CHUSA) in Uganda (IMAU, 1998; Kagimu et. al. 1998; Kagimu et. al 1995; Lyons, 1996).

While FBOs have long delivered social, educational and health services around the world, what has been lacking is independent analyses of their work and how that work is perceived by others, working in the field of HIV/AIDS (Daulaire, 1999). Against this background, the study will focus on the role of faith-based organizations in the fight against AIDS.

## **1.2 Statement of the problem**

HIV/AIDS is still a great challenge in the world today, various efforts have been made to combat the deadly pandemic but the need for appropriate and effective interventions is as urgent as it was 20 years ago.

Faith-based organisations are a vital part of society, providing a substantial portion of care in developing countries, often reaching vulnerable populations living under adverse conditions. These is therefore need to recognise them as essential contributors towards universal access efforts (WHO, 2007)

FBOs in the field of HIV/AIDS have for a long time committedly made positive contributions towards HIV/AIDS prevention, care and support, but criticisms by other players in the same field, particularly over some of their preventive messages that emphasise pre-marital abstinence and marital fidelity against condom use, stigma, fear and misinformation. Some of their messages that usually emphasise premarital abstinence and marital fidelity often clash with secular emphasis on condom use safer sex. It is further argued that some religious leaders throughout Africa and other parts of the world continue to portray HIV/AIDS as a punishment from God for sexual sin or to express opposition to condom use on the basis that condoms encourage promiscuity (Agadjanian and Sen, 2007)

Few of their efforts have been appreciated; documented or even evaluated, most of the literature on the role of FBOs in dealing with the HIV/AIDS crisis is therefore scarce and primarily addresses the influence of religious beliefs and organisational structures on HIV/AIDS by promoting and even enforcing less risky behaviours. Relatively little and unbiased evidence exists to show how their potential has been realised in practice, as well as the volume and frequency of HIV/AIDS related assistance provided by FBOs as well as the relative distribution of that assistance between members and non-members generally remain unknown.

It is against this background that an unbiased assessment of the role of FBOs, specifically Kamwokya Christian Caring Community (KCCC), in HIV/AIDS prevention, care, and support, has been undertaken.

### **1.3 Study objectives**

#### **1.3.1 Overall Objective**

The overall objective of the study was to examine the response of FBOs to HIV/AIDS, particularly their contribution to prevention, care and support.

#### **1.3.2 Specific objectives**

The specific objectives were:

To establish the nature and categories of HIV/AIDS prevention activities by KCCC.

To identify the nature and categories of care and support services carried out by KCCC.

To explore the challenges faced by KCCC in HIV/AIDS prevention, care and support interventions.

To explore ways in which KCCC can strengthen its role in HIV/AIDS prevention, care and support.

#### **1.4 Scope of the study**

The study specifically focused on the efforts made by KCCC to stop the spread of HIV/AIDS among both the infected and non infected; as well as the medical, physical, emotional, and spiritual help given to both the people infected and affected by HIV/AIDS, in order to help them cope with the challenges of the disease.

KCCC is located in Kamwokya II Parish, Central Division, Kampala District. Focus was on the various beneficiaries (men and women of all ages), community members and leaders, management of KCCC, and focal HIV/AIDS persons at the Central Division.

One theory- the Ecological Systems Theory, guided the study. The study was carried out in a period of seven months.

#### **1.5 Significance of the study**

The main aim of the study was to examine the contributions made by FBOs, and KCCC for this matter, towards HIV/AIDS prevention, care, and support, by looking at the nature and categories of their interventions respectively, as well as challenges faced in implementing the interventions. To all the players in the field of HIV/AIDS, this information will help them identify particular strengths for them to build on in the fight against a common enemy, and weakness to be avoided. But most importantly perhaps, it will bring about a better understanding and appreciation of the work of FBOs.

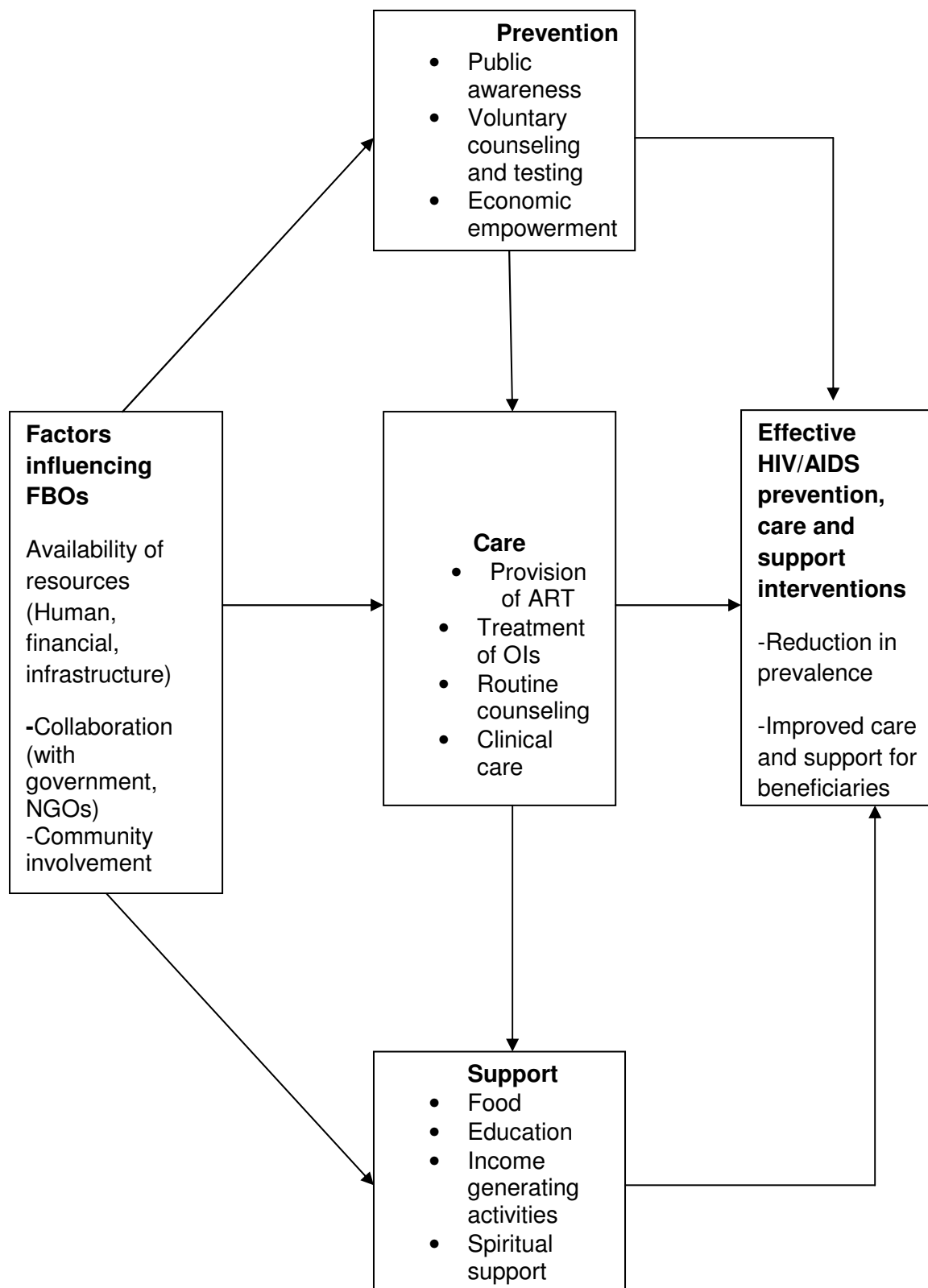
In addition, the knowledge acquired should also be useful to international and national planners in designing effective HIV/AIDS interventions.

Sometimes challenges are never considered as challenges until they are highlighted, and problem identification is the first step in attempting to solve a particular problem, therefore identifying the challenges faced by KCCC was a very important step for not only the

organisation but also other FBOs in the field of HIV/AIDS, in overcoming the barriers to successful implementation of their various interventions.

Lastly, as it is with all research work, there are always gaps, so to academicians and researchers, the study should help to generate more intensive knowledge for further research on the response of FBOs to HIV/AIDS.

## 1.6 Conceptual Framework





Faith based organisations in the field of HIV/AIDS provide a wide range of interventions to various categories of people as far as HIV/AIDS prevention, care and support are concerned. However, certain conditions or factors like adequate resource availability, collaboration with the government, non-governmental organisations, public health agencies and other actors in the field of HIV/AIDS; community involvement for sustainability purposes, among others, must be in place for effective implementation and success of these interventions. Similarly, shortage of these factors poses challenges to FBOs in trying to implement their interventions. Item 1.6 explains the nature of interrelationships between these variables.

### **1.7 Organisation of the dissertation**

The work is organised and presented in five chapters; Chapter one is this introduction of the study. Chapter two is a review of related literature. Chapter three discusses the methods of data collection- this is comprised of methods used in selection of respondents, data processing, analysis as well as the problems encountered during data collection. The study also explains how some of these problems were minimised, and describes the study area in detail.

Chapter four presents the study findings as well as the interpretations of these findings. The research questions formulated are used as guidelines to interpret the findings.

Chapter five gives a summary of findings, conclusions to the study, recommendations for policy formulation and implementation, suggestions to future researchers, and shortcomings of the study. The references then follow appendices -, questionnaire, interview guide, and discussion guide.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1 Introduction**

This section presents the literature and studies done on the role of FBOs in HIV/AIDS prevention, care, and support. It focuses on faith-based organisations and HIV/AIDS, the nature of activities and categories of people served by FBOs, challenges of FBOs in HIV/AIDS prevention, care, and support, and collaboration of FBOs with other stakeholders. The Ecological Systems Theory was reviewed to guide the study.

### **2.2 Understanding Prevention, Care, and Support**

#### **2.2.1 Prevention**

According to the Centre for Diseases Control (CDC), disease is an interruption in, or disturbance of the bodily functions or organs that causes or threatens pain and weaknesses (CDC, 1998). Disease prevention involves two aspects namely; behavioural change and detection;

#### **Behavioural Change**

Disease prevention involves two aspects of behavioural change and detection. First, prevention involves efforts of stopping a specific diseases or conditions at the onset through behavioural change at the individual, family and communities, and the general environment in which people live. Such efforts may for instance include a program that tries to get people to stop smoking to prevent lung cancer, or regular exercise, to prevent heart attack and strokes (CDC, 1998).

#### **Early detection**

Secondly, prevention efforts of death or illness from diseases may be through early detection such as the case with cancer that relies on a regular mammogram for women (CDC). It is generally accepted that early detection is not only the key to preventing subsequent complications and further deterioration in the patient condition but also in addition to avoiding unnecessary patient suffering, the costs associated with early detection and prevention are far less compared to treating advanced stages of disease. The advantages end there and problems of early detection emerge. To begin with,

Primary Health Centres (PHC) serve Health care needs of rural communities and these centres may not be able to deal with early detection of diseases, due to a lack of multi-disciplinary medical expertise and laboratory facilities. In addition, patients usually do not visit PHCs in the early stages of their diseases, while health care providers are forced to focus on only seriously ill patients due to the volume of cases (George Foundation, 2000).

In the USA, in 1997, the Advisory Committee for HIV and STD Prevention (ACHSP) reviewed data on the relation between curable sexually transmitted diseases (STDs) and the risk for sexual transmission of human immunodeficiency virus (HIV). ACHSP considered that the evidence was strong that early detection and treatment of other STDs was an effective strategy for preventing sexually transmitted HIV infection but this strategy had not been clearly articulated or implemented as a core strategy for HIV prevention in the United States (CDC, 1998)

### **2.2.2 HealthCare and Quality**

Quality is the degree, grade of excellence or worth. To recognize quality of a health care one needs to ask questions such as: What is the experience level of my doctor? Is he/she board certified? How many times has this particular facility done this procedure? High-quality health care is achieved through innovation and the use of the latest technology available (Sentara, 2008).

Studies show that physicians and hospitals have better results when they treat a high number of patients for a particular disease and perform large numbers of procedures to treat it (Sentara, 2008).

The majority of studies find a lower patient mortality rate for a given procedure when the hospital or physician has a high volume of experience performing that procedure (Sentara, 2008).

While it is impossible to eliminate all risks of medical complications or death, particularly for seriously ill patients, choosing a hospital with a lower mortality rate and/or a higher long-term survival or success rate can reduce risks. It is important to compare the hospital one attends with other hospitals in terms of mortality rates (Sentara, 2008).

Keeping pace with the latest advances in technology is difficult in the health care industry, although it distinguishes types of health care providers from their peers. Frequent new equipment purchases, the introduction of state-of-the-art, minimally invasive surgical techniques and the implementation of new, computerized work processes are key to success (Sentara, 2008).

### **Types of Palliative Care Interventions**

Palliative care has traditionally been associated with terminal or end-of-life care. However, current thought and practice take the broader view that palliative care includes care provided from the time that HIV is detected and throughout the continuum of HIV infection (GoUSA, 2006).

Palliative care for HIV-infected individuals increases with the disease progress. In the USA, the Emergency Plan can support four categories of essential palliative care including clinical care, Psychological care, Spiritual care, Social care (GoUSA, 2006)

Clinical care includes a wide range of treatment and care including: routine, confidential HIV counselling and testing; routine follow-up to determine the optimal time to initiate ART; prevention and treatment of opportunistic infections (OIs) such as tuberculosis (TB); HIV prevention and behaviour-change counselling, alleviation of HIV-related symptoms and pain; nutritional support for clinically malnourished PLWHA; and support for adherence to anti-retroviral therapy (ART). Illustrated below are types of interventions that Emergency Plan programs should provide, based on the presence or absence of clinical symptoms. Clinical care may be asymptomatic clinical care, symptomatic clinical care, and End-of-Life and bereavement care (GoUSA, 2006).

End-of-Life and bereavement care is directed toward the individual and family members in need of intensive management of symptoms and pain. They include culturally appropriate end-of-life care and bereavement interventions, as well as appropriate succession planning and referrals for orphans and vulnerable children.

Psychological care addresses the non-physical suffering of individuals and family members, and includes mental health counselling; family care and support groups; support for disclosure of HIV status; bereavement care; development and implementation of culture- and age-specific initiatives for psychological care; and treatment of HIV-related psychiatric illnesses, such as depression and related anxieties (GoUSA, 2006).

Spiritual care addresses the major life events that cause people to question themselves, their purpose and their meaning in life. The interventions should be sensitive to the culture, religion(s) and rituals of the individual and community, and can include (but are not limited to): life review and assessment; counselling related to hopes and fears, meaning and purpose, guilt and forgiveness; and life-completion tasks (GoUSA, 2006).

Social care assists individuals and family members in maintaining linkages to and use of care, preventing HIV infection, and ensuring adherence to treatment. These can include: community-based support groups; community mobilization and leadership development of PLWHA; efforts to reduce stigma; legal services to assist with succession planning, inheritance rights, and legal documentation (such as a living will or power of attorney); assistance to secure government grants, housing, or health care; linkages to food support and income-generating programs; efforts to increase community awareness of HIV care, treatment, and prevention; and other activities to strengthen affected households and communities.

Prevention for HIV-infected persons has been shown to be both effective and efficient at preventing new infections. Emergency Plan programs should incorporate prevention for positives into palliative care and treatment. Models to provide these interventions can include: interventions for sero-discordant couples, including confidential testing and ongoing counselling; community and clinic-based support groups; case-management and provider-delivered prevention messages focused on disclosure; partner testing; correct and consistent condom use for populations engaged in high-risk behaviour and mutual fidelity (GoUSA, 2006).

### **2.2.3 Health Support**

A key element in HIV/AIDS care and support is the provision of psychosocial support. Counselling, spiritual support, support to enable disclosure and risk reduction strategies, medication adherence, and end of life and bereavement support are all part of psychological support. This should be part of the care package at all levels. At its most basic level, this requires the establishment and support of peer-support groups for those found positive, and those affected by HIV. Many good examples of such services - which act as a focus for education, training, and provision of material, basic economic, spiritual and psychosocial support - currently, exist in many countries. Those most affected often create such groups through a need for solidarity in the face of broader public stigma and discrimination. The

greater involvement of people affected by HIV/AIDS (GIPA) is a vehicle for generation of psychosocial support in communities, and needs to be incorporated and encouraged in designs for care and support (UNAIDS, 2000: 31)

#### **2.2.4 Obstacles in HIV Prevention, Care and Support**

Several obstacles have been encountered in the fight against HIV/AIDS including poverty and drug abuse, trust, culture, care, and PLWHAs involvement.

##### **Poverty/Developed Communities**

Social scientists see HIV/AIDS as closely linked to poverty and development and lack of appropriate strategies to prevent and control HIV/AIDS accounts for its rapid spread in Africa. Based on health education model, of IEC (Information Education and Communication) as applied in western countries where individual psychology of locus of control and self-efficacy enhances behaviour change at individual level, contrasts with Africa where AIDS is not an individual disease but a society disease requiring group psychology approach strategies. The locus of control is within society. Modification of society's perception and structures that enhance or mitigate the impact of the disease are paramount before individual behaviour change can take place. The need to address the social and behavioural factors can either enhance or restrict the spread of HIV. More particularly regional co-operation and policy formulation focusing on the multi-sectoral approach as well as research, technical support and advocacy at the highest level are also strategies that seem effective for the prevention, control and management of the future course of the epidemic (Radulich, 2002)

In more relatively better communities; HIV/AIDS spread is associated with drug abuse. More than 43% of the notified cases of HIV/AIDS are associated to intravenous drug use. Considering the group of drug users in the poorest strata of society, the HIV/AIDS prevalence oscillates between 48% and 50%. From 1997 - 2001, three HIV/AIDS prevention programs with active participation of drug users and their communities of reference in Buenos Aires, in Argentina. The Asociacion Somos Ciudadanos (ASOCI) complements its community interventions with systematic research and specific studies (Radulich, 2002).

In Ireland, part of the AIDS/HIV Prevention Campaign for two involved placing small poster style adverts in toilet/washroom facilities in a way that those who use the facilities would be exposed to the message. A particular attraction of this strategy is that it allows tailor made

messages to be placed in specific locations with specific target audiences in mind. It also gives results of an analysis of the effectiveness of the strategy and refers to take up by other countries in Western Europe (Metcalf, 1993).

### **‘Trust’**

Research has also shown that one of the obstacles to HIV/AIDS prevention has been inconsistent use of the condom among partners especially for fairly permanent relationships. The reasons for the inconsistent use of the condom include: maintained regular and sexual relationships hence the demand for trust proof, because to continue asking for condoms is like a distrust proof; increased knowledge and use of oral contraceptives to prevent unwanted pregnancies, to mention but a few. Hence, the values, norms and emotions involved in relationships, sexuality, love, romance, and intimacy does not change with the discussion of scientific information (Silva, 1998)

### **Culture**

In Kenya, Rwanda, Swaziland, and Zimbabwe which operate AIDS awareness and prevention projects campaigns, results reveal that even though most respondents know about AIDS, they see it as a problem for others and not themselves. Further, most people know that sexual contact is a mode of HIV transmission, but they also hold misconceptions about transmission. For example, some believe casual contact transmits HIV. Moreover many never use a condom and believe there is no need to use a condom. Several organisations use focus group discussions (FGDs) to gather much needed qualitative data. A common belief in Zimbabwe is that bad air spreads diseases, which may be the reason for the common fear of getting HIV through casual contact. Another belief in Zimbabwe is that men and women must have children to be accepted into the spirit world. This could explain why women do not require partners to wear condoms or choose to have children if they are HIV positive.

In conclusion, all players responding to HIV/AIDS must understand the local cultural and social context of AIDS (Scott and Mercer, 1991).

In the remote village of Kyakatwire in western Uganda, people stick rigidly to their traditional customs and cultural behaviours that include Polygamy, inheritance of widows, sharing of wives among brothers, and high dowry charges. A group of 15 people was trained as AIDS counsellors during two months. Counselling by oral interviews with individuals and discussions with clan heads and elders was done to influence traditional customs and cultural

behaviours. Although the AIDS counselling programme has been well received in the rural community, changes of traditional customs are difficult to achieve. One reason for these obstacles to HIV/AIDS intervention is the fact that women in this rural setting have no final word on sex to their partners. Slowly, men are educated through counsellors to share ideas about sexual issues with their female spouses. Traditional habits that favour the spread of HIV/AIDS can be changed only slowly in a remote rural African community (Rwegiza, 1998).

In Cameroon HIV/AIDS; rose from 0.5% in 1987 to 5.5% in 1994. In reaction to such a threat, the Ministry of Public Health through the AIDS Programme has initiated a multi-sectoral mobilization plan that associates religious forces (FBOs) and traditional healers to the social communication programme for the AIDS prevention. It was revealed that the emergence of controversial views, especially within the ranks of religious sects and traditional healers who claim to possess a cure for AIDS distorted the public understanding of the scientific message. Qualitative analysis of data collected on tape recorder. Preliminary results indicated that the religious domain (FBOs) sects claim special powers that can enable them to cure all believers who are infected by HIV/AIDS. Worst of all, they even claim to have successfully healed AIDS patients through intense prayers. On the other hand, imposing sign boards can be found on strategic points in big cities, inviting HIV sero-positives and AIDS patients to speedy and accurate treatments by traditional practitioners. Such messages are considered with much attention, in our society where some diseases believed to be induced by sorcery, are treated only by traditional healers. In this light, there is an increasing demand for the services of traditional healers by AIDS patients that are rendered at exorbitant prices. Hence, In the present state of biomedical research on HIV, these messages and practices are likely to disturb social communication and to influence negatively the success of education campaigns (Kemmegne et.al, 1996).

## **Care**

In Nigeria, stigma affects access and utilization of preventive and treatment services by delaying appropriate help seeking. Studies have found out that some people cannot care for a family member who is infected by AIDS; some would not want or allow an infected person to continue working in factory, some students discontinue schooling in the same school with infected student, kiss or hug a person living with HIV/AIDS, to mention but a few. Hence, an integrated community- and religious-based (FBOs) initiative would tackle the problem of



HIV/AIDS-related stigma by challenging societal attitudes and beliefs that underlie stigma (Okemgbo and Odimegwu, 2004).

HIV/AIDS is regarded as a highly medical issue and as a result lack of comprehensive, multi-sect oral approach is one of the major obstacles in addressing the HIV/AIDS problem in Azerbaijan. Situation analysis was carried out through the review of HIV/AIDS-related activities undertaken by the government and NGOs. Major findings are as follows: 1) registered HIV rate remains at low level; 2) blood safety is not ensured; 3) official STDs rate has grown up 3-fold since 1991; 4) 10-fold increase in registered drug users was recorded from 1989 to 1995; 5) increase in commercial sex activities. Other factors contributing to the spread of HIV/AIDS: 1) lack of awareness about safe sex practices; 2) family life education is not introduced in schools; 3) very few activities were implemented outside the Ministry of Health (MOH); 4) poor relationship between the government and NGO sector; 5) lack of financial resources to ensure supply of disposable equipment; 6) lack of technical capacity in formulation and development of strategic HIV/AIDS planning. It was recommended to: 1) establishment of national inter-ministerial AIDS committee to develop a comprehensive strategic plan on HIV/AIDS prevention and care; as well as 2) active support strengthen the capacities of nascent NGO sector in the country to launch an efficient outreach programme targeted at the vulnerable groups of the population (Ibrahimova and Alekperov, 1998).

Lastly, Greater involvement of PLHA is a critical aspect of the response to the HIV/AIDS epidemic. A diagnostic study examined PLHA involvement in NGO prevention & care programs in Burkina Faso, Ecuador, India and Zambia. Extensive qualitative data were collected through interviews and focus group discussions (FGDs) with over 800 respondents. Participants were service providers of NGOs; PLHA & people affected by HIV/AIDS who use services; relatives of PLHA involved in NGOs; health workers; policymakers & community leaders. According to respondents, major factors limiting PLHA involvement include fear of stigma and discrimination as a result of being identified as HIV positive through involvement in AIDS organizations, limited education and skills to plan and deliver services, and high morbidity & mortality. Poverty is also a key-limiting factor, and the need to earn a living & inability to meet even basic needs hinders involvement. Organizational obstacles include a lack of policies resulting in a lack of opportunities for PLHA involvement (or lack of PLHA information on these), lack of or inappropriate allocation of resources, and judgmental and discriminatory attitudes of service providers. NGOs need to build an environment that helps PLHA overcome social & organizational obstacles to their

involvement in programs by ensuring confidentiality and providing psychological support to PLHA; making peer support available to reduce the fear of stigma; giving material support to PLHA, including direct provision of care and/or a referral that guarantees access to care; providing PLHA with information and training specific to the tasks they will be carrying out; and by networking with other organizations to fight discrimination and facilitate referral (Cornu et.al 2002).

### **2.3 Faith based organisations and HIV/AIDS**

FBOs in all sectors reach farther than any other institution, are sustainable and ideally suited for long-term community outreach, education, and support contact, maintain moral authority and espouse values of compassion, care, and youth outreach. Thus, the programmatic and philosophical interventions they undertake have the potential for long-term continuity, possess a reservoir of volunteers, local leadership, existing groups, and youth activities on which local efforts can draw for their community-based interventions, are important partners with government, are there for the long haul, which helps the sustainability of the services they provide (Green, 2003).

Many FBOs in the field of HIV/AIDS have been working patiently, compassionately, and effectively for years in AIDS mitigation and prevention. This is true of large, internationally recognized FBOs and smaller ones as well. Specifically, FBOs in the field of HIV/AIDS have been providing care, support, and counselling for people living with HIV/AIDS, including care for AIDS orphans, income generation projects for people living with HIV/AIDS and their dependents, and a variety of HIV prevention activities.

Workshops and seminars have been conducted for leaders of Buddhist, Christian, Hindu, Muslim, and other faith groups, and these efforts often have resulted in programs aimed at followers of the religion as well as others in local communities. These efforts demonstrate the ability of FBOs to bring AIDS support and education to communities not being reached by government campaigns, often using creative educational approaches (for instance Campolino and Adams,1992; Farill et al. 1992; Ariyaratne, 1998; Kagimu et al. 1998; Roesin, 1998).

## **2.4 FBOs role in HIV/AIDS prevention**

As FBOs carry out their interventions in prevention, they too have delivered messages of abstinence, faithfulness after marriage, voluntary testing, as well as behavioural change messages, and there have been significant linkages between the involvement of faith-based organisations in campaigns to prevent and mitigate HIV/AIDS, and the success of countries in reducing the pandemic (Green, 2003).

Experience shows that good leadership and open discussion on HIV/AIDS are key factors in attaining stable and declining sero-prevalence rates, but so is the involvement of religious leaders and FBOs in HIV/AIDS prevention (Green 2003). In countries where religion is important, faith based involvement is as necessary as condom social marketing, treatment for sexually transmitted infections, voluntary counselling and testing, and other state of the art interventions in HIV prevention. In Uganda, FBOs have adopted a promotional approach in the fight against HIV/AIDS and as such however, educational messages focusing on HIV prevention and actual behavioural change are delivered. Such messages aim at promoting pre-marital abstinence, and marital fidelity,

Just as open and frank discussion about AIDS by the highest government authorities helped to reduce stigma in Senegal and Uganda, faith based leaders have similar authority and influence. For example, the Christian Church Association of Lesotho implemented a project, the objectives of which were “to prepare communities for accepting and supporting all people with HIV and AIDS,” and to promote “destigmatization of STD/HIV/AIDS patient care” (Barton et al. 1997, 8). Catholic Relief Services, which works with partners on more than 80 HIV/AIDS projects in more than 30 countries, has facilitated awareness workshops with clergy in several countries in order to “demystify and destigmatize HIV/AIDS” (Stecker, 2003).

Uganda has found great success in publicly promoting abstinence until marriage for its young people. In 1994, Uganda launched 'True Love Waits,' an abstinence-until-marriage program that was also supported by schools, religious institutions, non-governmental organizations and local communities" (Dobson 2002).

Uganda's to the abstinence component is also attributed to their comprehensive sex-ed program: "Uganda, where more than 30,000 children have signed abstinence pledges, has seen a 50-percent reduction in AIDS since 1992 because of its emphasis on abstinence."

(Kellogg 2002). Reinforcing the government education efforts, faith communities have helped promote a change in sexual mores; a culture of abstinence and marital fidelity are held out as realistic and responsible lifestyle decisions.

Challenging HIV/AIDS is possible - it is a preventable disease. Christian Aid sees prevention as a fundamental element of a meaningful response to the HIV/AIDS crisis, and believes this can properly be achieved when wider development issues are also addressed. Concerted efforts, at national and community levels, are beginning to show success in some countries. With strong political and religious leadership, increased education and care at community level, vigorous and targeted campaigning at all levels, and a willingness to fight the stigma and prejudice often associated with HIV/AIDS, countries like Uganda, Senegal and Thailand have been able to reduce the incidence rate of new infections (Christian Aid 2005).

## **2.5 FBOs role in HIV/AIDS care and support**

Faith-Based Organisations are providing holistic comprehensive care across a continuum and are major contributors to the national response. This involves providing support for people living with HIV/AIDS (PLWHA) and their families through a network of resources and services. A continuum includes care between hospital and home over the course of the illness. The care incorporates clinical management and care, education, prevention, counselling, palliative care and social support.

Orphans are an extremely vulnerable sector of the population. Not only are they subjected to all forms of abuse and exploitation but their situation often limits their choices. There is little motivation to consider the risks of HIV when day-to-day survival is all they can cope with.

Faith-based organisations have all over the world been very instrumental with the provision of care for orphans and vulnerable children (OVC). This care has taken the form of institutional care, community based, fostering and adoption, day Care centres, street children programs and hospices for abandoned and HIV positive children. The provision of psychosocial support, the training in parenting skills for child headed households, skills training and life skills provision to orphans has provided lessons for other agencies to emulate. However, the magnitude of the orphan crisis is yet to be felt right across Africa. Though there are currently millions of such children, there are millions more to come, given the high sero prevalence in Africa (Tearfund, 2004).

In a study across six countries (Kenya, Malawi, Mozambique, Namibia, Swaziland and Uganda), Foster identified the key role played by faith-based organisations in supporting orphans and other children made vulnerable by HIV/AIDS. More than 9,000 volunteers working out of 686 FBOs supported more than 150 000 orphans and vulnerable children. This was mostly through community-based initiatives, combining elements of spiritual, material, educational and psychosocial support (Tearfund, 2004).

In communities that are facing desperate situations as a result of AIDS and where most people have some kind of spiritual belief, the input of FBOs is critical. This has been found to be especially true of Christian organisations in Africa. Households affected by AIDS-related sickness and bereavement, or with orphans and vulnerable children, value the combination of practical, emotional and spiritual support. The activities of an FBO may provide a means to bring affected people together when otherwise they would be isolated.

Whilst many FBOs, particularly church congregations, are very active in caring for those affected by HIV/AIDS they are reticent about tackling issues linked to prevention. They may be reluctant to speak about sexual practice. Significantly, the teaching and practice of faith-based organisations may reinforce traditional patriarchal attitudes towards gender. This may contribute to increased HIV infection amongst women, as men hold that they have a right to determine sexual behaviour, and women are socialised to be submissive and not negotiate safer practice.

Whilst in some communities the responses have been muted and activities are limited to simple prevention messages on World AIDS Day, in other communities FBOs are providing holistic comprehensive care across a continuum and are major contributors to the national response. This involves providing support for people living with HIV/AIDS (PLWHA) and their families through a network of resources and services. A continuum includes care between hospital and home over the course of the illness. The care incorporates clinical management and care, education prevention, counselling, palliative care and social support (Parry, 2001).

Since the 1990s, the Buddhist monks of Wat Kien Kes Temple in Battambang Province, Cambodia, have devoted themselves to AIDS education, care and support activities in their community. With technical support from USAID's Implementing AIDS prevention and care (IMPACT) Project (managed by FHI), the monks and members of a volunteer network based at the temple assessed community needs as a first step in creating programs to provide people

living with HIV/AIDS (PLHA), orphans and vulnerable children with counselling, vocational training and income-generation opportunities, including modest grants of materials, seeds and animals. Family Health International also helped the temple's volunteer network strengthen program management and community mobilization programs, including educational campaigns to reduce the widespread stigma that isolates individuals and families affected by AIDS. (Didan, 2004).

## **2.6 Challenges of FBOs in HIV/AIDS prevention, care, and support**

Faith-based organizations have been the recipients of many accusations: of being a 'sleeping giant'; of promoting stigmatising and discriminating attitudes based on fear and prejudice; of pronouncing harsh moral judgments on those infected; of obstructing the efforts of the secular world in the area of prevention and of reducing the issues of AIDS to simplistic moral pronouncements, that have not made Churches or Mosques places of refuge and solace, but places of exclusion to all those "out there" who are but 'suffering the consequences of their own moral debauchery and sin.(Parry, 2001)

While we may not deny that, in some instances, these accusations may tragically and regrettably be justified, it has not been always and everywhere. Whilst the moral debate – particularly around the condom issue – has raged in many circles, stalemating action, and in many eyes discrediting the Churches' commitment to tackling AIDS and saving lives, congregations and parishes have themselves been in the forefront of care and support right across Africa. A great number of these initiatives did not wait for funding in order to begin, they just responded. Their courage and determination in the face of so many obstacles is a humbling lesson to many, and a reflection of deep compassion in the real world of suffering.

Faith based organisation's efforts have been questioned due to their stand on some of the preventive mechanisms particularly condom use. As long as they're calling it ABC (Abstinence, Be faithful, Use condoms) and not bashing condoms, that would be no problem. What would be a problem is to deny support for condoms (Uganda MP).

There is no common ground between contraception educators and authentic abstinence educators. That is because, like oil and water, abstinence and condoms never mix (Unruh, 2005).

Whereas official statements against condom use contradict the Uganda Ministry of Health's National Condom Policy and Strategy (June 2004), which states that "correct and consistent condom use shall be widely and openly promoted to all sexually active individuals as an effective means of preventing HIV/STI transmission and as a family planning method", on at least one occasion, the Ugandan Government has supported an organization that spreads false information about the effectiveness of condoms against HIV. The Family Life Network, a faith-based organization that claims to have received a grant from the Ugandan government supported by the Global Fund to Fight AIDS, TB and Malaria, teaches young people that latex condoms contain microscopic pores that can be permeated by HIV pathogens. In an interview with Human Rights Watch, FLN presented a diagram comparing the small size of an HIV pathogen with the larger particles of sperm, syphilis and gonorrhoea and stated. (Human Rights Watch, 2004).

Public health organisations and non-governmental organisations working for the prevention of the spread of HIV recommend both the use of condoms. The Church's teachings have not supported these practices, arguing that they send the wrong message about sex and drugs and may ultimately lead to the increased spread of HIV. The statements recommend education and treatment aimed at changing behaviour. One exception to this teaching was a statement by the Social Commission of the French Bishops' Conference in 1996. In a very limited and nuanced way, the statement acknowledges that the use of condoms to prevent the spread of HIV may be necessary (Karanja, 2005).

Political factors are threatening the FBO's fight against the disease. In Zimbabwe, President Robert Mugabe cracked down non-governmental organizations, which he said, in August 2005, were being used as "conduits of foreign interference" in his country. The government then introduced a law that would give it more control over these bodies (Karanja, 2005).

Collaboration between Faith-Based organisations and other public health agencies seems a big challenge. According to an important study by the World Health Organization (WHO) in Zambia and Lesotho, efforts are needed to encourage greater collaboration between public health agencies and faith-based organizations, if progress is to be made towards the goal of universal access towards HIV prevention, treatment, care and support by 2010. The report estimates that between 30% and 70% of the health infrastructure in Africa is currently owned by faith-based organizations, yet there is often little cooperation between these organizations and mainstream public health programmes. (WHO, 2007). The study focused on Lesotho and

Zambia, which had HIV prevalence rates of 23.2% and 17% respectively in 2005. It found that Christian hospitals and health centres are providing about 40% of HIV care and treatment services in Lesotho and almost a third of the HIV/AIDS treatment facilities in Zambia are run by FBOs. According to the report, FBOs play much a greater role in HIV/AIDS care and treatment in sub-Saharan Africa than previously recognized. The report concludes that greater coordination and better communication are urgently needed between organizations of different faiths and the private and public health sectors.

Health, religion and cultural norms and values define the health-seeking strategies of many Africans. The failure of health policy makers to understand the overarching influence of religion - and the important role of FBOs in HIV treatment and care - could seriously undermine efforts to scale up health services. WHO has done a great service in quantifying the role of the faith community in providing HIV/AIDS care and treatment in sub-Saharan Africa, as it reports that Pastors, imams, and volunteers who minister to those who are suffering from deadly diseases are fully aware of their constituents' needs, and have responded with care on the front lines (WHO, 2007).

Religious leaders are sometimes accused of stigmatising people with AIDS. Because of their stand for good morals in society someone who will have contracted the disease will be looked as having not taken the advice of the church the reverse. The religious community's sober approach to the AIDS threat helped to reduce stigma attached to the disease while challenging people to adapt safer sexual behaviours. (UNAIDS, 2003)

In March 2004, Sibambene, an AIDS and orphan organization run by the Catholic diocese of Bulawayo, became a casualty of the new law. The region's District Administrator ordered it to close its operations until it registers. The organization offers home-based care to over 200 orphans and AIDS sufferers. Another organization, Souls' Comfort, was ordered to stop taking photographs of people living with AIDS. (Karanja, 2005). The law needs a concerted response from Church leaders and other human rights groups. Our health and education institutes could be under threat, says Alouis Chaumba, National Coordinator of the Catholic Commission for Justice and Peace.



## **Gaps**

From the above discussion of literature, it is evident that many studies have been done on faith based organisations and HIV/AIDS, however, most literature focuses on the influence of FBOs in promoting and enforcing less risky behaviours as a way of preventing HIV/AIDS, support for orphans. Perhaps, there could sound reasons for choosing this path, but more importantly to that FBOs doing it very well in this as their area of specialisation, and all they need is support from other players to help them cover gaps. However, this is not all that FBOs are doing, to respond to the challenges posed by HIV/AIDS, a lot more uncovered work is being done, in as far as HIV/AIDS prevention, care, and support.

## **2.7 Theoretical perspectives**

### **Introduction**

Only one theory-The Ecological Systems theory (Bronfenbrenner, 1979) was used to guide the study. This theory has been widely adopted in HIV/AIDS interventions because of its focus on not only the individual and his behaviour but also the environment that surrounds him or her.

#### **2.7.1 Ecological Systems Theory (EST)**

There are a number of different versions of ecological models, but in general, they recognise that successful activities to promote health, including HIV risk reduction, should not only address changing individual behaviours, but also multiple levels surrounding individuals, such as families, communities, institutions, and policies. The Ecological Systems theory (Bronfenbrenner, 1979) is one such a theory.

The ecological theory can be traced back to the biological theories that explain how organisms adopt to their environments. Bronfenbrenner (1979) suggests four levels of ecological components as a useful framework in understanding how individual or family processes are influenced by hierarchical environmental systems in which they function: The micro system is the most basic system referring to an individual's most immediate environment. For example the effects of personality characteristics on other family members; the Meso system is a more generalised system referring to the interactional processes between multiple micro systems. For instance the effects of spousal relationships on parent-

child interactions; the Exosystem consists of settings on a more generalised level, which affect indirectly on micro and Meso system levels; and the Macro system.

The theory recognizes the fact that successful activities to promote health, including HIV risk reduction, involve changing individual behaviours, but also advocacy, organisational change, policy development, economic supports, environmental change, and multi-method programs- the comprehensive approach to HIV/AIDS prevention, care and support is a good example of multi method programs

According to the ecological systems theory, human behaviour is viewed as being determined by five factors or levels of influence and interventions are more successful if they intervene within most, if not all, levels of influence.

**Intrapersonal factors:** This refers to characteristics of the individual such as knowledge, attitudes, behaviour, skills, or intention. Interventions here should therefore focus on changing these characteristics to comply with certain behavioural norms.

**Interpersonal processes:** This includes formal and informal social networks /social support systems. This involves relationships with family, friends, neighbours, co-workers, and acquaintances. An individual can belong to one or more social networks. Through these ties in social networks, people acquire norms upon which change-seeking efforts should concentrate.

**Institutional factors:** These social institutions with organizational characteristics and formal and informal rules and regulations for operation. Organizational characteristics can be used to support behavioural change. Organizations, such as school, work, church, professional or neighbourhood groups, may have positive or negative effects on the health of their members. Since they are important sources and transmitters of social norms and values, organizations can provide the opportunity to build social support for a desirable behaviour change. The assumption here is that organizational changes are needed to support long-term behavioural changes among individuals

**Community Factors** - Community refers to the face-to-face primary groups to which an individual belongs. These "mediating structures," such as family, church, informal social networks, and neighbourhoods, may provide social identity and resources.

A Community can also be concerned with the relationships among organizations within a political or geographic area. Many organizations competing for scarce resources usually result in the inefficient use of these resources, unless there is coordination and coalition building among community agencies in planning health education interventions.

A community can also be defined as a population, which is political and has one or more power structures. These power structures play a crucial role in defining this community's health problems as well as allocating its resources. Often those with the most serious health problems in a community are also those with the least access to its power structures (e.g. poor, rural, uneducated, homeless, the unemployed, minorities, and handicapped).

**Public policy:** this includes local, state, and national laws and policies.

Within the public health sector, the health of the population has been emphasized. Regulatory policies, procedures, and laws have been passed (national, state or local) to help protect the health of communities. These policies have been traditionally focused on reducing death and disease from infectious agents

Interventions are more successful if they intervene within most, if not all, levels of influence.

### **2.7.2 Strengths and weaknesses of the Ecological Systems Theory**

Unlike most behavioural and psychological theories, the Ecological Systems Theory focuses on interrelation transactions within and between systems and stresses that all existing elements within the eco system play an important role in maintaining a balance of the whole.

However, some scholars argue that the ecological theory is not a theory in the formal sense. Rather, it is a structured framework for identifying influences at numerous levels.

Thus it is not falsifiable. Its value is in alerting clinicians to factors that otherwise might be neglected.

## **CHAPTER THREE: METHODOLOGY**

### **3.1 Introduction**

This chapter presents the methods employed to collect data for the study. Respondents were selected randomly from the beneficiaries of the prevention, care and support services of KCCC and from the communities around. After establishing the methods of data collection, data processing and analysis followed. Editing, coding and creating of themes showed how the data was processed while data analysis was done using SPSS. Lastly, the researcher summarised the problems she encountered during data collection and how these problems were minimised or overcome.

### **3.2 Research design**

The study was cross-sectional meaning that data was captured on one period of collection in time. The cross-sectional study has advantages in that data can be collected from several different categories of people in a relatively short period of time. It is used when purpose of the study is either descriptive or aims at finding the prevalence of the outcome of interest: 1) Usually there is no hypothesis as such, but the aim is to describe a population or a subgroup within the population with respect to an outcome and a set of risk factors; and 2) The purpose of the study is to find the prevalence of the outcome of interest, for the population or subgroups within the population at a given time point.

### **3.3 Study population**

The study population included both beneficiaries of both primary and secondary prevention services, beneficiaries of care and support services, management and staff of the organisation, as well as opinion and community members in the area surrounding KCCC.

### **3.4 Study Area**

The actual area of study is Kamwokya Christian Caring Community (KCCC), a Faith-Based organisation that was founded in 1987, under the umbrella of the Catholic Church with activities related to HIV/AIDS prevention, care, and support. It is located in Kamwokya II parish, Central Division, Kampala district in the Central part of Uganda. Kamwokya II Parish is comprised of up of 10 zones with a total population of 40,000 people as per the last census, excluding the numerous people who come to stay with relatives and friends for longer periods.

### **3.5 Sample Selection**

The study was carried out at KCCC; a sample of 100 respondents was selected randomly and purposively for the quantitative survey. These 100 respondents were beneficiaries of both secondary prevention and care and support programs. It was chosen because beneficiaries of secondary services were also beneficiaries of care and support services.

Five key informant interviews and six focus group discussions were used for to gather qualitative information. Respondents for FGDs and key informant interviews were selected purposively according to the position, knowledge of the informants as regards prevention, care, and support interventions of KCCC. These respondents also provided vital information on primary prevention programs.

### **3.6 Data collection Procedure**

The researcher obtained an introductory letter from the Department of Social Work and Social Administration. This letter introduced the researcher to the management of KCCC, - and these in turn introduced her to the study population. Informed consent was obtained from all respondents before including them in the study. Confidentiality was also promised and kept. The respondents were informed about the nature and purpose of the study and their right to participate or not to participate. Upon agreeing to participate, the respondents were notified of the time, date and location where the interviews would take place. The semi-structured interviews lasted for about 45 minutes. The in-depth interviews and focus group discussions lasted one and a half hours. The researcher used a tape recorder while conducting the FGDs and interviewing KIs but after seeking respondents' consent.

### **3.7 Data collection**

For the qualitative method, key informant interviews, focus group discussions and observation method were used; while structured questionnaires, which also had a likert scale were used for quantitative data. A likert scale is a scale used when responding to a questionnaire whereby respondents specify their level of agreement or disagreement to a statement. It is recognizable when you are asked to indicate your strength of feeling about a particular issue on a 1-5 rating scale. A typical test item in a Likert scale is a statement, which is also a statistical measurement of people's attitudes and opinions.

The five-point scale which included the following kinds of answers was used; 1) Strongly disagree, 2) Disagree, 3) neither agree nor disagree, 4) Agree, and 5) Strongly agree was

used, and the respondents were asked to indicate their degree of agreement with the statements on prevention, care and support services at KCCC.

The likert scale helped to generate more responses on particular prevention, care and support services provided by the organisation, but were not mentioned by respondents in the structured questionnaire. Responses from the likert scale therefore complimented the restricted closed questions in the questionnaire hence obtaining meaningful quantitative answers. A tape recorder was used to capture and store information from the discussions. Document review was also carried out using a checklist.

The following methods were used to collect data:

### **3.7.1 Exit interviews**

Structured questionnaires were administered to 100 respondents who were beneficiaries of both secondary prevention services, as well as care and support services. Respondents were interviewed after receiving services for which they had come for at KCCC on particular days of the data collection. Officials of KCCC guided the respondents after explaining to them the purpose of the study. They were then led to the research assistants to begin the interview.

The exit interviews helped the interviewer to get obtain information on the social-demographic characteristics of the respondents, the nature and categories of services provided by KCCC in respect to primary prevention, care, and support, accessibility to the services in terms of distance, affordability, and availability, their level of satisfaction with the services, challenges they face in accessing the services, among others. The face to face interview coupled with incidental observation of the verbal and nonverbal reactions were advantageous because it allowed probing for more information, flexibility, and clarification of some questions when need arose.

### **3.7.2 Key Informant Interviews**

A key informant guide was used to capture data from five key informant respondents namely; the director of KCCC, the co-ordinator for prevention services, the head of care and support unit, the pastoral leader, as well as the Central Division HIV/AIDS focal person.

Key informant interviews enabled the researcher to get information from the planners/ policy makers and the providers of the prevention, care and support services at KCCC and the Central division in which KCCC is located at large. Specifically, KIs at KCCC provided

background information about the organisation, the nature of services provided by KCCC including HIV/AIDS prevention, care, and support services, the categories of people for which the services are meant for and in what geographical area, the organisation's stand on the use of condoms as a preventive method, challenges faced by the organisation in providing services to its clients, as well as ways in which the organisation can strengthen its role in extending HIV/AIDS interventions, among others; the Central division HIV/AIDS focal person provided useful information on the social-economic characteristics of the people as well as the HIV/AIDS situation in the area where the organisation operates from, the guiding HIV/AIDS policies within which KCCC is supposed to operate, the kind of support government gives to the organisation, advantages faith based organisations in the field of HIV/AIDS, KCCC inclusive have over secular organisations, challenges facing KCCC, as well as ways in which the organisation can strengthen its role in HIV/AIDS response, to mention but a few.

### **3.7.3 Focus Group Discussion**

A focus group guide was used to gather information from six FGD, each having between eight to ten participants. These included two FGDs for beneficiaries of primary (one for men and one for women), two FGDs for beneficiaries of secondary prevention as well as care and support services (one for men and one for women), one FGD for opinion and community leaders, and one FGD for community based health workers as well as community based volunteers.

The FGDs were used to collect data on the nature and categories of primary and prevention as well as care and support services provided by KCCC, community involvement in all the interventions provided, ease of access by the intended beneficiaries to all services provided, challenges faced by KCCC in providing services as well as those faced by its clients in accessing these services and ways in which they overcome these challenges, different opinions about the services provided by KCCC, their quality, advantages KCCC has over other secular organisations, and ways in which KCCC can strengthen its position in the fight against HIV/AIDS, were also gathered, among others. A tape recorder was also used to aid capturing the responses.

The discussions availed information, which the researcher believes were not biased since most of them were not employees of KCCC.

### **3.7.4 Observation**

An observation checklist that included and was not limited to the following; how stigma is dealt with, set up of clinics, counselling rooms, the general wellbeing and appearance of the clients, the schools, the SACCO, the church, space, believers and non-believers of the catholic faith, informal observation helped the researcher to study certain situations, which could not be covered by other instruments.

### **3.8 Data processing and analysis**

The researcher was then faced with a task of processing the data she had collected in a meaningful pattern and in a way communicable to others. This involved both questionnaires used in exit interviews, focus group discussions data, and key information, reducing the data to manageable proportions, summarising it in order to bring out its major features and interpretations as well as presentation of the report. This involved various stages namely; editing, coding, tabulation and interpretation. All this was done in a period of one month.

Raw qualitative information from the key informant interviews and focus group discussions was transcribed and written as narratives. The data was then organised into themes according to the objectives of the study. The general trends were developed from the codes before analysing them for report writing.

A coding frame was developed for the quantitative information and entered into Epidata and later exported to SPSS for analysis. Frequencies and cross tabulations were used and they involved tabulating the lowest and highest values of the study variables for each respondent type and analysing measures of central tendency and variability. Frequencies were generated for the socio-demographic characteristics.

Results from the likert scale were analysed using parametric statistical tests- analysis of variance because the components are not more than five. Data from the likert scales was then reduced to the nominal level by combining all agree and disagree responses into two categories of "service provided " and "service not provided".

Furthermore information from reports and documents supplemented quantitative and qualitative findings of the study.



### **3.9 Quality control**

The research instruments were pre-tested in Rubaga Deanary and final instruments developed and administered in the main study. At the end of each interview, the researcher edited the questionnaire before releasing the respondent. The researcher together with the RA checked all completed research instruments to make sure that all questions were answered properly and clearly recorded at the end of each day. During data analysis, quantitative data was cleaned using an in-built check program within the SPSS package for windows to customize data entry, for automatic skip patterns and validation of data.

### **3.10 Ethical Considerations**

The researcher obtained informed consent from the KCCC authorities in order to access documents on the subject especially concerning secondary data. The respondents were given a brief description of the purpose and procedure of the study. They were also told that participation in the study was voluntary and their identity would be protected. Confidentiality was kept in this study.

### **Problems encountered during data collection**

The researcher faced financial constraints, as there was no facilitation from any Organisation. The researcher herself, who had to toil and look for all the money that she used, purely financed the research.

The researcher on the first day also found it a bit hard to translate the questionnaires from English to the local language (Luganda), a language that was understood by all respondents. However, through practice and consultation with the people who understand the language very well, the researcher was able to come with valid translations the next day.

The researcher also met un-co-operative respondents who were unwilling to give information; this was on a small scale though. However, with the help of a guide, the researcher managed to build rapport with the respondents and explained succinctly the purpose of the study.

One key informant was not available for the interview despite earlier appointments; several efforts to locate her turned futile. The researcher overcame this by using the data she had

collected from other interviews since her interview was going to be a supplement to what the researcher already had, and document reviews. Similarly, most of the documents were considered private property so the researcher had to explain clearly the purpose of the research before they were availed.

Late coming of focus group discussion members was yet another problem. Because it was a free thing without payment, most of them took their time and came many minutes late and after others had arrived. The researcher and members who arrived earlier were patient and agreed to wait for the rest.

The researcher was also faced with a challenge of loss of a key informant interview few days after it was recorded, and the researcher had to repeat it or else it would greatly impact on the quality of data.

## **CHAPTER FOUR: STUDY FINDINGS AND INTERPRETATIONS**

### **4.0 Introduction**

The findings are organised in relation to the objectives of the study. The findings are discussed and interpreted inter-alia. The data is presented using frequencies, percentages and narratives. Lastly, conclusions are drawn and recommendations that will be useful to all stakeholders are presented.

### **4.1 Socio-Demographic characteristics of respondents**

Some of the socio-demographic characteristics that the study took into consideration included; age, marital status, the economic activities engaged in, educational level, religion, and gender of the respondents.

**Table 4.1 Socio-Demographic characteristics of study respondents**

N (100)

| Characteristic    | Variable      | Frequency | Percentage |
|-------------------|---------------|-----------|------------|
| Gender            | Male          | 30        | 30         |
|                   | Female        | 70        | 70         |
| Marital status    | Single        | 14        | 14         |
|                   | Married       | 47        | 47         |
|                   | Separated     | 13        | 13         |
|                   | Divorced      | 1         | 1          |
|                   | Widowed       | 23        | 23         |
| Economic activity | Agriculture   | 4         | 4          |
|                   | Business      | 44        | 44         |
|                   | Student       | 4         | 4          |
|                   | Civil servant | 6         | 6          |
|                   | Others        | 21        | 21         |
|                   | None          | 19        | 19         |
| Education level   | None          | 13        | 13         |
|                   | Primary       | 52        | 52         |
|                   | Secondary     | 25        | 25         |
|                   | Tertiary      | 9         | 9          |
| Religion          | Catholic      | 48        | 48         |
|                   | Protestant    | 24        | 24         |
|                   | Muslim        | 9         | 9          |
|                   | Pentecostal   | 18        | 18         |

*Source: Field data**Note: The missing values are non-responses*

#### **4.1.1 Gender of the Respondents**

The table 4.1 above shows that female respondents, 70% were more than male respondents, 30% who were male. This does not only imply that females utilise services more than males, but also reveals the fact that females have been affected more by HIV/AIDS than males. In this regard, one of the key informants reported that though KCCC had carried out several evaluations for its 15 years of existence, it has been observed that the number of men who come to access services is lower than that of females. And reasons given include; that men basically do not want to associate with free things because they think they have the money to buy these services elsewhere unlike the women; that men, being the sole bread winners are always busy, working from 6:00 am until midnight and therefore cannot access these services during the day; that women are unfaithful and have extra marital relationships therefore are always eager to know their sero status, and if they are found to be positive, they rush to get treatment without the consent of their spouses; that some men are just lazy, and just don't mind about many things including their own health; that most men have the "I know it all attitude"- that they know everything therefore see no need for involving themselves in AIDS awareness activities, whereas the women are always willing to learn and add knowledge onto what they already know, to mention but a few.

#### **4.1.2 Marital status of respondents**

The marital status of the respondents was taken in to account in order to examine its influence on the utilization of prevention, care and support services. It is assumed that married couples have greater access to health services than those that are single, widowed, or separated. Moreover (Gage, 1997), observed that, marital status is closely related to the disadvantages women face in the household, which influence their capacity to use existing health facilities. Analysis of the marital status of the respondents indicated that there were more married couples 47%, followed by the widowed 23%, the single 14%, the separated 13%, while only one person reported having divorced.

Further cross tabulations indicated that there were more females (11) than males (3) who were single. Similarly, there were more females (12) than males (1) who had separated. There were also more females (21) than males (1) who were widowed.

#### **4.1.3 Education level of respondents.**

Each respondent was asked about the highest level of education they had attained. It is clear from the table above that most of the respondents had primary education (52%), 35% had attained secondary education, 9% tertiary education, and only 3% reported not to have had any formal education. Relationship of sex and education level revealed that although most of the respondents who had not received any formal education were women (3), women also had higher numbers of attaining tertiary education (7)

#### **4.1.4 Religion of Respondents**

Since the study was carried out in a faith-based organization, religion was a very important factor as it helped to establish whether KCCC serves only members of their congregations or it serves all without prejudice and discrimination. Analysis of religion indicated that most of the respondents were Catholics represented by 48%, Protestants 24%, Pentecostals 18%, while the Muslims were represented by only 9%. Further responses revealed that despite the fact there are more clients that believe in the Catholic Faith, the services are none-the-less open to everyone regardless of their religious background.

*“I am a Muslim but I do get treatment from here, KCCC has also paid fees for my children”  
(Female FGD, beneficiaries of secondary prevention)*

Asked how the organisation incorporates religion in its services, responses reveal that first of all incorporating all religions in all their activities makes them unique, and different from all other organisations. Respondents said that prayer is a key foundation in the organisations' life and this explains why each working day of the organisation starts with prayers; that all their interventions have biblical scriptures for reference while attending to clients. FGDs had related responses;

*As other people have said, many times we trust God in all that we do and we always say that if it is God's will, that's why people taking medicine trust in God and not the medicine. Even when we go to visit them we do tell them that medicine only can't heal them unless God has worked through that medicine that is why their faith foundation remains strong and important. (Female FGD-CBHW)*

#### **4.1.5 Economic activities of the respondents**

Table 4.1 also shows that the number of the respondents who were self-employed or engaged in business was more 44%. It was discovered that most of them were at one time employed but because of being sick, sometimes they would be on and off work, a habit their employees could not stand hence ended up losing their jobs. They therefore opted to start their own small businesses to sustain themselves, with the help of the micro finance institution in place; 19% were unemployed, 6% were employed by public service, and 4% were engaged in agriculture and being students. 19% of the respondents were engaged in other occupations other than the ones listed above.

It was reported that employment of people in the area is highly dependent on petty trading and among the trade they are doing is the selling of alcohol, which contributes, to the spread of HIV/AIDS. The Key Informants also reported that there is a lot of prostitution that is going in the community.

#### **Age of respondents**

The age of the respondents was another important factor considered in the study. Descriptive statistics revealed that the mean age of the respondents was 39.6 years with a Standard deviation of 10.1, while the Inter Quartile Range was 14. The 25th and 75th percentile was 32 and 46 respectively.

### **4.2 Nature and categories of HIV/AIDS Interventions at KCCC**

#### **Introduction**

The first two objectives of the study were to examine the nature and categories of prevention, as well as care and support interventions provided by Kamwokya Christian Caring Community (KCCC). This section therefore presents the nature and categories of HIV/AIDS prevention as well as care and support services provided by KCCC.

It was discovered that KCCC was among the first organisations to implement the multi-sectoral approach to HIV/AIDS prevention, care, and support, a strategy that does not only address HIV/AIDS from the individual point of view but rather considers other factors outside the individual, and in most cases of which the individual may have no control over. For example issues like poverty, domestic violence, to mention but a few; likewise, care and

support interventions do not focus only on medical care but also deals with other issues that could interfere with effective medical care, like food and nutrition, worrying and anxiety, among others.

*Experience had taught us that only giving medication was not enough; HIV/AIDS goes beyond treatment and remember by then we had no treatment we had care. We started looking at other factors that contribute to the spread of HIV/AIDS and most of the factors were related to poverty. We said how do we deal with poverty. When you look at this community, 70-75% of the people don't have a permanent kind of employment they mainly depend on petty trading around and among the trade they are doing is the selling of alcohol, which contributes, to the spread of HIV/AIDS. There is a lot of prostitution that is going in the community and so many other things. (Director, KCCC)*

*We asked ourselves, now that poverty is contributing a lot to the spread of HIV/AIDS, how we address it, and so we started looking at that site and we have got a comprehensive approach to that. We also looked at the counselling component, spiritually. Because every time we talked to these people they could say they know they have HIV/AIDS and are going to die. They are always were condemning themselves; why them and not someone else. Am I the worst sinner? There was that self-rejection. We decided to build in our programme the spiritual component. People needed someone to accompany them in this journey, spiritually. To affirm to them that although they were sick now, God still loved them. (Director, KCCC)*

#### **4.3 Prevention interventions**

Findings revealed that some of these interventions target both the people living with HIV/AIDS while others are particularly target people that have not been infected by the HIV/AIDS; prevention interventions for the former were categorised as secondary prevention strategies while the ones for the latter, as primary prevention strategies. Beneficiaries of secondary prevention strategies were at the same time beneficiaries of care and support.



*But you see, you will never find anyone who is not infected, at least not in Uganda. Rarely do you find people that are not affected. Our programs therefore rotate around the infected and affected people (Director, KCCC)*

#### **4.3.1 Primary prevention Strategies**

These strategies specifically target individuals who have not yet been infected by HIV/AIDS, and the main targets are the young and the married people. The organisation developed two strategies in line with the AB strategy- the value of life strategy, which is a behavioural change intervention that promotes pre-marital abstinence and the faithful house, which promotes marital fidelity.

Various reasons were given for emphasising AB against C and the main reason being that fact that the Catholic Church on whose foundation the organisation is laid does not support the use of condoms. Other reasons these include but are not limited to the following:

Condoms are not 100% safe and therefore not reliable, as one FGD member commented;

*We have got people from Youth Alive, who came here and taught us that condoms are not 100% safe, because of the long process between transportation and storage and also the wrong way in which people use them. From my point of view, that all puts people's lives at risk. So the Catholic Church is against using condoms. (Pastoral counsellor)*

The Director of KCCC had this to say,

*Our founder member, Sister Miriam Dugan, went to parliament to tassel it out. Very few people by then could understand what she was saying but I am happy to tell you that right now people have started picking on what she was saying because the condom is not the answer to this problem. This lady, the doctor said these things 22 years ago, actually, she is a gynecologist and she said that she had ever seen a woman get pregnant yet she had been using condoms. She actually questioned that if someone can get pregnant while using condoms, then what do you think can stop the virus? (Director, KCCC)*

Condoms encourage irresponsible sexual behavioural. Because condoms offer protection to a certain extent, people see no problem with having multiple partners. This is not only against the religion on which the organisation was founded which emphasises faithfulness to one sexual partner, but also predisposes those involved to HIV/AIDS.

*‘If the organization starts giving out condoms it will encourage people to have multiple partners because with condoms they have got protection. The religion on which the organization is founded stresses that you should not give out condoms’* (pastoral counsellor).

The key primary prevention activities and services include but not limited to the following: public awareness campaigns, voluntary HIV/AIDS counselling and testing (VCT), diagnosis and treatment sexually transmitted infections (STIs), rehabilitation and resettlement, sports and recreation activities, economic empowerment, and advocacy.

### **Public awareness campaigns**

KCCC is involved in public awareness campaigns to sensitise the public not only on HIV/AIDS prevention but also prevention of other diseases like malaria; and other public health issues that affect the community;

*KCCC has also organised an AIDS week every December where we come and march with a band. We are given T-shirts. In doing so we remind people the reality of AIDS, since Kamwokya is a slum area, it is easy for someone to contract the disease. They also give us condoms every time we meet in large numbers. Then they also take us to visit those patients that allow to be visited (Male FGD-beneficiaries of primary prevention services).*

The various programs developed by KCCC to reach out to people at the grassroots include; capacity building also referred to as the peer-to-peer strategy, mainly targets the youth. It involves training the youth to reach out to fellow youth on issues relating to HIV/AIDS prevention. Here the youth are trained to train many other young people; this is because young people easily identify with peers other than the people who are older than them.

The community and school outreaches: Study findings revealed that the community is fully involved in all their interventions-through different avenues; first they have the intended beneficiaries, specifically the people living with HIV/AIDS who share their own experiences and pioneer preventive activities within the communities in which they live; peer educators who mainly target groups of people in public places for instance car washing bays, market places, special hire drivers stages, taxi drivers' and conductors, among others; visiting schools both primary and secondary, and other institutions, to sensitise them about HIV/AIDS;

Child care advocates who are trained to address the needs of the children at the community level like child abuse, neglect, and violence against children in the community; community based health workers (CBHWs) who train members of the community to become community based volunteers (CBVs); advocacy focal persons who are members of the community trained in identifying advocacy issues within the communities in which they live, for the organisation to further action, local councils, and other community based organisations (CBOs) that are doing work related to prevention.

The structures are represented at every program level so the views and opinions of the community are considered during the planning process.

*In this organisation we have trained over 300 community volunteers for the last 20 years in these aspects ranging from child abuse, community related health issues and so many others. We have trained them and they have got skills and all we need from them is their commitment, people who will be there actually our ART programme have been ranked the most successful. We have had less people die at our clinic here. We were cubed 90 plus and the main reason is our volunteers (Director, KCCC).*

*KCCC invites community members and leaders during their midterm reviews and evaluations. They then ask for the neutral view of the common man. Usually these people from the community talk about the weaknesses of KCCC and we improved in that area. This is a way that helps involve the common man and giving him a chance to run the organisation (Female FGD opinion leaders/community members).*

## **Diagnosis and treatment of sexually transmitted infections (STIs)**

Because sexually transmitted infections (STIs) predispose individuals to HIV infections, KCCC open up a general clinic, the Treasure Life Youth Clinic, targeting mostly the youth who are considered the most vulnerable to STIs, and it works in partnership with Naguru Teenage Centre.

*Here we provide treatment of Sexually Transmitted Infections (STIs). STI infections predispose the young people and make the chance of a person to get HIV so high if you are already found to have STI, so we provide STI treatment at our youth clinic which opens every Tuesday but we do that in partnership with Naguru Teenage information and health centre (co-ordinator for preventive programs).*

## **Sports and recreation:**

This is one of the unique interventions in HIV/AIDS prevention that targets the youth. Indeed as the saying goes “an idle mind is a devils workshop” after discovering that many youth were engaging in risky sexual behaviour due to idleness, a youth centre-Treasure Life Youth centre was established to engage the youth in useful games like basketball, table tennis, net ball, to mention but a few.

It is a behavioural change intervention that involves using sports like football, net ball and basketball, among others not only as a leisure activity that occupies young people during their free time but also purposely use it to as development intervention to develop the young people in totality. For example they do HIV prevention drills as they play, and a manual was specifically developed for this purpose. It involves talking to young people about issues of career through the peer educators who are at the same time the coaches in the respective games.

## **Advocacy**

Responses from focus group discussions indicated that KCCC has put in place a department of advocacy that has been very instrumental in teaching and sensitising people about domestic violence for example, what to do and where to go in case you have been abused at home. This has drastically reduced the oppression of women. Domestic violence is one of the leading factors responsible for high prevalence rates of HIV/AIDS because it leads to have extra marital relationships in search for revenge and comfort.

*Domestic violence has been contributing a lot in spreading HIV/AIDS in this area. But now KCC put in a place a department of advocacy that has been very instrumental in teaching/sensitising people about domestic violence – how someone can be helped in case she/he is being abused at home. It has stopped the oppression of women. Domestic violence has been contributing faster in increasing HIV/AIDS because it leads to have extra marital relationships in search for revenge and comfort (Female FGD-beneficiaries of primary prevention services).*

### **Rehabilitation and resettlement**

Rehabilitation and resettlement is one approach that cuts across, and it involves rehabilitation and resettlement of people involved in drug abuse. This is done by visiting their collection centres, referred to as bases. They are called bases because they are just collection centres for the young people- where young people meet on a temporally basis at particular times to use drugs; those who have the will to change are identified and incorporated in the vocational school. This is one way of reducing their vulnerability most especially girls who might be involved in transactional relationships or commercial sex as a way of earning.

*The organisation is the reason we don't have street children. They put in place a vocational school, even if you stopped in primary 5 whatever level you dropped out of school from, they have courses that everyone can afford – whether you stopped in primary 5, primary 6 on senior 1, they have different courses they give them to be able to sustain themselves financially instead of going to beg on the streets ( FGD- community members and opinion leaders).*

*KCCC has helped some of us who were on the street; they gave me a home where to stay, educated me and even gave me a job after educating me (Female FGD-beneficiaries of primary prevention services)*

### **Economic empowerment:**

The savings and credit co-operative was established to empower people economically hence making them less vulnerable to HIV/AIDS infection. For example women have been able to start up their own businesses instead of engaging in commercial sex for survival; parents are able to send their children to school hence reducing their vulnerability.

*‘Once the house hold gets some money, the children are also able to go to school and once they go to school and become educated so education is an empowerment that helps towards prevention’ (coordinator, preventive services).*

*KCCC borrows us money at low interest rates to start our own businesses so we do not have to do prostitution to earn a living, we are able to look after ourselves, pay our children’s fees, and look after our mothers and fathers ( Female FGD-beneficiaries of primary prevention services)*

### **Voluntary counselling and testing**

Study findings revealed that counselling is not only centralised at the clinic but also rather taken nearer to the communities, to the people who need it. Trained community based health workers in counselling skills pioneer this program, and each zone, of the 10 zones in Kamwokya has one community based health worker who also trains community members to help people at the grassroots.

*It has helped in voluntary counselling and testing for HIV among women to know your sero status. It goes into communities sensitising people about HIV, how it is spread how to avoid it, the dangers etc, and this has encouraged many women to test. That’s why you see that women have put in a lot of efforts in business relating to HIV/AIDS than men. Women have come out to test and speak openly about HIV/AIDS, because they are the pillars of their homes unlike men who in most cases do it in secrecy (Female FGD-beneficiaries of primary prevention services).*

#### **4.3.2 Secondary prevention interventions**

Unlike the primary prevention strategies, secondary prevention strategies mainly target people living with HIV/AIDS (PLWHAs), with the main aim of preventing further spread of the disease, and these include but are not limited to the following; routine counselling and testing, public education programs, accessible diagnosis and treatment of other sexually transmitted infections (STIs), prevention of mother to child transmission, HIV/AIDS partnerships and referrals, prevention between sero discordant couples, diagnosis and treatment of opportunistic infections, information on the use, and actual supply of condoms, among others.

**Table 4.2 brings out the range of secondary prevention services.**

(N=100)

| <b>Secondary prevention strategies</b>           | <b>Service provided<br/>(%)</b> | <b>Service not provided<br/>(%)</b> |
|--|---------------------------------|-------------------------------------|
| Routine counselling and testing                  | 89                              | 2                                   |
| Public education programs                        | 73                              | 8                                   |
| Accessible diagnosis and treatment of other STIs | 69                              | 9                                   |
| Prevention for maternal-to-child transmission    | 17                              | 77                                  |
| Prevention between sero-discordant partners      | 63                              | 22                                  |
| HIV partnerships and referrals                   | 81                              | 6                                   |
| HIV/AIDS prevention capacity building activities | 55                              | 20                                  |
| Prevention of other diseases than HIV/AIDS       | 61                              | 25                                  |
| Prevention for people living with HIV/AIDS       | 45                              | 32                                  |
| Information on the use of condoms                | 68                              | 10                                  |
| Supply of condoms as a preventive measure        | 30                              | 55                                  |

*Source: Field data*

*Note: Missing values account for non-responses*

### **Prevention between sero- discordant couples**

This is done through partnership with other health and social support agencies learning and referral purposes but to also cover the gaps, and 81% of the respondents reported to have benefited from partnerships and referrals initiated by KCCC.

Through partnership with other organisations like Naguru teenage centre, Reproductive Health Uganda, KCCC is position to avail its clients with preventive interventions like condom supply, and other family planning methods that the organisation may not be in position to supply due to its religious beliefs and values. Various responses revealed that the values of the faith on which the organisation was founded do not permit it to provide all

family planning services, the use of condoms inclusive, so to cover this gap, the organisation found necessary to partner with RHU to help their clients who are in need of such services.

*KCCC does not give us condoms but they bring other people who give us condoms (FGD-male beneficiaries of secondary prevention)*

There were mixed reactions from the particularly those living with HIV/AIDS on whether they receive both the knowledge and the actual supply of the condoms, and 68% and 30% responses respectively were recorded.

However, one key informant refuted claims that the organisation distributes condoms to its clients but rather agreed to the fact that they do share information regarding condom use and then work in partnership with organisations that promote condom use to help those who would have made a choice of using the condoms, particularly the discordant couples.

*We also share the information about the condoms by the way but we don't distribute them. We talk about the benefits and disadvantages so that someone can make an informed decision just like the same way we do with abstinence and faithfulness; we talk about the benefits and the disadvantages so that someone at the end of the day makes an informed decision. (Co-ordinator for the preventive programs-KCCC)*

### **Prevention of other diseases**

Responses from the focus group discussions revealed that KCCC has organised seminars and workshops in communities and the themes included HIV prevention, helping women on personal hygiene, nutrition for example emphasizing that even if they do not have money to buy expensive foods, they can still have a balanced diet with the little money that they have.

*“We are involved in sensitising and training both the infected and affected people in disease prevention; this includes all diseases, HIV/AIDS inclusive” (co-ordinator for preventive services).*



#### 4.4 Care and Support services

**Table 4.3 shows categories of care and support services  
(N=100)**

|  | <b>Service provided<br/>(%)</b> | <b>Service not provided<br/>(%)</b> |
|--|---------------------------------|-------------------------------------|
| <b>Medical care</b>  |                                 |                                     |
| Routine clinic care and referral                               | 83                              | 2                                   |
| Provision of ART   | 84                              | 2                                   |
| Treatment of OIs like tuberculosis                             | 81                              | 5                                   |
| Time limited support for clinically malnourished PLWHA         | 38                              | 24                                  |
| Support for adherence to ART                                   | 72                              | 9                                   |
| Treated mosquito nets  | 46                              | 29                                  |
| Nutritional assessment and counselling                         | 71                              | 4                                   |
| Promotion of good personal and household hygiene               | 72                              | 11                                  |
| Basic preventive care for PLWHA and their families             | 41                              | 10                                  |
| <b>Psycho-social support</b>                                   |                                 |                                     |
| Mental health counselling and treatment                        | 45                              | 11                                  |
| Support for disclosure of HIV status                           | 67                              | 11                                  |
| End of life and bereavement support                            | 39                              | 27                                  |
| Peer support groups for those found HIV positive               | 87                              | 15                                  |
| Nutritional support  | 31                              | 31                                  |
| Efforts to reduce stigma                                       | 74                              | 11                                  |
| Legal services like in succession planning, inheritance rights | 21                              | 27                                  |
| Support to income generating programs                          | 71                              | 17                                  |
|  |                                 |                                     |

|  |    |    |
|--|----|----|
| <b>Spiritual support</b>   |    |    |
| Interventions sensitive to cultures and religions of individuals and community | 78 | 6  |
| Life review and assessment   | 48 | 13 |
| Counselling related to hopes and fears   | 81 | 8  |
| Counselling related to meaning and purpose                                     | 76 | 8  |

Source: Field data

Note: The values account for non-responses

#### 4.4.1 Medical care

Medical care provided by KCCC consists of routine clinic care and referral, provision of AR for people whose CD4 count is between 200 and below and septrin for those whose CD4 count is above 200- and by the beginning of 2009, a total of 1500 people were on ART; treatment of opportunistic infections, Time limited support for clinically malnourished PLWHAs, support for adherence to anti-retroviral therapy, provision of treated mosquito bed nets, nutritional assessments and counselling, promotion of good personal and household hygiene, and basic preventive care for PLWHAs and their families.

Responses from the focus group discussion revealed that there was reduction in mortality rates, an implication of the effectiveness of the medical care given.

*People are no longer dying because they are counselled and given treatment. Before, many people were dying of HIV/AIDS but KCC has reduced the number, thanks to KCCC, which has done a big job in sensitising people about HIV/AIDS. People around the community have been encouraged to test. In 1989 before KCCC came in place, I lost many children but had there been treatment, they would still be alive, because their peers who started taking medication immediately KCC started giving are now healthy and alive. (FGD- opinion and community leaders).*

Another key component of medical care is HIV paediatric care and support for children living with HIV/AIDS aged 18 years and below; it involves provision of Anti-Retroviral therapy (ART), HIV/AIDS counselling and testing, two peer support groups, among others.

It was revealed that a total of 239 children had been reached in 2009, of which 26% were positive. The number of children on ART is 72% while the Non ART are 28%.

It was discovered that most of the patients on Anti Retro Viral treatment responded positively, indeed as one FGD member asserted;

*'It has given us medicine very well, the first time they checked my CD4 count before I started taking medicine it was 210 but now it is 1098'(Female FGD –beneficiaries of secondary prevention and care and support.)*

*I felt bad when my children died because there was no medicine at that time and whenever I see people who have come to KCCC and received and get better, I think about my children and believe that if they had fallen sick at the time KCCC was in place, they would not have died (FGD- community and opinion leaders).*

### **Routine clinical care and referral**

KCCC provides routine clinical care and referrals and clients with cases that are too serious to be handled by the clinic are referred to hospitals like Mulago, Nsambya, Mengo, among others. This was also supplemented by clients responses on how often they come to the clinic - The majority of the respondents 71% reported that they access clinical care when need arises usually when they get ARV stock outs, 10% monthly, 5% on a weekly basis and 3% daily.

In addition, the researcher conducted the research during weekdays on normal working days and hours, which also happened to be the normal working days and hours for the clinic and she was able to observe the aspect of routine clinical care.

As far as referrals are concerned, the organisation is involved in networking with other clinics and hospitals that deal with HIV/AIDS or HIV/AIDS related issues. For instance, Nsambya hospital, Mulago hospital, The AIDS Support Organisation (TASO), Joint Clinical Research Centre (JCRC), Mild May Centre, to mention but a few.

*There are complicated cases we cannot handle; we refer these people to other hospitals for example Nsambya hospital. When we refer these people, we monitor them and take care of them too. Other examples of network are TASO, JCRC- Joint Clinic Research Centre, Mbuya and many others. With the children we refer them to the specialised people at Mild may.*

*Mildmay also helped us set up that laboratory to diagnose and also test (Head, Care and Support, KCCC).*

### **Support to Drug adherence**

Adherence is a client's behaviour coinciding with the prescribed health care regimen. Regimen is agreed upon through a shared decision making process between the client and the health care provider. Adherence is perceived as a patient agreeing to make behavioural changes that improve his or her health.

Study findings established that people are not only given treatment and left on their own but a follow up is made to ensure that they take the right amounts of the drug, at the right time and on the right diet. Community-based workers follow up patients to their residential places, irrespective of the distance, mainly do this.

*Before you start ARV, KCCC counsels you and prepares you for treatment, so the Medical care has helped the sick people because they have followed the rules and regulations of the ARVs, so counselling has helped a lot because by the time you start taking medicine, you already know what to do. In addition to the above, KCCC has community based health workers who follow up patients and monitor how they are taking the medicine, the problems they are facing and they help them in overcoming them". (Male FGD –beneficiaries of secondary prevention).*

### **End of life and bereavement care**

End-of-Life and bereavement care is directed toward the individual and family members in need of intensive management of symptoms and pain as a result of HIV/AIDS.

The spiritual leader had this to say;

*"We have got desperate patients without extended families. Recently we lost one of them and she was supposed to be buried in Lusaze cemetery, we got one of our ambulances, bought a small piece of land in Lusaze cemetery and buried her there.*

*She left behind a teenage daughter who also, like the dead mother, did not have an extended family to fall back to. So you can see what kind of support we give. We mainly give this kind of support to people who totally have no one to help, for those who still have an extended*

*family we provide transport. But the experiences we have gotten are where people leave village and by the time we take them back, their relatives died or sold their plots of land. We have gone through situations like this and also similar situations". (Pastoral leader).*

#### **4.4.2 psycho-social support**

This involves mental health counselling and treatment, support for disclosure of HIV status, end of life and bereavement care, efforts to reduce stigma, peer support groups for those found HIV positive, nutritional support, legal services like succession planning and support to income generating services.

##### **Efforts to address stigma**

KCCC has a very good approach of addressing the issue of stigma. Their clinic is also open to members of the general public as well, so one cannot tell what kind of treatment one is coming for. Indeed as the Director stressed;

*When you go down there, you won't know who is positive and who is negative. My own children come here, my youngest son was brought here for treatment and personally when I am sick, I get my treatment from down there so one doesn't need to know whether I am HIV/AIDS negative or positive; all our members of staff to get their treatment from down there. The HIV positive patients share the same toilets with everyone. So I think we have got a different approach and for us we have dealt with the stigma (Director, KCCC).*

Other responses indicated that the organisation has endeavoured to sensitise people about stigma, indeed as one FGD member commented;

*"It has sensitised people about stigma you know women are naturally backbiters, and when they get to know that you are sick they start pointing at you because you are sick, KCC has helped to stop this"(Female FGD –beneficiaries of secondary prevention, care and support).*

The research also observed the fact that the organisation has made several efforts to fight stigma. While conducting research at the organisation, it was hard for the researcher to differentiate between people living with HIV/AIDS and those that are not, unless asked about their sero status. Similarly, all the people living with HIV/AIDS interviewed had no problem with revealing their sero status.

### **Peer-support groups for PLWHAs**

Study findings revealed that there is a peer support group for people living with HIV/AIDS known as the post- test club. Other responses from the respondents revealed that a post-test club was established in this respect, to bring them together so they can share their challenges and life experiences, to promote disclosure and sensitisation in the communities in which they live.

### **Support to income generating programs**

KCCC provides support to income generating activities in order to empower the beneficiaries financially. Other responses from the FGDs indicated that KCCC established a Savings and Credit Organisation (SACCO) to enable clients to save and borrow money to start and expand their income generating activities.

Study findings revealed that a credit facility (Kamwokya Christian Caring Community Savings and Credit Co-operative Society) was established to help boost the incomes of those affected and infected with HIV/AIDS, after discovering that many people had lost their jobs due to being on and off duty because of various illnesses, and that some could not cope with the job related challenges given their weak health. They are allowed to access loans with a very low interest rate. The majority of the respondents were in support of the existence of the credit facility, and its role in improving their household incomes

*‘It has established income-generating activities like the circle that borrows people money according to the purpose of borrowing’’ (Female FGD-secondary prevention and care and support).*

### **Support for Orphans and Vulnerable children (OVC)**

Findings from the study established that orphans and vulnerable children are categorised into three groups, namely; those children that have the extended family support and care after the death of both parents, however, this category is greatly affected by the fact that the extended system is dying out because people are overwhelmed.

The second category is the one where both parents are dead and they have no extended family system at all. This involves adoption although it’s a very sensitive and complicated area due to the legal procedures involved.

The third category is one where parents have died, there is no extended family system and no one is willing to take up the orphans for adoption. Here the organisation constructs its own homes known as foster homes and in the last 20 years they have had over 50 children in these homes. Here, foster mothers are identified from the community, these are good, single mothers who take up these children, look after them and bring them up as their own. The organisation comes in to provide all their basic needs including education.

A common example of these foster homes is a unique building that was constructed by the British Broadcasting Corporation (BBC) crew in one day in 1999.

*We have got special cases that I would like to share with you; there is a girl we found at the bus park with her mother and brother. The mother was HIV positive and dying, she had been married to a soldier who died and she had nowhere to stay, she resorted to sleeping at the bus park; that was during those years when we still had the bus park. We picked up this woman and brought her to one of our homes. She died after sometime, so did the young boy who was also infected. We took the young girl to school and later graduated at the university. She's now an assistant secretary of one of the Ugandan commissions (Director, KCCC).*

### **Education support services**

There have been several interventions introduced by KCCC to support education for its orphans and vulnerable children and the surrounding community at large. KCCC educates orphans from primary up to university level.

*"I for one I am very thankful to KCCC because they have educated my orphans (paid school fees for them) from primary to university. That is why they have educated many people and up to now they are still paying school fee for my children" (Female FGD-care and support)*

Sister Miriam Dugan Primary School was established in to cater for orphans and vulnerable children; and also members of the community, those who can afford are required to pay some small amount of money, while those that cannot afford-particularly those whose guardians are living with HIV/AIDS and are bedridden, are allowed to study for free.

One of the participants in the FGD for women said that after educating her, the organization employed her as a community based health worker.

In addition, a vocational institution called Kamwokya Vocational Training Centre (KUTC) was established, not only as a way of supporting orphans and vulnerable children but also as a preventive measure for HIV/AIDS by engaging the youth in various skills in carpentry, tailoring, brick claying. The institution has drawn many children from the streets. To the surrounding community, the institution enrolls students with all educational levels and the courses are tailored to the low incomes that are common to the people of the area. The vocational institution also offers Functional Adult Literacy (FAL) classes for those who stopped in primary and would like to study more.

### **Provision of shelter**

This involves construction and furnishing of houses for widows, orphans and vulnerable children, sick people, and other vulnerable members of the community like the elderly; and furnishing them with the basic necessities like mattresses, blankets, bed sheets, saucepans, plates, mosquito nets, to mention but a few.

The organisation also has its own houses where they house people infected and affected with HIV/AIDS with no immediate families. This is because Kamwokya is a migrant community, which is always on transit. There are so many people coming from other countries like Rwanda and when many of them fall sick, they don't have support from their extended families to help them. One official emphasized this point;

*Some people live in shacks, when we go out to them we find them in these places and we build them houses for example, recently there was a lady that had separated from her children and was living in a shack, we built her a house and some three more rooms for renting off, now she has where to live and also get some financial support. Not only her but also their other people that have gotten small houses to stay but at least houses in very good conditions (Head, care and support, KCCC).*

*To add on that, us who cannot help ourselves, they have constructed for us houses – fully furnished with beds, blankets, mattresses, bed sheets, saucepans, plates and all other things, they give you everything, we also get food - soap, sugar, mosquito nets. They gave us everything (Female FGD-secondary beneficiaries).*



## **Home and hospital outreach programs**

These are follow-up programs for beneficiaries. The organisation's policy is that once one becomes a client, he becomes part of the organisation's family and the organisation follows that person up until death. One of the reasons for these outreaches is to ensure that the client takes his/her drugs as prescribed, to identify any other problems that the client may be facing, among others.

The organisation has trained over 300 community-based workers in the last twenty years for this purpose.

Responses from the key informant interviews revealed that the organisation has got outreaches on a daily basis, done by the Community Based health workers and volunteers, who reach out to its clients in their homes and hospitals for those that are referred.

*In an institution like a hospital, you cannot know where these people live when they leave, but here we visit them at home, we find a way of getting to their homes and build a relationship with them. When we don't see them here, coming for treatment we go to their homes and find out what is wrong. We also teach them basic skills of nursing themselves at home and also teach these people who take care of themselves (Head, Care and Support Department, KCCC)*

### **4.4.3 Spiritual support**

KCCC does provide spiritual interventions that are sensitive to culture, religion(s) and rituals of the people for which they are meant for and this takes the form of counselling related to life review assessments, counselling related to hopes and fears, and counselling related to the meaning and purpose of life.

Study findings revealed that pastoral or spiritual support is a key component in the well-being of not only people living with HIV/AIDS and those that have been affected by the pandemic in one way or the other, but to the organisation as a whole. Responses from the respondents revealed that the organisation starts everyday with prayers. The researcher also observed this during her one month's stay at the organisation while conducting research.

*That's why you see that even the organisation itself never starts a day without prayer. We gather all the employees for morning prayers and this has helped us a lot. There are times*

*when the donors can't give us any more funds but through the prayers, miracles do happen (head, care and support).*

*Pastoral counselling helps them release forgiveness for self, others and to God. (Pastoral leader)*

This kind of support had its origins from the weekly meetings of small Christian community commonly known as “kabondo”, where the members used to pray together, share bible readings, and practice mutual support and services to others, to help bring about a renewal of their church as a community of believers who care about other people, as well as ways of coping with AIDS, a disease which had provoked a mixture of confused emotions and responses-including fear, shame, denial, censure, and outright panic, not only in Uganda but the world over. Quoting the bible in Acts 2:37-40, where early Christians used to meet to share the gospel and when they found needy brethrens, they would sale their land and share the proceedings with the needy.

Pastoral care addresses the major life events that cause people to question themselves, their purpose and their meaning in life. The majority of the respondents 68% revealed that the interventions are sensitive to the culture, religion(s) and rituals of the intended beneficiaries.

*The organisation is catholic based but even us Moslems are there. They organise 2 retreats for clients twice in a year, with different people giving testimonies and thanking God for keeping them alive and happy despite the fact that they are sick. These retreats have clients from different religious backgrounds-Catholics, Moslems (I am a Moslem but I attend), and even born again Christians (Female FGD-beneficiaries, care and support)*

*...We are very sensitive not to discriminate people. When we are counselling, we make sure that in the first dialogue we get to know you, including your faith foundation then we start a relationship that i not discriminatory. By the way for example if I am counselling a Moslem, I try so hard not to mention Jesus' name but when I pray of course I pray to him because to me he is the supreme power that heals (Pastoral leader).*

It was also discovered that various messages are passed on to beneficiaries during pastoral counselling and some of them include the following;

*“No prayer is little or insufficient, every prayer is so powerful.”*

*“Your life is in God’s hands, hence the need to turn to God because it is not only HIV/AIDS that is killing people but several other illnesses, if someone turns to God, he/she gets courage and believes that with God all is possible”.*

*“If it is God’s will you will get well, trust in God but not the medicine because medicine alone cannot heal unless God has worked through this medicine”.*

*“God does not condemn you, he still loves you”*

*“There is a living God that you can trust, put your life in His hands”*

*“God is with you through your pain and since you are a part God’s body he feels the pain too”*

*“Intentional spread of HIV/AIDS is sin and punishable by God”*

*“If it is God’s will you will get well, trust in God but not the medicine because medicine alone cannot heal unless God has worked through this medicine” (Pastoral leader)*

#### **4.5 Evaluation of Prevention, Care and Support services by KCCC**

The evaluation was done in terms of accessibility to the services by the intended beneficiaries, reasons for the respondents’ choice of KCCC for services, the impact of these services on the intended beneficiaries, challenges beneficiaries faced in accessing these services and the advantages beneficiaries think KCCC has over other organisations in the same field.

##### **4.5.1 Accessibility to prevention, care and support services**

Accessibility in terms of distance, availability and affordability of services to respectively by the intended beneficiaries was the main focus

##### **Distance**

The study sought to establish the average distance of the beneficiaries from their residences and the findings indicated that the average distance from respondent’s residence to KCCC is 5km, with a standard deviation of 12, inter quartile range of 4km. however; the 25th and 75th percentile was 1 and 5km respectively. 88% and 75% of the respondents found it easy to access care and support, as well as prevention services respectively, compared to 10% and

8%, who said that they were accessing the same services with difficulty, because of the long distances travelled from their homes to the organisation.

This implies that the services are within the reach or are accessible to the beneficiaries, who from the findings are the people within Kamwokya Parish and the surrounding communities though spreading on a small scale to other surrounding areas.

From the key informant interviews, the study established that by registration, the organisation is supposed to operate within Kampala District, but because people do appreciate their services, people come from as far as Masaka, Mbarara, Jinja, and even DR, Congo. The organisation makes referrals to these people that come from far but even then, they insist on coming to Kamwokya because to them, services provided at Kamwokya are different from those that are provided elsewhere.

*Our emphasis, though has 80% of our efforts to the community here and the neighbourhoods like Kyebando, Bukoto, part of Ntinda and Mulago, then the 20% has been spiced in the city, but because of the other experiences of the transit community we are working I, we have been forced to follow up on our clients even beyond Kampala district, for example if one is put on treatment and they are in Luweero, because of that adherence component, we are forced to follow them up. But our plan is to ensure quality service delivery and that's why we have so much concentrated around here. (Director-KCCC).*

### **Affordability:**

For the clients, the services are free except for a fee of 1500 meant for treatment of opportunistic infections, and for the general community, the services go for between 5000 and 6000 Uganda shillings regardless of the treatment, which is considered to be much less than what is offered on the market.

*There are no payments at KCCC, ARVs are free of charge and for other opportunistic infections, you only pay 1,500/= however expensive the drugs may be, compared to other hospitals which charge highly for diagnosis and treatments of other Opportunistic infections even for their clients, even if you do not have the 1,500/=:, they still treat you and give you medicine (Male FGD-beneficiaries of secondary prevention).*

*We have a clinic called Treasure life clinic that treats us when we get sexually transmitted infections. Treatment is not completely free but we pay 1500 even if they give you drugs for 20,000, they still charge you 1500, and even if you don't have the money, they treat you for free (Female FGD- beneficiaries of primary prevention).*

### **Availability**

The study also sought to establish whether the various services were available to the intended beneficiaries whenever and wherever they needed them. In relation to medical care, most of the respondents (60%) agreed that they were able to access medical services with ease on weekdays, and that doctors are always available to see the patients. However, the services could not be accessed on weekends (Saturday and Sunday) because the clinic does not open. The researcher sought to establish why the clinic does not open on weekends and this was the response;

*KCCC is a faith-based organisation and on Saturdays the employees have to rest and go to church on Sunday*

*This organisation operates on a budget; it has a budget work plan it submits to the funding bodies. So depending on the budget work plan, the workload is also planned, weekend in the technical world is overtime so the employees will ask for extra pay and that strains the budget (Head, Care and Support Department).*

In relation to the availability of psychosocial and spiritual support, the study established that spiritual support was incorporated in each and every kind of support. In other words being a faith-based organisation, faith is incorporated in each and every intervention, and most of the respondents 65% were in support of this view; in regard to psychosocial support, respondents agreed that all the other services are readily available apart from nutritional support. They were concerned that the organisation used to provide nutritional support (provision of food to all its clients) to all its clients but this had long ceased to exist without explanations. However some respondents 22% as shown in table 4.4 were in agreement of the view that food and nutritional support still exists.

As far as prevention is concerned, 52% of the respondents agreed that they were receiving sensitisation messages easily while 30% agreed to be receiving condoms from the organisations partners easily.

*KCCC sends people with experience in HIV/AIDS to the community, Churches and Mosques and they are given chance after prayers to sensitise people about HIV/AIDS, how it is spread, how to avoid it.*

*They even put seminars to educate people for example Moslems are known to have more than one wife so they are educated to stay with only the ones they have and to be faithful to them and to avoid extra-marital relationship, and the dangers of not being faithful to your partner (Male FGD-beneficiaries of primary prevention).*

Respondents were also asked how they got to know the preventive activities available at KCCC. Analysis of data showed that the majority of the respondents 54% knew about the availability of KCCC services from friends, 10% from household members, 6% from the church, and 2% from the radio/TV. Other avenues were represented by 23%.

Respondents were also asked how they got to know the availability of the care and support services. 60% reported that they knew about KCCC providing care and support services through friends who had accessed the same services and medication made them better, 23% from household members, 10% from the church, and 18% through other means. Only 1% said they got knowledge about KCCC services from the radio/TV.

#### **4.5.2 The choice of accessing services at KCCC**

The study also required knowing why respondents decided to access services at KCCC and not from other organizations. As far as prevention is concerned, 58% of the respondents reported that KCCC is near their homes, 46% said it was due to the fact that the services are cheap and the organization being the faith foundation represented by 9% and others 8% respectively.

The majority 60% of those accessing care and support services reported that they decided to access the services because the medical care given makes people well, 20% said the doctors are polite, 15% said the services are free while 5% said because of their faith foundation.

### **4.5.3 Impact of the services on the beneficiaries**

Asked whether the services sought at the organization have had a positive impact on their lives, 88% said Yes to care and support services compared to only 2% who said No. Several reasons were also identified for the positive impact on the respondent's lives. 21% said they now look good and healthy, 19% said they do not get sick easily, 15% reported that they have hope, 15% that they get free treatment, 8% that they were sick but now can easily express themselves, and 7% that the medication given has no side effects.

For preventive services, most of the respondents (59%) agreed to have changed their risky behaviours and lifestyles- such as having multiple partners, having irresponsible sexual intercourse, over drinking alcohol, smoking, to mention but a few, because of the organisations sensitisation campaigns; 25% of the respondents reported that they now know their HIV status, 18% of the respondents have used the information to sensitise others.

More responses from the key informant interviews revealed that the services have really had a great impact on the intended beneficiaries; that the medication has given people more years to live hence helping them to raise their children; children have been able to study using our education services-acquiring skills in carpentry, tailoring, brick claying; for those who have died, they have died with dignity and peacefully; the information given has been able to help many live positively without infecting other people, among others.

Respondents from the female FDG expressed how the information and experience they have gained from KCCC has helped them too, in turn, advise other people from their communities. They said that;

*Most people, when we see friends who don't look healthy, we talk to them and even encourage them to go to KCCC for help and these people believe in what we tell them. So they go to KCC C and get treatment and when they get better, they also refer to other KCCC (Female FGD beneficiaries of care and support).*

#### **4.5.4 Advantages FBOs have over secular organisations**

The study sought to establish what advantages faith-based organisations have over secular organisations in the field of HIV prevention, care and support, as far as service provision is concerned.

23% of the respondents reported that FBO staff are quick to attend to patients, 10% said that they provide good hospitality, 18% reported that they do not discriminate. Other reasons given included: counselling that is provided gives them hope and purpose of living (20%) while 30% said that the services provided are cheap - ART is free of charge and the drugs for other opportunistic infections cost only 1,500/= compared to other secular clinics which charge highly for diagnosis and treatments of their clients, among others.

*“At KCCC even if you do not have the 1,500/=:, they treat you” (Female FGD-beneficiaries of care and support).*

Responses from the key informant interviews revealed that the FBOs have a much wider perception in terms of reaching out to support and provide care, especially given the fact that HIV/AIDS is not only a medical issue but cuts across and therefore the FBOs have the capacity to provide for this kind of a multi sectoral approach to HIV/AIDS.

The community-based approach is another advantage; respondents noted that FBOs have been able to achieve their goals because of the community-based approach that takes services nearer to the people

Further responses argued that FBOs are governed by the principles of the faith which they belong to and to be called an FBO, the background of a faith component has to be really apparent in the work that they do, so FBOs exhibit the values of care, love and compassion that are embedded in their faith during service delivery.

#### **4.5.5 Challenges faced by beneficiaries**

The study also sought to find out the various challenges faced by the clients in accessing the HIV/AIDS Prevention, Care and Support services from KCCC. They identified the following challenges. These ranged from KCCC staff being slow; Respondents observed that staff at KCCC is slow when serving clients, however, further investigations revealed that staff at KCCC is overwhelmed by the ever increasing numbers of clientele every day, and that each



time their clients come, they are subjected to a number of clinical investigations for follow up purposes;

Not working on weekends: 25% complained about KCCC not working on weekend

However, several reasons were advanced in support of the organisation's failure to operate on weekends, ranging from operating on a tight budget that has no provision for weekend allowances, operating a clinic and not a hospital, and being a faith based organisation hence cannot work on Sunday in particular.

Patients lack money for transport to KCCC 20%, particularly for those who have to travel long distances to the centre

*"People come from as far as Jinja, Mukono, Luweero Masaka) and reach the next appointment when they don't have money for transport to KCCC, well, they are given excess tablets but at times they even finish them and fail to get transport to come and pick more (Male FGD- beneficiaries of care and support).*

Other problems included limited space for the clinic; where by big numbers of patients have to squeeze in a small area. Through observation, the researcher observed that the clinic and offices stand on a less than half a hectare piece of land that was donated by the Catholic Church.

Study respondents also complained about some of their CBHW are not approachable. One of the issues talked about in the female FGD was;

*"You can call a girl to come and help but instead she looks at you and laughs. They should strengthen CBHW by educating them because they are the ones that make the communities know about the organisation (FGD-community and opinion leaders).*

Asked how they communicate their problems to the management of the organisation the respondents had this to say;

The majority of the respondents said that they tell the counsellor about the problem 22%, others inform the doctor 12%, 11percent address their concerns during the clients monthly meetings, 3% inform the community based health workers, 3% tell the other KCCC staff members. However, 11% of the respondents reported that they do not report their problems anywhere.

In view of the above mentioned challenges experienced in accessing services at KCCC, the study sought to establish how the client were supported by their household members, and responses were that these help with finances.

In conclusion, the findings revealed that a number of quality services are provided and easily accessed by the intended beneficiaries, and that these services have impacted positively on their quality of life.

#### **4.6 Challenges faced by KCCC in HIV/AIDS prevention care and support services**

The study sought establish the challenges faced by KCCC in providing prevention, care and support services to its clients and the findings revealed that there are challenges

that are unique to the organisation because of the values of its faith foundation, for instance the failure to adopt condom use as a preventive strategy; while others are general could cut across all faith-based organisations like inadequate resources, sustainability, documentation, among others.

##### **4.6.1 The condom issue**

The organisation's preference of the AB strategy against the C has not only attracted various criticisms to the organisation from other players in the field of HIV/AIDS but also financial losses. One of the key informants reported that the organisation has on several organisations lost donor funding because of this because to some donors, as long as it is AB without C, then no money.

*We have lost money, we have made proposals and we have received regrets because we don't promote condoms. One time we had received over 3000 million but they said unless you change your strategy, we had to stick to our guard and we said we know condoms are not the answer and it is very evident today, you have just heard recently in the parliament the condom makers said, they have got a failure rate (Director, KCCC).*

##### **4.6.2 Sustainability of programs**

Study findings revealed that continuity of programs or services by the organisation after the donors have withdrawn is a big challenge; most especially given the fact that 95% of the organisation's budget is donor dependant. Further findings established that the organisation has embarked on a program of handing over the projects and programs to the various

committees in the communities in which the projects are established-Programmes like the vocational school, a youth program and the SACCO have already been handed over to various committees in the community- these have been trained and introduced to donors and some of the workers who have been working with the organisation have been sent to monitor these programs for 5years, and are now independent programs hence reducing the pressure previously amounted on the mother organisation in terms of finance, human resource among others. However, the question of sustainability still stands-can these communities ensure continuity of these projects without financial support from donors?

#### **4.6.3 Inadequate resources**

The study established that like all other FBOs, the organisation has got an overwhelming number of clients who exert pressure on the already limited resources- reasons for the overwhelming numbers included; the charity background-people expect all their basic needs to be met by the organisation; the faith and satisfaction the clients have in the services provided to the extent that some of them do not accept referrals; that the services being affordable and also the fact that the services provided are of a good quality; the community outreach programs that have attracted people in big numbers; the fact that increasingly, the social service providing entities of the government have really collapsed or they are also faced with the challenges of management and resource allocation, corruption, so in a way money that should be facilitating peoples access to services is reduced, among others.

By registration, the organisation is supposed to operate in Kampala district. However, as noted earlier, the wide range of services offered has attracted clients from as far as Masaka, Luweero, Mukono, DR-Congo, and many other areas. Accessibility of services is a little hard given the long distances they have to trek to the centre; some cannot even afford transport to the centre. Responses from the key informant interviews revealed that these people are given referrals to public service providers in the field of HIV/AIDS but turn them down and instead insist on coming to KCCC-to some clients the drugs given at this organisation are different from those from other organisations because they make one recover faster.

However, other responses noted that the organisation has embarked on establishing outreach centres in different areas of the country- Nabitale in Gayaza, Bwaise parish Kisenyi, Lungujja, semuto in Nakaseke, Ssii in Buikwe district, to mention but a few; by training,

empowering and sharing information with the people in these areas to help those clients that move long distances to kamwokya. Nabitalo in Gayaza. This is intended not only to ease access to services by the clients from far areas, but also to reduce on the ever-increasing numbers of clients that access services at the Kamwokya branch.

It was further revealed that the overwhelming number of clients is heightened by fact that funds are inadequate. Various reasons were advanced as to why the funds are inadequate; apart from the overwhelming numbers of clients, responses from key informant interviews revealed that the organisation receives time-based funding-programs are funded for a particular period of time and when this period elapses, the funders pull out; because of corruption, some donors are discouraged by their focal persons from releasing funds to the organisation if the organisation is not willing to part with a certain percentage of the donor fund to these focal persons; apart from the annual 3 million grant for drugs for opportunistic infection, the conditional grant of tax free drugs through the private partnership government recommendations to the organisation when requesting for funds from donors, and the good working conditions, the government has not come out to fund FBO activities yet they take care of large clientele just like the secular or public health organisations-; most donors are unwilling to fund the organisations budget because of their stand on the use of condoms. Perhaps this explains why the organisation is 100% funded by the Catholic Church and Catholic based donors like catholic relief services (CRS), catholic international AIDS fund (SCIAF), caritas Norway, caritas Switzerland, among others.

*... I would say we look at the church as our source of support though we are registered independently because we can be sued and can also sue.*

*Internationally, we are working with other agencies like the catholic relief services (CRS); they give us money and today we get our funds through CRS for ARVs, we are also working with the catholic international Aids Fund (SCIAF) that funds almost 60% of our budget, CARITAS Norway and CARITAS Switzerland, and many others (Director, KCCC).*

Further responses noted that the organisation has embarked on a series of income generating activities to overcome the challenge of over dependence on donors for funds, which are in most cases inadequate. Agricultural farms in Nabuti, Mukono, and buildings have been established to this effect.

#### **4.6.4 Inadequate documentation.**

One of the biggest challenges facing not only the organisation but also most FBOs is the failure to document their work. The study established that the organisation had done a lot as far as HIV/AIDS prevention, care and support are concerned but very little of this work had been documented. This perhaps explains why FBOs have faced various criticisms from other service providers in the field of HIV/AIDS. Responses from key informant interviews attribute the problem to lack of money-most donors are unwilling to fund documentation because to them, it has no direct benefits like giving drugs to a patient and the patient gets better.

#### **4.6.5 Political interference**

The study discovered that some faith-based Organisations not only have various religions or faiths on which they are founded, but also have particular political parties they affiliate to. Study findings revealed that some members of the organisation have a particular opposition political party they belong to. For instance the director of the organisation belongs to the Democratic Party;

*For me as a director I want to be very open to you, I belong to the Democratic Party and I am a counsellor at the central division, Kampala but thousands of members of the National Resistance Movement Party come to the clinic. Annually we have got a clientele in the clinic of over 40,000 people and I don't think all these are Democratic Party members alone (Director,KCCC)*

Various responses acknowledged the fact that politics is a challenge because some members of the organisation use the organisation achievements as a platform to solicit for votes hence spoiling the good name of the organisation; that at one time some party leaders tried to stop their members from accessing services from the organisation, with fear that they would be recruited into opposition party; that government does not give financial support to the organisation because of the political differences;

However, further responses from the key informant interviews agreed to the fact that some staff members of the organisation are partisan but refuted claims that political involvement has been a challenge to the organisation because it does not affect service delivery in any way.

*You see politics is everywhere, you will never run away from politics. Some of us are politicians and we think politics is part of us right from our families but there is a lot of*

*political maturity in our people today and I think what people are looking for today are the services. Thousands of people from all political parties come here to get services (FGD-community leader).*

#### **4.7 Suggestions on how KCCC can strengthen their role in HIV/AIDS prevention, care and support**

##### **4.7.1 Strengthening the community approach**

There is need to strengthen the community based approach by training more community based workers and volunteers, because they are the ones that make the organisation activities and services known to the communities.

##### **4.7.2 Improvement in co-ordination**

Other respondents suggested that there is need for co-ordination between all stakeholders in HIV/AIDS prevention, care and support interventions-donors, public, private for and not for profit organisations, nongovernmental organisations, faith based organisations under different religious affiliations, community based organisations, and other civil society organisations to avoid duplication, conflict of interests and strategies.

*I can give you an example of the Catholic Church; there is nothing that goes on in any organisation under the catholic faith that is not supervised by the Catholic Church. Someone somewhere is following up on what they are doing. So there must be a lot of coordination, supervision, sharing experiences between these various organisations (Director, KCCC).*

##### **4.7.3 Strengthening commitment in service provision**

There is need for KCCC to be committed to offering the services for which they were registered to deliver and derive satisfaction in seeing that the intended beneficiaries are really getting what they deserve.

##### **4.7.4 Improve documentation**

Further responses suggested that there is need for FBOs to document their work for purposes of evaluation and of attracting donor funding. One key informant noted that the reason why KCCC and most FBOs as well are not get funding is probably because they have not put their work on paper for others to read, appreciate and recommend. To many respondents, documentation is as important as any other services delivered by these FBOs, because without it, no one will get to know about the good work they are doing.

*“Documentation is another issue that can give you a basis. Documentation helps you in evaluations and a way forward. Even new donors or any donor need documentation to see that you are effectively used the funds before they can release more (Head, care and support)”.*

#### **4.7.5 Management**

Management was also reported as one of the ways KCCC must put in place to strengthen their role HIV/AIDS interventions as it leads to effectiveness. Respondents reported that it is true the resources FBOs have are meagre but sometimes not managed well. There is need for good resource management both at the organisation level and also community level.

#### **4.7.6 Strengthen networking and partnerships**

According to the respondents, the organisation needs to get into more partnerships with other organisations, for reasons other than medical.

*Networking is very necessary because you cannot do everything alone, there are chances that you will not cover everything you intend to do. There are issues like land grabbing in case one dies, leaving the helpless orphans in endless land battles, and yet if we work in partnership with the police and the judiciary, such problems would not arise (Head Care and Support).*

## **CHAPTER FIVE: SUMMARY AND CONCLUSIONS**

### **5.1 Introduction**

The study was intended to examine the role faith based organisations play in HIV/AIDS prevention, care and support. This chapter therefore summarises the main findings, conclusions, recommendations, and shortcomings of the study as well as suggestions to future researchers.

Faith based organisations have increasingly become involved in HIV/AIDS prevention, care and support activities but few of their efforts have been appreciated, documented or even evaluated. They have instead faced various criticisms over some of their preventive strategies, particularly the use condoms, stigma, fear and misinformation. Some of their messages, which usually emphasise premarital abstinence and marital fidelity, often clash with secular emphasis on safer sex.

Most of the literature on the role of FBOs in dealing with the HIV/AIDS crisis is scarce and primarily addresses the influence of religious beliefs and organisational structures on HIV/AIDS by promoting and even enforcing less risky behaviours.

However relatively little and unbiased evidence exists to show how their potential has been realised in practice, and the volume and frequency of HIV/AIDS related assistance provided by FBOs as well as the relative distribution of that assistance between members and non-members generally remain unknown.

The study was carried out at Kamwokya Christian Caring Community and a sample of 100 respondents was selected for quantitative survey while five key informants and six focus group discussions were conducted for the qualitative survey.

### **5.2 Discussion of summary of findings**

The study aimed at examining the role played by faith based organisations in HIV/AIDS prevention, care and support.

Kamwokya Christian Caring Community (KCCC) provides a wide range of HIV/AIDS prevention, care and support interventions to various categories of people.



Study findings revealed that the organisation employs a comprehensive approach to HIV/AIDS prevention, care and support intervention also known as the multi-sectoral strategy is used, which looks at the beneficiary in totality hence finding solutions not only to the direct problems that affect him/her but also the surrounding environment. For instance, as far as prevention is concerned, interventions are not only geared towards behavioural change but also tackle other factors that predispose people to HIV/AIDS like poverty, drug use, domestic violence, to mention but a few.

Similarly, the care and support interventions do not only involve provision of medical care and treatment but also finding solutions to many other factors that may hinder the success of medical care, for instance, food, worrying and anxiety, financial problems, lack of shelter, children's education, to mention but a few.

HIV/AIDS Prevention is categorised into two components i.e. Primary and secondary prevention, with the former targeting people who have not yet been infected with the virus, while the latter mainly targets people already living with HIV/AIDS and these interventions are intended to stop further spread and re infections.

Primary prevention strategies to a larger extent target mainly the youth and the married people, while secondary prevention strategies target all ages, but women constitute the biggest percentage of beneficiaries for secondary prevention, as well as care and support services.

Emphasis is on premarital abstinence and marital fidelity against condom use, and this is mainly because the religious values and principles that guide the organisation are not in line with condom use.

However, the organisation provides all the necessary information about condoms for their clients to be able to make informed choices, and also partners with other organisations that emphasise ABC strategy to help those categories of people that inevitably need condom supply.

More responses revealed that the organisation opted for partnerships because the values of the faith on which it is grounded are against the use of condoms, so there is just information sharing about the use of condoms, giving the benefits and doubts, to help those who might be in need of them make informed decisions.

There is however more emphasis more on the provision of primary prevention-helping people who have not yet acquired HIV/AIDS not to get it through sensitisation; and little emphasis on secondary prevention-helping people living with HIV/AIDS (PLWHAs) from spreading the virus further to those who are not infected and re infecting themselves.

All the services provided are accessible to the people for which they are intended, in terms of distance, accessibility, and availability.

More responses revealed that the organisation opted for partnerships because the values of the faith on which it is grounded are against the use of condoms, so there is just information sharing about the use of condoms, giving the benefits and doubts, to help those who might be in need of them make informed decisions.

KCCC provides some unique interventions in HIV/AIDS prevention, care and support, and these include; the use of sports and recreation activities as a preventive strategy, community outreach or follow up programs for people on care and support, community involvement in not only identifying areas of intervention and executing the interventions but also in reviews and evaluations, among others.

Further analysis revealed that both prevention and care and support have changed positively the lives of the people for which they are intended, implying that they are effective. This was not only observed but also discovered through the various testimonies given. In relation to prevention, the majority of the respondents 59% reported that the interventions had greatly changed their behaviours and lifestyles and reasons ranged from not having multiple partners anymore, living sexually responsible lives, no longer engaged in irresponsible drinking; whereas those accessing care and support services reported that the services had changed their lives and well-being 88% and reasons ranged from looking good and healthy, no longer falling sick, having hope of living to see another day, feeling energetic, to acquisition of skills and knowledge, economic empowerment, among others.

Study findings discovered that KCCC has certain advantages over secular organisations in the field of HIV/AIDS- being quick to attend to patients, good hospitality, not discriminatory, counselling that is provided gives them hope and purpose of living, services provided are cheap and others free of charge, the multi-sectoral approach, the community based approach, and the values of love care and compassion exhibited in all their interventions, among other reasons.

Lastly, the study discovered that there is no significant relationship between religion and the provision of services. The services are utilised with ease by all religious denominations, although beneficiaries who share the same faith foundation with the organisation are many 48% compared to others, Protestants 24%, Muslims 9%, and Pentecostals 18%

### **5.3 Conclusion**

From the findings above, Kamwokya Christian Caring Community (KCCC) has proved that faith based organisations have great potential in not only educating people about the prevention of HIV/AIDS, but also in providing care and support to people living with HIV/AIDS (PLWHAs) and their families, by providing a wide range of interventions to both the people infected and affected by the pandemic irrespective of their religious backgrounds. It is true their preventive interventions emphasise premarital abstinence and marital fidelity as opposed to condom use which is a ground for criticism from secular and other organisations, however, it is important to note that the organisation has really done well in what it has specialised in and need to be complimented other than criticising it; but even if it had not succeeded in the AB strategy, the organisation has other areas other than prevention-specifically in care and support, were they responded exceedingly well irrespective of the challenges ahead of them.

KCCC did not wait for funding in order to begin, they just responded. Their courage and determination in the face of so many challenges is a reflection that they can survive and continue to deliver services and messages of hope, love, care and compassion to people who desperately need them.

KCCC has demonstrated that it is possible, with only limited resources to respond to the many of the urgent needs of the people with HIV/AIDS and their families. But more importantly, it has shown that it is possible through deep human commitment and faith in God to combat fear and stigma with a vision of hope. But more importantly, it has shown that it is possible through deep human commitment and faith in God to combat fear and stigma with a vision of hope. Whatever they have chosen to do, they have done it with all their might and to the satisfaction of the people for which the services are intended for.

## **5.4 Recommendations**

This section suggests various recommendations to policy makers, to secular and public service providers in the field of HIV/AIDS, to faith based organisations, to donors, and to future researchers.

### **To Policy makers**

There is need to address the various needs and appreciate the various contributions made by faith based organisations in the same way they do address and appreciate the needs and contributions of secular organisations respectively in the field of HIV/AIDS.

Each FBO has its own guidelines and policies, in addition to the National policy guidelines within which they operate, as long as faith based organisations are not de-campaigning national programmes, policy makers need to appreciate and do positive criticisms to the policies and guidelines that govern the work of faith based organisations as far as HIV/AIDS prevention, care, and support are concerned.

### **To the donors**

Forcing faith based organisations to adapt to certain strategies that are against the values of their faith and conscience before they could be given financial support will not solve HIV/AIDS related challenges. Denying faith based organisations financial support because of their failure to comply to a small extent affect the managers, directors and the staff of these organisations who are only channels through which services are delivered but greatly affects the helpless masses at the grassroots, who desperately need support if they are to overcome the challenges posed by HIV/AIDS-as the saying goes that when elephants fight, it is the grass that suffers. FBOs have proved through experience that they can effectively handle HIV/AIDS related issues; however their contributions are greatly affected by inadequate financial resources. Allocating more resources to faith-based organisations will strengthen their role in HIV/AIDS prevention, care and support.

## **To secular and other public health organisations in the field of HIV/AIDS**

There is need to attack the enemy-HIV/AIDS, and not faith based organisations. Criticising faith based organisations because of their emphasis on premarital abstinence and marital fidelity is of no use. It is time accusations and counter accusations stopped and instead unite against a common enemy that knows no differences in interventions.

Specialisation means concentrating on what one can do best. Just as secular and other public health organisations have specialised in promoting the use of condoms strategy, faith based organisations have also specialised in the AB strategy because it is what they can do best.

There is therefore need to devise ways of how to complement each other's interventions, learn from each other and share knowledge and experiences for better interventions

## **To faith based organisations**

The greatest challenge that faith-based organisations are facing is failure to document their work, because most of the challenges that they are facing are as a result of the fact that little is known about their potentials and capabilities. There is practically little evidence to prove that faith based organisations have made tremendous contributions towards HIV/AIDS prevention, care and support, and most of the allegations and criticisms have no well-grounded evidence. Moreover most of these criticisms have been over blown- a good example is the issue of condoms. The picture one gets from the available literature about FBOs failure to adopt the condom strategy, one would imagine that they do not even mention the word condom anywhere yet they even go all the way to talk about the benefits and doubts about condoms to help those who wish to use them make informed decisions; and even partner with other organisations that promote the use of condoms to help those who may need them.

It is high time faith based organisations realised that documentation is as important as any other service they provide and their efforts should be made towards achieving it.

## **To KCCC**

There is need to direct efforts to secondary prevention interventions targeting the sero-discordant couples and unborn babies from picking the virus from their mothers.

Develop the clinic into a 24-hour operational clinic to enable clients to access services whenever they need them.

Establish or strengthen partnerships other service providers outside the field of HIV/AIDS to complement services provided by KCCC, for example linking clients to organisations providing income generating activities like National Advisory Agricultural Services (NAADS), Prosperity for all program, to mention but a few.

## **Suggestions for future research**

This research could be improved if supplemented by other research methods or if completely new ones are used.

It is not always enough to read other researchers' work for purposes of knowing the right format to be followed, compare research methods used, among other reasons. Future researchers should endeavour to identify gaps for future research. For example this research could be improved if supplemented by other research methods or if completely new ones are used, there is need to examine the utilization of both primary and secondary the preventive messages given by the FBOs, the issue of how FBOs partner with other organisations to offer services to their clients- especially to give them condoms needs further research, among many other issues.

When undertaking research studies, researchers should look beyond academic purposes, but rather bear in mind that their research can be instrumental in policy formulation.

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## APPENDICES

### Appendix 1: Structured Questionnaire - Exit Interview

#### Section A

Social-Demographic characteristics

Sex of the respondent

- A. Male
- B. Female

Age of the respondent

.....(Years)

Marital status of the respondents

- A. Single
- B. Married
- C. Separated
- D. Divorced
- E. Widowed

Educational level of the respondents

- A. None
- B. Primary
- C. Secondary
- D. Tertially
- E. Others

Religion of the respondents

- A. Catholic
- B. Protestant
- C. Muslim
- D. Pentecostal
- E. Others

Economic activity of the respondents

- A. Agriculture/Peasant
- B. Business
- C. Student
- D. Civil servant
- E. Others

Number of household members.....

What is the distance of your residence to KCCC ..... (Km)

**SECTION B: PREVENTION**

What preventive activities do you access at KCCC?

- A. Sensitisation
- B. Condoms
- C. Others (specify)

How did you get to know about these preventive activities at KCCC?

- A. Radio/TV
- B. Household member
- C. Friend
- D. Church
- E. Others (specify)

Why did you decide to access these services at KCCC?

- A. KCCC near my home
- B. Cheap services
- C. My faith foundation
- D. Others (specify)

When do you access these services

- A. Daily
- B. Weekly
- C. Monthly
- D. When need arises
- E. Others (specify)

How have these activities helped you change your behaviour

Yes

No

Give reasons for Qn. 13 above

.....

Is there any other member of your household accessing services at KCCC

Yes

No

If yes, who is this member

A. Spouse

B. Child

C. Other relative

Do you find it easy to access these services

Yes

No

Give reasons for Qn. 17

Is there any other organisation that provides HIV/AIDS preventive services like KCCC

Yes

No

If yes what is the name of this organisation

Do you access these services from this organisation

Yes

No

What particular programs/activities do you receive from this organisation



Is the organisation faith based

Yes

No

What advantages do you think FBOs have over secular organisations as far as prevention is concerned

Are you satisfied with the services provided by KCCC

Yes

No

Give reasons for Qn. 25

Please indicate your level of agreement or disagreement with the statements in the table:

1=strongly agree; 2=Agree; 3=Disagree; 4=strongly disagree; 5=neither agree nor disagree

| <b>At KCCHIV/AIDS prevention there is</b>        | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> | <b>5</b> |
|--|----------|----------|----------|----------|----------|
| Behavioural change counselling                   |          |          |          |          |          |
| HIV counselling and testing                      |          |          |          |          |          |
| Public education programs                        |          |          |          |          |          |
| Accessible diagnosis and treatment of other STIs |          |          |          |          |          |
| Prevention for maternal-to-child transmission    |          |          |          |          |          |
| Prevention between sero-discordant partners      |          |          |          |          |          |

|  |  |  |  |  |  |
|--|--|--|--|--|--|
| HIV partnerships and referrals                   |  |  |  |  |  |
| HIV/AIDS prevention capacity building activities |  |  |  |  |  |
| Disease prevention programs other than HIV       |  |  |  |  |  |
| Prevention for people living with HIV/AIDS       |  |  |  |  |  |
| Information on the use of condoms                |  |  |  |  |  |
| Supply of condoms as a preventive measure        |  |  |  |  |  |

List obstacles faced in HIV Prevention, care and support.....

State why you think these obstacles occur.....

Suggest solutions to obstacles encountered in accessing HIV/AIDS prevention, care and support.....

## SECTION C: CARE AND SUPPORT SERVICES

What care and support services do you access from KCCC

- A. Food supplements
- B. Medication
- C. Others (specify)

How did you get to know about these care and support services provided at KCCC

- A. Radio/TV
- B. Household member
- C. Friend
- D. Church
- E. Others (specify)

Have these services changed your life and well being

Yes

No

Are you satisfied with the services provided by KCCC

Yes

No

Give reasons for Qn. 31 above

Is there any other organisation that provides Care and support services like KCCC in your area.

Yes

No

If yes what is the name of this organisation

Do you access these services from this organisation

Yes

No

Is the organisation above faith based

Yes

No

What advantages do you think FBOs have over secular organisations as far as care and support is concerned

.....

Please indicate your level of agreement or disagreement with the statements in the table:

1=strongly agree; 2=Agree; 3=Disagree; 4=strongly disagree; 5=neither agree nor Disagree

| At KCCC HIV/AIDS care and support, there is            | 1 | 2 | 3 | 4 | 5 |
|--|---|---|---|---|---|
| <b>Medical</b>   |   |   |   |   |   |
| Routine Clinic care and referral                       |   |   |   |   |   |
| Provision of ART                                       |   |   |   |   |   |
| Treatment of opportunistic infections (Ois) like (TB)  |   |   |   |   |   |
| Time-limited support for clinically malnourished PLWHA |   |   |   |   |   |
| Support for adherence to anti-retroviral therapy (ART) |   |   |   |   |   |
| Treated mosquito bed nets                              |   |   |   |   |   |

|   |  |  |  |  |  |
|---|--|--|--|--|--|
| Nutritional assessment and counselling  |  |  |  |  |  |
| Promotion of good personal and household hygiene  |  |  |  |  |  |
| Basic preventive care for PLWHAs and their families   |  |  |  |  |  |
| <b>Psycho-social support</b>  |  |  |  |  |  |
| Mental health counselling   |  |  |  |  |  |
| Support for disclosure of HIV status  |  |  |  |  |  |
| End of life and bereavement care  |  |  |  |  |  |
| Peer support groups for those found HIV positive  |  |  |  |  |  |
| Nutritional support   |  |  |  |  |  |
| Efforts to reduce stigma  |  |  |  |  |  |
| Legal services like succession planning, inheritance rights                                     |  |  |  |  |  |
| Support to income generating activities   |  |  |  |  |  |
| <b>Spiritual support</b>  |  |  |  |  |  |
| Interventions are sensitive to culture, religion(s) and rituals of the individual and community |  |  |  |  |  |
| Life review and assessment  |  |  |  |  |  |
| Counselling related to hopes and fears  |  |  |  |  |  |
| Counselling related to meaning and purpose of life  |  |  |  |  |  |

What challenges do you face in accessing KCCC services

How do you communicate these problems to KCCC management

What support do you get from your household members to solve these problems

Suggest solutions to obstacles encountered in accessing HIV/AIDS prevention, care and support services

Do you have any other comment

## **Appendix 2: Focus Group Discussion Guide**

What are the socio-economic characteristics of the people in this community

What is the HIV/AIDS situation in this area

What preventive services does KCCC provide

Does KCCC supply condoms as a preventive measure

What is your comment on the use of condoms as a preventive method

What care and support services does KCCC provide

What type of people access services at KCCC

Which other organisations, faith based or secular, provide preventive services in this area

Which other organisations, faith based or secular, provide care and support services in this area

Is the community involved in these prevention, care and support services

What is the gender uptake of these services

How easy is it to access these services

What unique challenges do FBOs face in providing prevention, care and support services

What general challenges do FBOs face in providing prevention, care and support services

How do you think FBOs can increase their involvement in HIV/AIDS interventions

### **Appendix 3: Interview Guide for KCCC Management**

What is your name, position/title, with respect to the organisation

When was the organisation founded, and for what reasons

What particular services do you provide in regard to HIV/AIDS prevention, care and support

Do you provide any other interventions outside the above

What geographical area and people does the organisation cover as far as service provision is concerned

What advantages do you think faith based organisations have over secular organisations as far as provision of prevention, care and support services is concerned

Who are the various stakeholders that you partner with

Is there any collaboration between KCCC and government, nongovernmental organisations and other FBOs in the same field

How does central and local politics affect your operations as an FBO

What unique challenges do you face as an FBO in extending prevention, care and support services

What general challenges do you face as an FBO in extending prevention, care and support services

How do you overcome these challenges

How do you think FBOs can strengthen their role in providing HIV/AIDS prevention, care and support service

### **PREVENTION**

What is your name, position/title, with respect to the organisation

What prevention interventions does KCCC provide for both the infected and non infected people



What geographical area and people does the centre serve in respect to prevention?

Is the community involved in these interventions

How do you incorporate faith in these preventive activities/services

What unique preventive interventions do you provide that are not provided by secular organisations in the same field

What is the gender uptake of these services and why

What is your stand on the use of condoms as a preventive strategy

How do you address the sexual needs of discordant couples

How easy is it to access preventive services in terms of; availability, proximity, geographical location and cost

According to experience obtained, what conditions give an effective HIV/AIDS prevention?

Are the conditions in question above, available at KCCC and if not why?

What advantages do you think FBOs have over secular organisations as far as HIV/AIDS prevention is concerned?

What unique challenges do you face in extending these services?

What general challenges do you face in extending these services?

How do you overcome these challenges?

How do you think FBOS can strengthen their role in HIV/AIDS prevention interventions?

## **CARE AND SUPPORT**

What is your name, position/title, with respect to the organisation

What care and support services does KCCC provide for people infected and affected by HIV/AIDS

What are the objectives of KCCC regarding HIV/AIDS care and support

Who are the intended beneficiaries, and in what geographical area

What is the gender uptake of these services

According to experience obtained, what conditions give an effective HIV/AIDS support?

Do you have any unique care and support services that are not provided by secular organisations in the same field

How easy is it to access these services in terms of; availability, proximity, geographical location of KCCC, and cost.

How do you incorporate faith in the provision of care and support services

Is the community involved in the provision of these services

According to experience obtained, what conditions lead to effective HIV/AIDS care and support

Are these conditions stated above available at KCCC, and if no, why

What unique challenges do you face in providing HIV/AIDS care and support services

What general challenges do you face in providing HIV/AIDS care and support services

How do you overcome these challenges

How do you think FBOs can strengthen their role in providing HIV/AIDS care and support services

## **PASTORAL LEADER**

What is your name, position/title, with respect to the organisation

What services do you provide in relation to spiritual support to the people infected and affected by HIV/AIDS

Who are your intended beneficiaries

How do you ensure that your faith foundation does not interfere with the clients faiths, beliefs, norms, and values, given the fact that your target group cuts across different religions

Do you provide any services in relation to HIV/AIDS prevention

What is your stand on the use of condoms as a preventive method

How do you address the needs of discordant couples

What role does faith play in the provision of these services

How does KCCC faith foundation complement the services provided

What advantages do you think FBOs have over secular organisations as far as provision of spiritual support is concerned

What unique challenges do you face in providing HIV/AIDS care and support services

What general challenges do you face in providing HIV/AIDS care and support services

How do you overcome these challenges

### **CENTRAL DIVISION HIV/AIDS FOCAL PERSON**

What is your name, position/title, with respect to the organisation

What are the social-economic characteristics of the people in Kamwokya

What is the HIV/AIDS situation in Central Division as a whole and Kamwokya parish in particular

What are the policies of Central Division regarding HIV/AIDS prevention, care and support

What role do you think FBOs have played in the provision of HIV/AIDS prevention, care and support services

How do you think FBOS have performed as far as HIV/AIDS prevention care and support services are concerned

What advantages do you think FBOs have over secular organisations as far as HIV/AIDS prevention care and support services are concerned

What support does Central government in general and Central Division in particular give to FBOs as far as HIV/AIDS prevention, care and support is concerned

How does local politics affect the operations of FBOs

What challenges do you think FBOs face in providing HIV/AIDS prevention, care and support services

How do you think FBOs can strengthen their role in providing HIV/AIDS care and support services.