

**AN INVESTIGATION INTO THE CHALLENGES FACING ASSOCIATIONS OF
PEOPLE LIVING WITH HIV/AIDS IN KARONGI DISTRICT-
WESTERN PROVINCE, RWANDA**

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DECLARATION

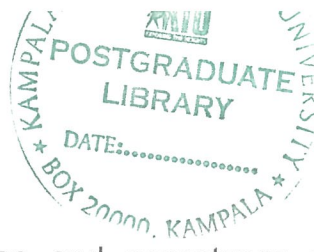
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APPROVAL



This thesis has been submitted for examination and acceptance with my approval as the supervisor.

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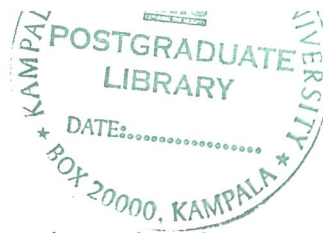
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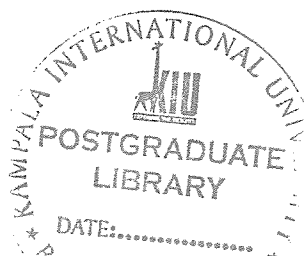
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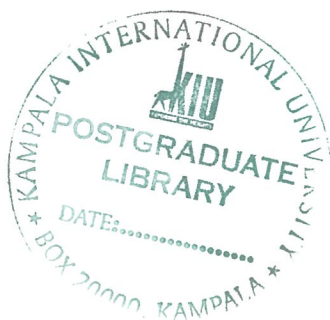
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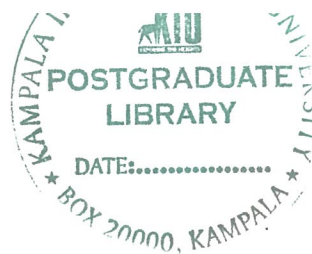


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LIST OF ACRONYMS



ADRA	Adventist Development and Relief Agency
AIDS	Acquired Immunodeficiency Syndrome
APLWHA	Association of People Living With HIV/AIDS
ART	Anti-Retroviral Therapy
ARVs	Anti-retroviral drugs
CBOs	Community Based Organizations
CCSOBI	Consultation Council of Supporting Organizations on Basic Initiatives.
CNLS	<i>Commission Nationale de Lutte contre le SIDA</i> (The National AIDS Control Commission)
EABC	Education, Abstinence, Being faithful and Condom use
FAO	Food Agricultural Organisation
FBOs	Faith Based Organizations
HIV	Human Immunodeficiency Virus
IGA	Income Generating Activities
MDGs	Millennium Development Goals
NACP	National Aids control program
NGOs	Non Governmental Organizations
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
STIs	Sexually Transmitted Infections
TBAs	Traditional Birth Attendants
UAC	Uganda AIDS Commission
UN	United Nations
UNAIDS	United Nations Program on AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
UNIFEM	United Nations Development Fund for Women
USA	United States of America



ABSTRACT

The study is linked to investigating the challenges facing association of People Living with HIV/AIDS in Rwanda, with particular emphasis on Karongi District. The variables treated in the study included factors leading to the formation of APLWHA, the activities they carry out, their challenges and coping mechanisms. The category of respondents included: association leaders, and members, family members, local leaders, medical workers, staff of NGO/FBOs, and PLWHA.

The methods/ techniques of data collection involved were questionnaires, focus group discussion guides, interview guides, and observations on activities of PLWHA. These were useful instruments in the investigation.

The major findings of the study reveal that: Poverty, stigmatization of PLWHA, high prevalence of HIV/AIDS, lack of information and the burden of caring for orphans are among other factors that led to the formation of APLWHA in Karongi district. The activities undertaken by association members include mobilization and sensitization, home visits, lobbying and advocacy, farming, counseling, food sales and support supervision. The APLWHA face the following challenges: poverty, stigmatization of PLWHA, difficulty in accessing ARVs, the burden of caring for orphans and other vulnerable children, lack of collateral and poor loan repayment which had negative implications. The coping mechanisms used by APLWHA include holding of regular meetings, soliciting for help from donors and the government, frequent home visits, and involvement in IGAs.

The major conclusions were that it was necessary that the APLWHA be formed so as to enhance care and support being offered to those infected and affected by HIV/AIDS and from these recommendations were made to various stakeholders like government and donors to increase on financial, material, and technical support. These were deemed as essential in implementing the desired changes so that effective and efficient implementation of the association activities and dealing with challenges that they face can be achieved.

CHAPTER ONE

INTRODUCTION

*"There are only two kinds of people in Africa.
Those infected with HIV and those affected by it."*

~ Orr, undated

(Source: Jackson 2002)

1.1 Background of the Study

Associations in this study refer to community based groups or organizations or self-help groups collectively using their available resources to respond to the management of the challenges PLWHA face. A person (or people) living with HIV/AIDS (PLWHA) refers to people who are HIV positive and aware of their seropositive status, whereas a person(s) affected by HIV/AIDS are those living with a PLWHA (wife/husband/partner, children, parents, brothers/sisters) or those who are part of the close circle of a PLWHA but not living with them, who are personally involved in the care and support of one or more PLWHA.

This study therefore sought to establish the challenges facing Associations of People Living with HIV/AIDS (APLWHA) in relation to the experiences of the infected and affected by the scourge in selected areas of Karongi District. There were prospects and perspectives for further development of best practices based on strategies for management of HIV/AIDS through the adoption of cost-effective prevention and control activities and other coping mechanisms in a resource poor community. The study was mainly concerned with highlighting the challenges the associations face in dealing with the infected and affected persons by the



disease and their contribution in managing the ramifications that come along with the disease among the most vulnerable population groups in particular. It looked into the negative socioeconomic impact faced by the associations in the management of their activities and sought to chart the way forward in coping with these challenges in the wave of the epidemic at the individual and societal levels in general.

A UNAIDS (2004) report reveals that until recently, most HIV/AIDS programs in non-industrialized countries neglected care and support for People Living with HIV/AIDS (PLWHA) which refers to efforts that aim to improve the quality of life and life expectancy of PLWHA and people affected by HIV/AIDS, their families, and communities. Many governments and donor agencies supporting HIV/AIDS programs chose to focus solely on prevention because they believed that preventing HIV infection would prevent the need for care and support because of the high costs involved.

In sub-Saharan Africa, people have faced calamities brought about by diseases, famine, drought, civil strife and the like for generations. But somehow the strong extended family and kinship networks that are the backbone of the African social structure have been able to cope with these catastrophes, Leonard (2001) and Reid (1995) observe.

Saying that with AIDS it is a different matter, she adds that with almost two-thirds of all estimated cases of AIDS to date thought to have occurred in the region, the potential social and economic devastation faced by the people of sub-Saharan Africa is enormous. What makes the situation even more difficult she argues is that the AIDS epidemic has struck at a time of economic downturn when most African governments are faced with implementation of economic structural adjustment policies that reduce, rather than support, their ability to provide health care and social services to their citizens, (ibid). In response to this, innovative community-based projects related to the AIDS pandemic have responded to care

and support needs by linking with medical and social support services to provide medical treatment for opportunistic infections, counseling support, palliative care, and support for dependents and orphans since the onset of the disease Tonya et. al (2007) observe.

These experiences have shown that improving access to HIV/AIDS care and support services helps destigmatize HIV, improves demand for voluntary counseling and HIV testing services, and allows for early management and prevention of infectious diseases among both HIV-positive and -negative people.

Leonard (2001) says that, despite the magnitude of the crisis and the scarcity of resources at their disposal, Africans are responding to the challenge of AIDS with unyielding courage and creativity. She observes that building on the inherent strengths of family and community, people are getting involved in the fight to stop the spread of the disease and to support and care for those who have been affected and not just those who are infected with the virus, but their families as well.

Lyons (2005) says the impact of HIV/AIDS extends beyond those living with the virus, as each infection produces consequences which affect the lives of the family, friends and communities surrounding an infected person. Just as the virus depletes the human body of its natural defenses, it can also deplete families and communities of the assets and social structures necessary for successful prevention and provision of care and treatment for persons living with HIV/AIDS.

In agreement, Reid, (1995) contributes by saying community resources such as time volunteered; food, firewood and insights shared; counsel given; transport provided; labor contributed, funds raised; children cared for - lie at the heart of sustainable response, but these resources must be supplemented. They are not without end and are themselves depleted by the epidemic. They are not usually sufficient.



At the national level, the Government of Rwanda has put in place a strategy to tackle the HIV epidemic including a strategy for treatment, care and support of people living with HIV/AIDS. Rugira (2005) reveals that whereas most of the strategies, plans of action, and protocols are very clear as to how adults affected by HIV/AIDS will be managed, the treatment, care and support of PLWHA is not well elaborated. He adds that the extent of the problem and the services available to them in this situation is also not clear.

APLWHA in Rwanda came on board as a result of the need to address the prevailing challenges PLWHA face in their communities as an overall consensus of expanding Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA) to include those most affected as well as PLWHA. This approach has been found to be one strategy of facilitating the fight against the disease and management of the infections.

Rwanda's strategic approach to a national response to HIV/AIDS is integrated across sectors, decentralized and community based. The multi-sectoral approach comprising several networks has been established to fight the scourge. These include *Commission Nationale de Lutte contre le SIDA (CNLS)*-(National AIDS Control Commission), National AIDS Control Programme (NACP) established in 1987, the Ministry of Health, Treatment and Research AIDS Center (TRAC), United Nations Development Programme (UNDP), UNAIDS and other NGOs among others. With the help of these organizations, the National Network of People Living with HIV/AIDS *Reseau Rwandais Des Personnes Vivant Avec Le VIH/SIDA (R.R.P+)* - (Rwanda Network of People Living with HIV/AIDS) was formed at a conference held in 2003. Bensmann, (2003)

According to *(R.R.P+)* which is a national umbrella (NGO) network established in March, 2003 with 220 associations registered countrywide by and for PLWHA, the first case of HIV/AIDS appeared in Rwanda in 1983. The prevalence of

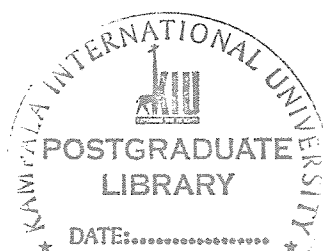
HIV/AIDS increased from 1.3% in 1986 to 10% in 1997, R.R.P+ (2006). Ten years down the line, the prevalence rate stands at 3%, CNLS, (2006).

APLWHA have since then been formed countrywide and registered under this umbrella with an aim of involving the PLWHA in all levels of decision making, planning, coordination, implementation, monitoring and evaluation of matters affecting them as stated in the GIPA Approach.

The GIPA Approach advocates *“Support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community-based organizations. By ensuring their full involvement in our common response to the pandemic at all – national, regional and global – levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments.”* (Declaration of the Paris AIDS Summit 1994)

The participation of PLWHA is generally recognized as fundamental to any response to HIV/AIDS. PLWHA need support and capacity development in order to go beyond the rhetoric of participation and genuinely get their voices heard, Declaration of the Paris AIDS Summit (1994). By June 13, 2005, CNLS, (2006) report confirms that there were 755 associations are registered associations countrywide (R.R.P+). However there exist several informal groups addressing the HIV situation in the same capacity.

In Karongi District, there are sixteen (16) registered associations although there are four non-registered ones. Their main aim is to involve PLWHA in their mission to fight against stigma and discrimination of people living with HIV/AIDS, and ensure access to ARVs and reinforcement of hospitality and catering for the needy people in different areas. In general, some of the fruits these associations have been found to bear are: PLWHA are now able to make themselves income generating projects, there is community care, home to home visitations in so



many families within the region, there are VCT centers whereby so many people are going willingly, and their involvement in the country's campaign in the fight against HIV/AIDS with an aim of reducing new infections. (The New Times May 13, 2006).

The membership of these associations is drawn from an array of individuals who are infected, affected, or afflicted by the epidemic. These include People Living with HIV/AIDS and their family members. It builds upon their social capital by harnessing community participation in the fight against HIV/AIDS, and strengthening incentives for participatory development. These groups also safeguard to provide voice to groups traditionally excluded from the decision making process such as women and ethnic minorities.

There are other stakeholders affected by the disease and work with these associations. They include local leaders, medical personnel, and religious groups. It is based on the need for the multi-sectoral approach to the fight against HIV/AIDS by involving all stakeholders in deciding their destiny as the epidemic issues are related to every human being.

In the context of the global HIV epidemic, millions of people desperately need care. UNAIDS (2006) recognizing how society has been affected says, enormous challenges remain as communities hardest hit by the epidemic struggle to find the capacity and resources to deliver care and support to those who need it.

These community efforts steered by PLWHA and are in direct response to the actual needs of those affected, including underserved groups such as women and children, who still continue to confront the challenges they face and struggle to do what needs to be done. They should not have to struggle alone as they have done throughout the AIDS epidemic, it is for this reason this study was conducted so as to voice out their challenges with the hope that its findings will benefit many stakeholders in finding solutions to them.

1.2 Statement of the Problem

Associations of People living with HIV/AIDS (APLWHA) came on board as a result of the need to address the prevailing challenges PLWHA face. Poverty and the prevalence of HIV/AIDS in the district has weakened families and kinship ties that have for long been the safety nets for people infected and affected by the HIV/AIDS scourge. Therefore the formation of the associations was supposed to provide a way for communities to deal with the impact of the disease.

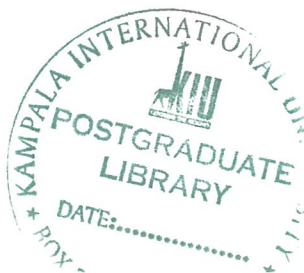
However, these associations have been faced with challenges that have hindered the smooth running of their activities. Whereas agencies dealing with issues related to HIV/AIDS emphasize the preventive and control mechanisms and the treatment of opportunistic infections, the issue of challenges the associations face while helping the infected and affected to cope with their situation has been neglected.

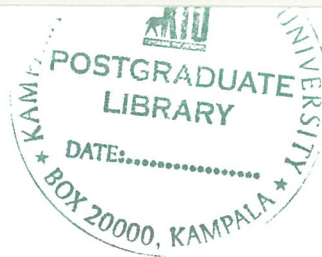
Consequently, there has been increasing pressure in evolving ways and approaches to address the problem facing APLWHA. Although a lot of funds and resources have been directed towards the implementation of project initiatives and schemes on how the associations could function effectively, there exists the problem of these resources being restricted to urban areas while associations situated in rural areas continue to languish.

These factors hindering APLWHA from functioning effectively precipitated the need to conduct the study to bring the challenges to light for redress.

1.3 Purpose of the Study

The purpose of the study was to identify the factors leading to the formation of APLWHA, the activities they undertake, the challenges affecting their work, and how they cope with these challenges so as to improve the performance and management of these associations.





1.4 Objectives

1.4.1 General Objective

To identify the challenges facing APLWHA in Karongi District and suggest measures to overcome them.

1.4.2 Specific Objectives

- 1) To identify the factors leading to the formation of Associations of People Living with HIV/AIDS in Karongi District.
- 2) To establish the activities undertaken by Associations Of People Living with HIV/AIDS in Karongi District
- 3) To identify the challenges affecting the work of Associations of People Living with HIV/AIDS in Karongi District.
- 4) To find out how Associations of People Living with HIV/AIDS cope with the challenges they face in Karongi District.

1.5 Research Questions

- 1) What are the factors leading to the formation of Associations of People Living with HIV/AIDS in Karongi District?
- 2) What activities are undertaken by Associations of People Living with HIV/AIDS in Karongi District?
- 3) What are the challenges affecting the work of Associations of People Living with HIV/AIDS in Karongi District?
- 4) How do Associations of People Living with HIV/AIDS cope with the challenges they face in Karongi District?

1.6 Scope of the Study

The study was conducted in Rwanda. The geographical location of the study area is Karongi District in Western Province, approximately 150 km from Kigali City. The area was selected because of the prevalence of HIV/AIDS in the localities and its proximity to the district hospital. Another factor considered was

the willingness of the respondents to take part in the study and the presence of NGOs working with APLWHA which facilitated the selection of respondents.

The concern for carrying out an investigation started as far back as October 2006 to May 2007 when a concrete requirement for the study arose.

This study sought to identify the factors leading to the formation of APLWHA, the activities they undertake, the challenges affecting their work, and the coping mechanisms they use in dealing with those challenges so as to improve their performance. Suggestions were made for further improvement of the functioning of the associations from which conclusions and recommendations of the study were drawn.

1.7 Significance of the Study

The study was undertaken so as to identify the challenges besetting APLWHA with an aim of finding solutions to them. What was believed about the study was that APLWHA face numerous challenges that put the members into a difficult situation. What was known about the study was that APLWHA were ill equipped, lacked support, and had challenges to deal with the management of their activities.

Previous studies show that the PLWHA should be supported in terms of financial and other materials so as to effectively manage their affairs. Furthermore, mitigation of the impact of HIV/AIDS had been highly advocated. The study was expected to reveal factors that led to the formation of APLWHA, their activities, challenges they face, and the coping mechanisms they adopt to sustain them.

It is hoped that the findings of the study will be useful in serving the interests of a number of stakeholders. These include: policy makers with suggestions to help them come up with useful policies geared towards assisting APLWHA to manage their affairs and Karongi District leaders in identifying and bridging the gap



CHAPTER TWO

LITERATURE REVIEW

2. Introduction

This chapter presents the theoretical framework on which this work is based. It also presents a review of works that have been written by other scholars on similar studies. It explores the challenges APLWHA face, the impacts on the functioning of APLWHA and also deals with mitigation measures in dealing with the HIV/AIDS pandemic.

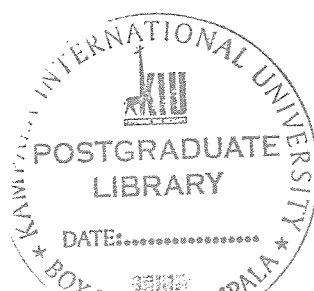
The literature cited in this review has been derived from a wide search using both print and electronic media, in various aspects of HIV/AIDS management and presented as per research question.

2.1 Theoretical Framework

The onset of HIV/AIDS pandemic has quickly transformed itself from a shock that randomly affects families to a more systematic shock that has had adverse effects on whole communities and countries, threatening households and communities that pool efforts together to cope with the fear and trepidation caused by the epidemic.

Throughout the years since it was first diagnosed, families, communities, nations, and the global village have formed networks that enable them brace themselves against the repercussions of the disease. This means that it enables them build on their social capital and also puts them on a platform to air their views with one voice to create a 'health-enabling social environment'.

This is because Narayan (1999) says; first, it focuses on the sources, rather than the consequences, of social capital while recognizing that important features of social capital, such as trust and reciprocity, are developed in an interactive





process. Second, it permits the incorporation of different dimensions of social capital and recognizes that communities can have access to more or less of them. The poor, for example, may have a close-knit and intensive stock of "bonding" social capital that they can leverage to "get by", but they lack the more diffuse and extensive "bridging" social capital deployed by the non-poor to "get ahead". Third, it presents the community (rather than individuals, households, or the state) as the primary unit of analysis, it recognizes that individuals and households (as members of a given community) can nonetheless appropriate social capital and that the way communities themselves are structured turns in large part on their relationship with the state, (ibid).

Building on the work of Narayan (1999), of the networks view, this kind of interactions stresses the importance of vertical as well as horizontal associations between people and of relations within and among organizational entities as community groups and firms. He recognizes that strong intracommunity ties give families and communities a sense of identity and common purpose as also understood by Tajfel and Turner (1979).

Their argument is based on "It's not what you know, it's *who* you know," a common saying that sums up much of the conventional wisdom regarding social capital. It says that when people fall on hard times, they know it is their friends and family who constitute the final safety net. Intuitively, then, the basic idea of social capital is that a person's family, friends, and associates constitute an important asset, one that can be called on in a crisis, enjoyed for its own sake, and leveraged for material gain. What is true for individuals, moreover, also holds for groups. Those communities endowed with a diverse stock of social networks and civic associations are in a stronger position to confront poverty and vulnerability, and take advantage of new opportunities.

In this context, it is argued that HIV/AIDS responses in communities precipitated the realizations that if put into use, social capital will enable even the poor have a

base from which they can deal with the disease. It empowers them in building in knowledge and basic skills; creating social spaces for dialogue and critical thinking; promoting a sense of local ownership of the problem and incentives for action; emphasizing community strengths and resources; mobilizing existing formal and informal local networks; and building partnerships between marginalized communities and more powerful outside actors and agencies, locally, nationally and internationally.

The formation of APLWHA was therefore viewed as fundamental in coming up with strategic interventions and coping mechanisms to deal with the epidemic. They were deemed to channel the desperately needed services to their clients though they are faced with challenges. These challenges pose bottlenecks, hindrances, drawbacks, or obstacles that prevent them from performing to their fullest potential, blocking them from realizing their goals and objectives, and in the long run, they experience poor performance and lack of sustainability. Such challenges take dimensions like lack of resources, project sustainability, lack of funding, lack of technical know how, and the burden of caring for orphans.

2.2 Literature Review.

2.2.1 Factors Leading To the Formation of Associations of People Living With HIV/AIDS (APLWHA)

Various scholars and researchers such as Kaleeba (2000), Mati (1997), Paterne (2005), and Staugård (1996) among others have addressed the issue of HIV/AIDS and its impact on individuals, households, communities and nations. Recognizing how it's spread is ravaging the society, in a later development Staugård (2004) states that figures and numbers of People Living with HIV/AIDS (PLWHA), orphans and other persons, directly or indirectly infected or affected by the HIV/AIDS pandemic, are difficult to comprehend. He indicates that the magnitude of the epidemic and the rate of its progression so-far tend to



camouflage individuals and local communities, carrying the main burden of the epidemic.



In this regard, society has taken upon itself to join hands along with the global community to fight HIV/AIDS by the formation of APLWHA which in other terms are referred to as Community Based Groups (CBGs) and Community Based Organizations (CBOs) for PLWHA.

The ultimate goal and mission of these associations' initiation is inspired by clearly defined goals and objectives. Their formation includes the inherent desire for PLWHA to belong and contribute to a supportive community, and the recognition that every person has a right to improve his/her circumstances and that others have a duty to help them (UNAIDS, UNICEF & USAID, 2004).

In relation to development, these associations which are also presented as specific Community Based Groups (CBGs) or self help groups that deal with HIV/AIDS management are in line with the Millennium Development Goals (MDGs) which include strategies for combating HIV/AIDS, malaria, and other diseases, poverty alleviation and improvement of the status of women and children infected and affected by HIV/AIDS as stated in the Global Poverty Report (2002) and Joint United Nations Programme on HIV/AIDS - UNAIDS (2006).

The *Reseau Rwandais Des Personnes Vivant Avec Le VIH/SIDA (R.R.P+)* - (Rwanda Network of People Living with HIV/AIDS) a network established by and for the People Living with HIV/AIDS takes into account the national policy against HIV/AIDS. (R.R.P+ 2006)

As a national body its mission is to promote the activities of the associations of people infected and affected by HIV/AIDS. Its objectives aim at serving as a key coordinating body to orient and facilitate activities of the association members in line with the national policy.

It advocates for care and support of people infected and affected by HIV/AIDS to the government of Rwanda and the donor government, contributing to the reduction of the socio-economic impact imposed by HIV/AIDS on people infected and affected by the disease (ibid).

Through this key organization, it is stated that the reason for forming the associations is to invite people infected and affected by HIV/AIDS in the fight against HIV/AIDS in general, and the fight against stigma and discrimination, and facilitating collaboration and exchange of information between associations of people infected and affected by HIV/AIDS. (R.R.P+ report 2006)

Most Associations' objectives aim at contributing to the reduction of HIV/AIDS rates, and other Sexually Transmitted Infections (STIs), and unplanned pregnancies among young people as a report by AYA (Oct 2003) indicates.

Jackson (2002) says that most people who join support groups in sub-Saharan Africa do so out of desperate need, and without financial, organizational, nursing or counseling skills.

Reid, (1995) also comments that most extended families form AIDS support groups because they need some form of assistance to deal with the burden of HIV. Citing examples he says Tanzania's Kagera district, the community mobilized and established self help groups to assist parentless children; and that residents in Zimbabwe's urban areas formed burial societies, with members contributing funds for funerals. He adds these voluntary societies could be used as models for raising funds to assist children and grandparents (p. 21)

Therefore associations aim at empowering PLWHA economically through participation in IGAs and training them on how they can live positively with others in society increasing their capacity to deal with issues that affect making them capable to improve their lives. They develop their capacity to participate in and



gain control over the decision-making process that affects them. It enables them to speak, be listened to, define their perspective on the issues in question, be recognized, respected and treated as equal citizens. This kind of empowerment is meant to enable them lead their lives manageably as it is also deemed to be a prerequisite for sustainable development with equity as understood by Mulwa (2006:74).

In a similar venture, the Uganda AIDS Commission (UAC) report (2002/03) reveals that it aims at encouraging vulnerable groups especially vulnerable children and those orphaned by HIV/AIDS to take advantage of available services without fear. They also aim at extending the parent – child relationship by reducing vulnerability and extending the age at which a child becomes an orphan through better nutrition, treatment of opportunistic infections, and improvement of food security as well as prolonging the lives of infected patients (ibid). Another objective is to prepare the family for transition by planning ahead by the infected parents for the future of their children and for the guardians who will take over their responsibility. This is also found to reduce the anxiety and vulnerability that comes along through counseling. It also enables them to establish an economic support system for their families (Ibid).

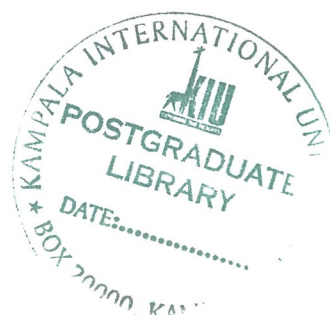
The researcher therefore understands associations or support or self-help groups that respond to HIV/AIDS as an important component of psychological support to PLWHA because they provide a non-discriminatory environment in which PLWHA can share experiences and information. To enhance their sustainability, they help members develop common objectives and expectations; focus on involving participants in a similar geographical area, thus avoiding unsustainable resource misuse; clarify the roles and responsibilities of support group members; develop mechanisms to cope with group such as death of members; and also provide opportunities for skills building.

2.2.2 Activities Undertaken By Associations of People Living With HIV/AIDS (APLWHA)

UNAIDS, (2004) advocates for Greater Involvement of People Living with HIV/AIDS (GIPA). In its Declaration on Commitment to HIV/AIDS June 25-27 2004 it shows how GIPA has been universally recognized as one of the most effective means of building effective international and national responses to the epidemic especially fighting stigma. A number of countries that have adopted different models of involving PLWHA in AIDS care and prevention programs that involve PLWHA and are known to be more responsive to their needs, while personal testimonies by PLWHA are known to have a profound influence on the risk perception of members of the public about HIV/AIDS (UNAIDS, 2004).

The *Reseau Rwandais Des Personnes Vivant Avec Le VIH/SIDA (R.R.P+)* - (Rwanda Network of People Living with HIV/AIDS) and several other bodies and networks that work with people infected and affected by HIV/AIDS in Rwanda have adopted the Greater Involvement of People Living with HIV/AIDS Approach (GIPA) approach of meaningful involvement of people infected and affected by HIV/AIDS. This is based on the understanding that no one can speak for a person living with HIV/AIDS except the person infected and affected by HIV/AIDS as perceived by UNAIDS. (Declaration of the Paris AIDS Summit 1994 – Section IV, Paragraph 1). As a national body of APLWHA it embraces the idea that meaningful community involvement looks at small communities where HIV and AIDS is a reality of daily life.

As a result, APLWHA welcome membership of the infected and affected especially with reference to vulnerable groups (that is, women, girls and children); they precisely attempt to address the challenges faced by HIV positive women and their children. (UAC 2002/03) This is done through offering Income Generating Activities (IGA), psycho-social support, revolving fund, Home Based Care (HBC), nutritional support, and information dissemination.





A report of UNAIDS (2002) says in Ethiopia, some Community-Based Organizations are dedicated to providing: outreach activities that engage individuals most at risk for HIV, those who are HIV infected and not currently engaged in health care, and those who do not yet know their HIV status. Individual and group level interventions; health communication and public information interventions that deliver HIV prevention messages and promote HIV programs and community events to increase awareness, build general support for safe behaviors and support personal risk reduction efforts; community-level interventions that influence community norms, attitudes and practices in support of reducing risk behaviors; support services to affected family members including bereavement counseling and support groups; and referrals to services are provided directly by the CBGs. Some do HIV counseling, testing and partner notification as well as primary care.

Kaleeba (2000) says in Uganda, the work of TASO and other CBGs has been central to encouraging greater openness about the epidemic and improving support and care to individuals, families and communities living with HIV/AIDS.

Some associations strive to ensure the children's future through education support and other life enhancing skills for the purpose of securing a stable livelihood, with aims of ensuring children do not drop out of school due to the challenges of the disease, Aganga (2006).

Other youth groups promote sex education by encouraging the delay of the first sexual encounter among non-sexually active youth, reduce the number of sexual partners, encourage the use of condoms and other contraceptives among the sexually active youth, and also aim at contributing to the elimination of harmful traditional practices and forced or coerced sex (AYA report Oct 2003).

Some associations equip their members with general coping skills like: how to come to terms with HIV infection and how to cope with stigma and discrimination,

general information about HIV/AIDS: transmission routes, epidemiology, positive living and information on: nutrition and healthy diet; care and treatment available, including side-effects of treatments. These are done through training and counseling sessions organized by their leaders.

Like any other service provider, PLWHA also receive training adapted to the kind of service they deliver, whether it is awareness-raising, giving testimonies, counseling or home-based care. Kaleeba, (2000)

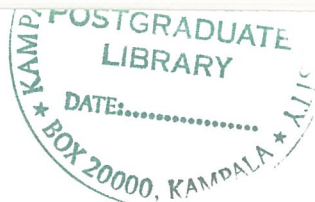
While describing the situation of orphans and other vulnerable children, the MOGLSD policy (2004, P.4) states that "One in four households in Uganda fosters at least one orphan by providing health, shelter, nutrition, education and other needs. However, many of these caregivers are over burdened and often lack the socio-economic capacity to provide adequate care and support for these children. Community organizations, religious bodies and other civil society members have stepped in by providing information, vocational skills training, and other life enhancing services.

A report by TASO – Uganda says one of their prime activities is offering psycho-socio support to the infected and affected by HIV/AIDS. Their counseling programmes aim at empowering the infected and affected persons to make informed decisions that improve the quality of life and facilitate the balance between rights and update information on facts about HIV/AIDS, STDs, TASO (2004).

Furthermore, care and support have been seriously advocated to include provision of basic physical, cognitive and psychosocial needs of orphans, other vulnerable children and their caregivers on a sustainable basis (P. 18).

It is implied that the APLWHA ensure that care and support are rendered to their association members and their families for those infected, affected and orphaned by HIV/AIDS.





Other organizations promote condom use as it has been highly advocated and scientifically proven that condoms are highly effective in preventing sexual HIV transmission. CNLS, (2006)

In a related development UNAIDS (2004) further indicates that social support comprises of services or clients that enhance practical positive living, skill building, educative music, dance and drama and fellowship with other clients in a day care center. In support of this, TASO – Uganda in response to the needs of orphans and vulnerable children and vulnerable children of clients provides formal education and vocational training, TASO, (2003) reports.

Further still, the report highlights that community mobilization and capacity building, AIDS Education and awareness are vital endeavors for APLWHA. This is done through community programmes, which utilize various gender and age sensitive methods such as seminars, client drama groups. It is strongly believed that capacity building can empower other partners to address HIV/AIDS challenges and it is mainly done at three levels, which include support to other organizations and institutions, provision of technical support in the area of organizational development, program and financial management.

Mann et al. (1999) identifies advocacy and networking in which HIV/AIDS NGOs are committed to ensure that the rights of PLWHA are protected. Advocacy in this case which is a process that brings about change in the attitudes, practices, policies and laws of influential individuals, groups and institutions, carried out by people proposing improvements on behalf of themselves or others deals with any issues which violates the rights of PLWHA. TASO, (2003) report reveals that this is done through collaboration of national, international organizations and relevant policy formulating bodies and governments. Efforts are made through collaboration and networking with government, NGOs, CBOs to avail quality care and support to PLWHA.

2.2.3 Challenges Faced By the Associations of People Living With HIV/AIDS (APLWHA)

While Paterne (2005) broadly identifies the challenges faced by PLWHA as financial constraints, lack of strategic plans, lack of toolkits, disruption of children from studies, increasing demand for school fees, sustainability, and difficulty in loan repayment among others, the researcher categorizes these challenges as social, psychological, cultural and household challenges, natural occurrences, economic challenges, political challenges, and challenges that originate from donors or aid givers.

These key challenges can be singled out with views from studies of findings by the UNDP report (2005), Clarke et al (2005), Jackson (2002), and reports by FAO (2004) as: Lack of resource identification; mobilization and allocation; poverty; financial constraints; lack of or poor or weak strategic plans; lack of information; lack of a permanent source of funds and uncertainty of future funding; increase and unmanageable numbers of People Living with HIV/AIDS (PLWHA); inadequate knowledge on Income Generating Activities (IGAs) operation; and inadequate or absence of training for IGA; limited funds to train beneficiaries (PLWHA or people affected by HIV/AIDS) on practical skills; inadequate training period on management; lack of training materials; loss of key players/leaders/founders of the associations, death weakening management; lack of initial capital to obtain loans; poor or lack of consistent contribution by client to association investment; poor loan repayment; disruption of children from studies due to illness and death or care for sick parents and relatives; funerals; participation in agricultural work; and poor sale of produce.

One of the challenges as identified in a joint report by UNAIDS, UNFPA, and UNIFEM in (2004) is that of economic empowerment to be able to meet the needs of the infected and affected by HIV/AIDS. Similarly, a report by Mujawyesu (2005) of Consultation Council of Supporting Organizations on



Basic Initiatives (CCSOBI) reveals that associations face the challenge of being unable to address each individual member's needs satisfactorily. She adds that "some people come into the associations with high expectations. Their anticipation for immediate change is too high. They relate their membership to a lump sum of food supply, sponsorship for child education, medical care and funds for IGAs among other benefits." Little is considered that they are the only source of labor and every good yield will entirely depend on their efforts.

⊗ In agreement with Reid (1995) who says communities invest most of their meager resources in their groups without yield out of them, the researcher notes that the activities in these associations are also too demanding that members are often torn between gardening, training sessions, meetings, and funerals, sale of produce and family responsibilities. The outcome is often too little to account for the time they invest on these activities.

Another key challenge faced at the level of the associations is that of poverty. Describing poverty, Sen (1999) emphasizes a much broader approach by looking at it as: lack of voice, saying, "people need means to express their needs or to obtain redress"; lack of empowerment, "that people need the resources and authority to take charge of programs meant for their benefit"; and lack of good governance, that, "people are worse off when officials are corrupt, unresponsive to local demands, and unaccountable".

Poverty identified as a cause and consequence of HIV/AIDS is a situation that draws many people to join these associations in order to attain redress.

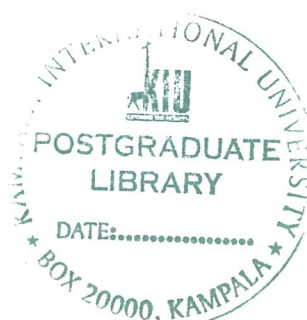
⊗ At community level, it is noted that most initiatives are tied to funds provided for specific activities, often with no long term commitment as Staugård et. al (1996) observe. Not only is funding often insufficient, it is sporadic or at times absent. Since they depend heavily on funding from outside and expatriates for managerial responsibilities, the cost and incentives extended to their beneficiaries is beyond the capacity of community based organizations to sustain

those activities and services even for a very short period. It creates difficulties in budget allocation and sustainability because most activities demand the use of funds for various activities like provision of food supplements, capital for IGAs.

④ In addition, a World Bank Global (2005) report reveals that for projects that rely on outside support for funds, the immediate success rate of these projects was high in the past. It was seen that participation by beneficiaries on projects meant for them improved project design, implementation, and outcomes. However, such projects remain almost totally dependent of outside financial support, and this reduces local ownership, sustainability, creativity and innovativeness.

④ The researcher accepts that the lack of continuous financial support of these associations poses the threat of sustainability. Most NGOs and other organizations that spearhead the formation of these associations operate as projects that have a time limit and specified objectives. It occurs that when such projects come to an end, their contact with the already established associations and self help groups is cut off; and they operate on the assumption that these groups have been empowered by their presence and working with them that they should carry on with the activities on their own. It is not usually the case. Because of this uncertainty, those in the leadership position may be tempted to serve their individual needs leading to corruption and a crippling effect of the group and eventually a total collapse.

④ Aid has also had the effect of significantly altering the lifestyles of its beneficiaries. For instance imported food aid undermines the local economies and makes agriculture less profitable. Experience has shown that when the aid comes to an end there are food shortages in the communities and they have to constantly rely on relief, weakening their capacity and capability to provide for themselves FAO, (2004); and as such, development is not realized and also deprives them of their right to access to adequate food.



① The practice of overdependence on donor support can not entirely be blamed on the beneficiaries, but sometimes NGOs fail to provide adequate or appropriate funds, training and other forms of practical support. While in other cases local groups fail to perform due to trying to carry out too many activities with unsustainable costs; for example, provision of food, clothes and scholastic materials, some carry out information programmes without Information, Education, and Communication (IEC) materials.

① Jackson (2002) comments that support groups and the networks that are supposed to assist PLWHA and the affected have tended to be weak and under funded. Some networks are rife with conflict and competition for the scarce resources that reach them. Many support groups do not last long as members die and recruitment is problematic because of stigma. In some that focus primarily on income generation, conflict may arise between those whose health no longer permits to contribute and who therefore become a drain on the group's resources. In principle, income generation should support home care, but in impoverished communities this may not be simple to achieve and sustain.

① Community based groups also are less motivated especially when they feel used. For instance when NGOs use these groups as a strategy to raise funds, they gain fame and accomplish their own publications.

① Much as Aid is used to and is meant to improve conditions not ideal for humanity, it has been found to bear fruit most of which benefits the donor, because its effects on the receiving country is always short lived. Even though it relieves suffering and improves some socio-economic situations of those in need, it has been found to create a sense of imbalance between donor and national objectives in most developing nations or recipient countries, Burkey (1998).

① Donors should never ignore the fact that observations are coming onto the surface and should be more focused on meeting the fundamental needs of poor

people. With this realization there is also need for recipient governments to strive in creating a balance regarding the positive and negative effects of aid so as to find a more beneficial position.

Another obstacle facing community based group initiatives as observed by Staugård *et. al*, (1996) and Mulwa (2006) is that most of its members experience extreme difficulties in obtaining loans from banks or those being offered by NGOs operating in their areas as revolving fund. Mulwa (2006) contends that such persons lack collateral for securing the loans. This is further escalated by the fact that women do not own property like land. As a way of coping, they are compelled to sell assets that could have otherwise served as security in order to acquire loans and pay medical bills.

ⓧ Apart from failure to find continuous financial support, these associations have difficulties in finding markets for their products according to a report by FAO (2004) and FANTA report (2006). Consequently, the meager income generated makes it hard to sustain their multiple needs in that it has to be shared among many mouths as a way of providing for their basic needs.

ⓧ Resources of any kind are the key to the effective and efficient functioning of local initiatives. Commenting on resource constraints, Paterne (2005) recognizes that Africa is the most badly hit continent with HIV/AIDS and experiences further challenges of limited resources to address the problem. He cites an example of the human resource for labor and productivity being affected by the disease, especially the young and would be productive people. It may be implied that APLWHA face the challenge of resource mobilization.

ⓧ With the growing realization that resources are being overstretched to meet the growing needs of ARV provision, food provision for adequate nutrition, production of materials for creating awareness and sensitization about the disease, condom use promotion, others are being used in holding meetings and conferences to

① address emerging issues about the disease. It all turns around and leaves the economy in a poorer state instead. Worse still is that most well financed, well staffed, and successful associations are found in urban areas while the rural poor are left behind the curtain.

② Reid (1995) says communities and their organizations should know what additional resources they need to be able to continue. They must be empowered to define these resources to others, select them, manage them and account for their use in appropriate ways (p.8, 9).

③ Burkey (1998) says that their mobilization is necessary to fuel the engine of development. And Mulwa (2006) adds that their existence goes beyond skilled manpower to financial and other material resources. He says that when they are mismanaged, not well mobilized and allocated, they become scarce and slow down the pace of community initiatives and development.

④ In Burkey (1998)'s opinion mobilizing these resources should begin with realization of their own meager resources as the basis of self-reliance, and that individuals must gradually acquire rightful access to external resources and services on mutually acceptable terms.

⑤ Commenting on the scarcity of resources, Sen (1999) quotes Callisto Madaro who says that empowering communities is a smart and dignified way to go, and is an integral part of poverty reduction strategies. And on how they are not well allocated, he adds that indeed many projects financed by donors are in this direction but still too few resources filter down to the communities.

Mulwa (2006) concludes by saying that development of any form may be hard to start in a resource poor community because most local communities are poor and are often not endowed with assets.

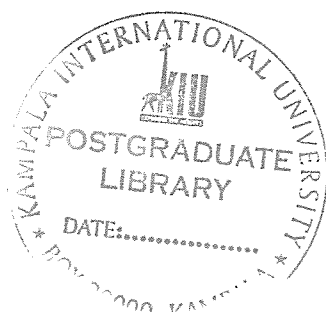
✓ According to Mati (1997) care givers are also exposed to chances of getting infected. Because of this fear many ailing people do not receive maximum attention regarding comfort measures for the patient. As such, it turns out to be that there is laxity among caregivers attending to the sick and volunteers from the associations have to come in and lend a hand on providing home-based care services. This is challenging because there are no sufficient volunteers to go from home to home to ensure that patients are well attended to. It is due to distance, lack of skills, lack of funds, materials to use in providing care and even poor infrastructure which hinders proper communication and accessing those in need.

✓ Mulwa (2006) asserts regarding technical knowledge and expertise, and studies in the same field have shown that rural communities have limited organizational and managerial skills. Many lack leadership skills or leaders lack legitimacy. Most of them are appointed those positions as a result of benefit of trust by other members and the community.

✓ Lack of technical know-how undermines the would-be good plans and implementation of activities may not be feasible as the cost of external labor inputs is high.

The same author says this not only exposes such communities to vulnerability against intentional mismanagement and theft of resources, but also causes projects to fail due to inadequate planning (ibid). In support of this argument, Nkata (2005) states that "all unfinished projects seen all over are manifestations of poor planning".

✓ Looking further into the challenges Mulwa (2006) observes that it is made more complex due to the fact that women who form the bulk of community force for community projects are often marginalized when it comes to information,





decision making, and access to opportunities for training meant for capacity building.

Another limitation is the lack of the capacity to provide training and other skills development opportunities for PLWHA. There is also a tendency to provide PLWHA with basic knowledge of HIV/AIDS but not with the technical skills necessary to deliver services and even cope with the disease. This may be because of perceptions that it is not worthwhile training PLWHA because of their higher levels of illness and death or because PLWHA cannot sustain regular involvement. In many cases, only a few individuals – always the same ones – are sent to workshops. Lack of training limits participation and greater involvement.

A report by the Consultation Council of Supporting Organizations on Basic Initiatives (CCSOIB) in Rwanda (2005) indicates that in most cases PLWHA are preoccupied with economic activities giving little attention to the issue of gender in the context of HIV/AIDS. In a related development, Staugård et al (1996) also observe that most Community Based Groups (CBGs) that deal with HIV/AIDS care and support comprise of women but noted further that they seem to be a partly hidden potential.

In addition, as caregivers, this gender category which makes up a big number of members of APLWHA is often obliged to stay home and look after the sick. It causes absenteeism from the associations' activities bearing in mind they are the significant source of labor and draws back the efforts of the associations for continuous support from its members.

Besides trying to meet the immediate needs of their clients, community based HIV/AIDS response initiatives are grappling with the growing phenomena of orphaned children who face discrimination, stigmatization and denial, social isolation, rights deprivation are among others.

A report by Interagency Coalition on AIDS and Development (ICAD) (2006) points out that "The number of child-headed households is on the increase as parents and caregivers die, leaving orphans unprotected, poorly socialized and under-educated." Conversely, children may feel isolated from the community, they lack adult protection, and they face mistreatment like physical abuse and sexual exploitation particularly in girls.

Staugård *et. al* (1996) comment that having to take care of orphans is another burden on these associations and that orphans and orphanages were unheard of traditionally since such children were taken care of by the extended family or the clan. A report by the United Nations (2005) shows that the impact of HIV/AIDS has placed severe burdens on community based initiatives' ability to take care of orphaned children.

Similarly, Aganga (2006) gives other challenges as increased demand for fees and formal education, overwhelming numbers of children to be supported through the association, poor performance of supported children in school, managing aid and donations like food aid, weaning off food beneficiaries and lack of sustainability of the programme.

The researcher reveals that the Food for Work (FFW) mode of distributing food in these associations affects children of school going age. Much as the associations want children to attend school, sometimes they have to be absent from study while they come for their food rations as infected children or to help their sick parents with agricultural work as required by the associations. They also have to wait on the queue to get food and carry it home. It draws back their efforts of wanting their children to attain quality education. To the children, this is tasking because it is tantamount to child labor and exploitation as they are exposed to adult-like responsibilities pre-maturely. This affects their normal growing pattern as compared to other children of the same age.



The researcher is of the view that counseling may be required for them to recuperate from their physical, psychological, and social problems. However the ability of their associations to address their physiological well-being to enable them increase their ability to adapt and cope with the epidemic amidst adversity and inadequacy of resources is challenged.

Clarke (2005) recognizes that with the traumatic effects and grief, loss and other hardships faced children infected and affected by HIV/AIDS, who are at the same time members of these associations, there is an increasing recognition that programs to help them strengthen their social and emotional support systems are overburdened.

Stigma is another challenge PLWHA face even in their groups. UNAIDS describes stigma as a mark of shame or discredit upon a person or group. It can manifest itself in a variety of ways, from ignoring the needs of a person or group to psychologically or physically harming those who are stigmatized. (UN Declaration of Commitment on HIV/AIDS, 25-27 June 2004).

Similarly, a UNAIDS report by Global Network of People Living with HIV/AIDS (2001) says stigma and discrimination can arise from community-level responses to HIV and AIDS. The harassing of individuals suspected of being infected or of belonging to a particular group has been widely reported. UNAIDS, (August 2001)

Stigma also causes poor involvement of PLWHA. A report by Horizon (2002) reveals that because of the existence of stigma and discrimination in their society, PLWHA fear that by being involved in AIDS organizations they may be identified as PLWHA and as a result labeled and discriminated against.

The same report says that failure to promote PLWHA involvement due to lack of information about opportunities for PLWHA to be involved in activities has



organizational limiting factors. This makes it hard to explore and exploit new talents. (ibid)

The task is building awareness and reducing the stigma that surrounds HIV/AIDS. This is due to the fact that lack of awareness has resulted in fear, shame, and denial as cited in the Uganda AIDS Commission (UAC) report (2002/03).

Identifying culture as a limiting factor for local initiatives' success, Mulwa (2006) observes that many times people are obliged to follow customs and traditions even when they work against development. He recognizes the fact that customs and traditions can be valuable resource as a point of reference for people's sense of identity and self-confidence. They however influence communities' perception of externally initiated ideas with suspicion and contempt. He substantiates the above view by giving an example of a situation that poses as a cultural threat like having men assuming the same responsibilities as those of women. For example, a man doing the cooking or laundry while the wife is sick or taking care of a sick child; or allowing a wife to attend a community women's meeting while he stays home with the children is unheard of in the African community.

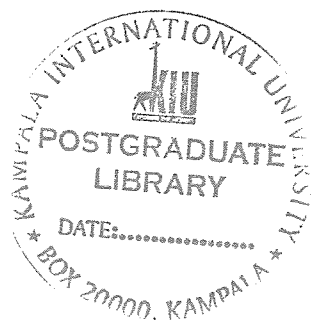
The researcher also acknowledges that in some cases customs and traditions work against the introduction of new and innovative development ideas while on other instances it is not the case. Another instance is the increasing number of dropouts due to early marriages, early exposure to sexual activities which predispose children to HIV infection, Ngozi, (2000). Such cultural practices are blamed of perpetuating school and group dropouts exposing them to the risk of getting HIV infection and draw back the efforts of local initiatives to fight the spread of HIV/AIDS and STIs

L A FANTA report of (2006) and Kirunda (2003) share the view that while the issue of sustainability is a concern, there is a dominating challenge that is hard to break through; this is the vicious cycle between food insecurity and HIV vulnerability. It is deemed that sustainability reduces vulnerability but the challenge here still is there is insufficient labor to till the fields and most crops require intensive labor.

J Furthermore, in his study carried out in Masaka on how access to food and nutrition can be increased in the context of HIV/AIDS, Kirunda (2003) sees the need to find innovative ways of encouraging food production. This is because HIV/AIDS is found to affect and threaten food security by affecting farming systems and rural livelihood and also weakens the purchasing power of most rural households.

J APLWHA face hardships on conducting their business, because of their HIV/AIDS burdens. As revealed by a report by the United Nations (2005) the HIV/AIDS epidemic has intensified labor bottlenecks in agriculture; increasing malnutrition; and adding to the burden of rural women, especially those who headed farm households.

J When communities are disturbed by HIV/AIDS, it is seen that the required labor for farming is limited. Such challenges compel families to change their living styles especially their eating pattern, the number of meals per day may be reduced, children become malnourished, receive less care, and in most cases are withdrawn from school particularly girl children. FAO (2004) report further observes that with increased food shortage and inadequate labor, communities continue to rely on foreign aid which is never adequate and sustainable especially in the absence of criteria for weaning off food beneficiaries from their feeding programmes. Most responsibilities of feeding households, providing psychological support and ensuring materials are shifted to the associations.



2.2.4 Coping Mechanisms for the Challenges Faced By Associations of People Living With HIV/AIDS (APLWHA)

Regardless of these challenges and their implications, APLWHA strive to innovate ways of dealing with these shortcomings. The associations may not have the capacity though the willingness to effectively overcome them may prevail. Some of the strengths they have in place in dealing with these challenges include: The use of training and support to members with necessary skills so that they are all involved in association endeavors like counseling and other activities. This is one important element present in varying degrees in most community initiatives responding to HIV/AIDS. Due to the nature of the disease, their leaders equip members with basic skills like counseling skills. By providing members with opportunities to participate in individual and, more importantly, group counseling sessions, they help in dispelling a sense of isolation and frustration often experienced by the challenges they face within their groups and by those affected by AIDS. UNAIDS (2002)

Burkey (1998) explains the role of participation in promoting community development initiatives. Borrowing from his ideology, it can be seen that by enabling APLWHA and those affected with the disease take part in addressing their needs through their associations, may lead them towards attaining success in achieving their concrete objectives. It also exposes them to learning opportunities on how to tackle the problems they face and also builds their own self confidence. Furthermore, he observes that self sufficiency is attained when their objectives are met.

Another coping mechanism is through reaching out. This entails engaging in exchange visits and information sharing with others involved in community response to HIV/AIDS. Their leaders ensure that these efforts are surviving and growing because they link them to a larger supportive community so as not to feel isolated. Others associations offer psychological support and non-discrimination with a friendly atmosphere, counseling, peer support made

available within or outside the group, pro-active training in coping with HIV status and positive living, and basic facts about HIV/AIDS. TASO (2004)

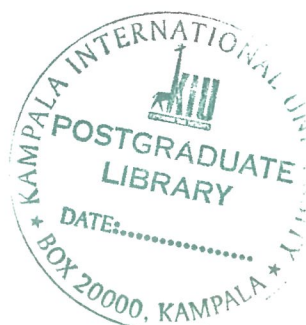
Most of them establish liaisons with networks for PLWHA, National Aids Control Programmes (NACP), as well as a variety of supportive relationships with both governmental and non-governmental organizations, the health sector and the private sector. These institutions are a major source of information, educational materials, commodities, expertise and, in some cases, financial support. (ibid) and (R.R.P+ 2006)

Building of strong foundations is another coping mechanism. As an element of success, it employs the recognition and utilization of strong and determined people in getting things off the ground. It needs strong willed persons, efforts of highly committed, resourceful and energetic individuals to spearhead and sustain such initiatives.

Mulwa (2006) contends that local initiatives become self-reliant when their reliance on external resources diminishes, which is in line with the overall goal of the role community participation in promoting development human dignity. When all the stakeholders are involved in deciding their destiny, they feel more confident rather than just waiting to receive handouts.

In agreement, the researcher believes that a participatory approach in the fight against HIV/AIDS could go a long way in managing the disease as well as developing the community.

From their recognition that women's groups constitute a not yet fully utilized resource, Staugård et al (1996) and Mati (1997) assume that a considerable community based women groups could be mobilized to perform home-based activities (Ibid), due to the fact that women in the local community possess good



CHAPTER THREE

METHODOLOGY

3.1 Introduction

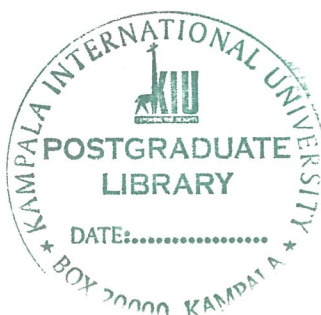
In this chapter, the methodological aspects of the study have been discussed. It covers the research design chosen, the study population and sample size, selection of respondents, sampling techniques and the area of study, the geographical area covered, the methods of data collection and techniques of data analysis besides the instruments that were administered with a view to collecting the expected data and also, the limitations of the study.

3.2 Research Design

The present study is descriptive in nature. The descriptive design was adopted while studying and describing the general situation of APLWHA in Karongi District. The researcher found that the available literature on APLWHA was scanty in Rwanda, and in particular, Karongi District. This design was beneficial to the study in the sense that it enabled the researcher to find out the situation of APLWHA from which opinions were built.

3.3 Study Population and Sample Size

The study targeted all the registered associations of the infected by HIV/AIDS actively functioning in the thirteen (13) sectors of Karongi District, which numbered sixteen (16) at the time of carrying out the present study. Four of the associations were selected considering various factors such as: their scope of work; availability and willingness of the respondents to take part in the study; interest and agreement of local government leaders to take part in the study; the age of these associations; proximity to each other and the presence of other youth groups in the area; high number of membership; to create gender balance and capture all age groups; PLWHA are both providers of services and



beneficiaries of the associations; and people affected by HIV/AIDS like family members and relatives are beneficiaries of the associations.

The following are the four associations visited during the study: Ngobokankomere Association is found in Gishyita sector. It is the oldest association which gave birth to the others in the region. It started in the year 2003 with twenty four members and currently it has one hundred and eighty members. Being the oldest group with a wider range of activities, it was deemed that from it information for the study would be obtained because of experience and composite membership.

Tubarere Association is also found in Gishyita sector. It started in 2005 with a membership of sixteen people and currently has forty eight members. It was selected for the study purposely because unlike other groups, Tubarere which means "Let's take care of them" is the only group that deals with PMTCT in the region. Its membership only comprises HIV positive women who at the time of testing their HIV status were pregnant and were encouraged to join the association. Other members are the babies born to these mothers from the pregnancies they had at the time of testing, meaning subsequent deliveries automatically disqualify the women from being members. When a mother dies the association takes care of the baby left up to a time the child wishes to change its membership.

Twubakane and Dufatanye Associations are found in Twumba and Mubuga sectors respectively. Twubakane which means "let's build each other" started in 2005 with a membership of twenty five people and currently has eighty five. Dufatanye which means "let's join hands together" started in 2005 with seven members and now has seventy two members. These two associations were also selected for the study representing other associations that came up much later and are actively participating in provision of care and support to PLWHA and those affected. Their membership is also well represented by different age and

