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A Grass Root Support Network of HIV/AIDS Infected/Affected Women

Selection of Self Help Groups in Kitui District, Kenya



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Dedication

This research paper is dedicated to my beloved dad, Rev. John K. Mahamah who passed away during the research period for this paper in Kenya. Dad always said, “If you accept defeat, defeat will always be yours”. He thought us never to accept defeat of any kind, but to give our very best and put our trust in God. It is with this thought in mind that gave me continuous motivation to finish this research paper. I say, *Asan ne kushun ga, Dada!*

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Abbreviations and Acronyms

AIDS	Acquired immune deficiency syndrome
APHIA II	AIDS, Population, and Health Integrated Assistance Project II
ARV	Antiretroviral
ART	Antiretroviral Therapy/Treatment
CAFOD	Catholic Agency for Overseers Development
CCC	Comprehensive Care Center
CSM	Cerebra-Spinal Meningitis
DFID	Department for International Development
ERS	Economic Recovery Strategy (Kenya)
FGD	Focus Group Discussion
HBCP	Home Based Care Program
HIV	Human Immune-deficiency Virus
ICRW	International Center for Research on Women
IRIN	Integrated Regional Information Network
ITPC	International Treatment Preparedness Coalition
KDHS	Kenya Demographic and Health Survey
Ksh	Kenyan Shillings
NCA	Norwegian Church Aid
NGO	Non-Governmental Organizations
PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of Mother To Child Transmission
PPKD	Population Projections for Kitui District
SHGs	Self Help Groups
UNAIDS	United States Agency for International Development
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session
UNICEF	United Nations Children's Fund
UNIFEM	United Nations Fund for Women
VCT	Voluntary Counseling and Testing
WCC	World Council for Churches
WHO	World Health Organization

Abstract

HIV/AIDS is no longer striking primarily men. Worldwide, women account for close to half of the 40 million people who are living with HIV. The rates of HIV infection among women and girls are a cause for deep concern, but when combined with the workload that women take on as well—in caring for AIDS patients, AIDS orphans and their own families—the situation becomes untenable, as it is in Sub-Saharan countries. HIV/AIDS is a development problem in which the disease impacts not only on the physical health of individuals, but also on their social identity and economic wellbeing, making it different from most other fatal diseases. Although progress has been made in developing programs in such a way that prevents new HIV infections and mitigates the impact of the epidemic, a lot is still to be done. In Kenya, women have started realizing the impact of '*Harambee*', of pulling together and finding support in numbers through the creation of Self Help Groups.

The study discusses the economic, health and social impact HIV/AIDS has on infected and affected women heading households in the district and the role Self Help Groups play in mitigating these impacts. To achieve the desired objectives of this study, nine different Self Help Groups in Kitui District of Kenya were selected for interviews and focus group discussions to get an in-depth understanding on the topic. In order for SHGs to be fully effective in its mitigation role for both infected and affected HIV/AIDS women heading households, development organizations need not only to integrate prevention and the fight against AIDS into development project related activities like income generating activities, literacy and education dissemination in creating awareness of the disease, but to encourage women in SHGs to take their own initiatives for a sustainable development.

Keywords: Infected and Affected, HIV/AIDS, Self Help Groups, Women Heading Households

1. Introduction

On his first visit to Africa, Pope Benedict XVI controversially describes AIDS as

“A tragedy that cannot be overcome by money alone, and that cannot be overcome through the distribution of condoms, which even aggravates the problems”

WHO/UNAIDS/UNICEF (2009).

1.1 Background

Over 40 million people worldwide are living with HIV/AIDS and 15,000 are newly infected every day according to WHO 2005 report. According to UNAIDS/WHO (2007), sub-Saharan Africa remains the most affected region in the global AIDS epidemic and more than two-thirds (68%) of all people infected with HIV live in this region and more than three quarters (77%) of all AIDS deaths in 2007 occurred there. It is estimated that since the beginning of the epidemic, more than 15 million Africans have died from AIDS (UNAIDS/WHO, 2007). It is also estimated that 1.7 million [range: 1.5 - 2.0] people were newly infected with HIV in 2007, bringing to 22.5 million [range: 20.9 - 24.3 million] the total number of people living with the virus (UNAIDS/WHO, 2007). This therefore represents 6.1% of the adult population. Unlike other regions, the majority of people with HIV in sub-Saharan Africa are women, accounting for 61% of those living with HIV/AIDS (FAO, 2005). The consequences are enormous, impacting not only the health of those infected with HIV/AIDS, but also depleting the economic and social resources of the people themselves, their entire families and communities.

Women are more vulnerable to HIV infection from heterosexual sex than men for various reasons. Research (WHO, 2005) shows that a woman's choices are often limited by her inability to negotiate when or with whom to engage in sexual intercourse or whether to use a condom; by society's acceptance of men having sexual intercourse before or outside marriage/committed relationship; and by the need for economic support from men. Also, there is a more exposed surface area in the female genitals than in the male genitals which allows for increased exposure to the virus during sexual intercourse, higher levels of HIV in semen than in vaginal fluid; more semen is exchanged during sex than vaginal fluids (UNAIDS, 2006). Also, women often have untreated sexual transmitted infections (STIs) which makes them more likely to get infected with HIV. The female genital tract has a greater exposed surface area than the male genital tract; therefore women may be prone to greater risk of infection with every exposure (WHO/UNAIDS/UNICEF, 2009). Physiologically, women and girls are 2 to 4 times more susceptible to HIV/AIDS. Infection in women and girls is compounded by their disproportionate vulnerability to social, cultural, economic and legal forms of discrimination.

Below is a graph¹ indicating the numbers of women and men living with HIV/AIDS. This is shown according to six regions; Sub-Saharan Africa, Caribbean, Asia, Latin America, and Eastern Europe together with Central Asia. It can be realized that especially Sub-Saharan Africa, women living with the disease far surpass that of the men. Below the graph is a brief explanation why this is so.

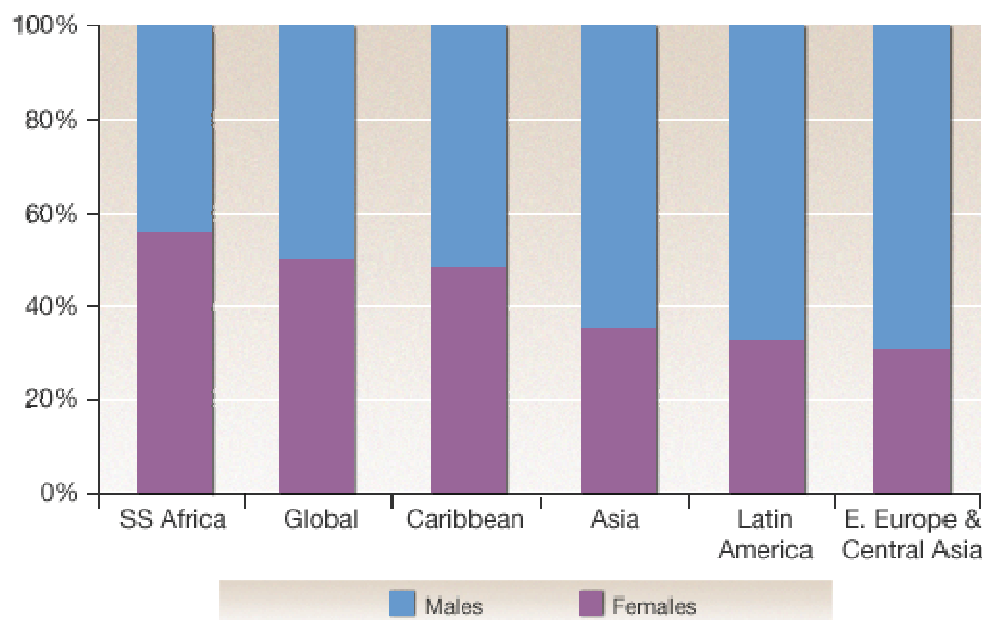


Figure I: Women and Men Living with HIV/AIDS by Region, 2007

Source: Chin, 2007, Global Health Council, 2000-2010

There are several reasons women and girls worldwide are at an increased risk, including the fact that they often are powerless in decisions to have sex or use a condom. Also, in some cases women who are married and faithful to their husbands may still be at risk of HIV infection. In most Eastern African countries such as Kenya, the highest rates of increase of HIV transmission occur among married women. Though marriage may appear to offer safety and sexual health benefits for women, research in Kenya and Zambia reveal that this is not always the case. Married women are predominantly more at risk if their husbands neglect to use condoms during extramarital relationships (Global Health Council, 2010). Because married females may have unprotected sexual intercourse husbands, who may be older and more sexually experienced, their risk of HIV infection is higher than usual (UNAIDS (2006) & Global Health Council, 2010). In some cases, women may experience they may also encounter violent behavior in their relationships with men which may conclude in unwanted sexual intercourse (Garcia-Moreno, et al, 2005). When household members of women are infected/ affected by HIV, the health of women is impacted. However, this impact is more

¹ The source of the graph was assessed on this website: Accessed in July/August, 2010:
http://www.globalhealth.org/hiv_aids/risk_groups1/ between June and August, 2010.

devastating when women themselves are HIV positive. The emotional, physical and psychological health overheads on the HIV patient and her family are often more significant. When people die of AIDS, the traditional family structures, already under stress by poor health, increased burden of care and poverty, are in many cases at breaking points (Nabila et al, 2001). For example, as the health impacts of HIV/AIDS set in, this could lead to loss of social networks which includes friends and family members.

A lack of economic opportunity can fuel migration and disrupt families. In some occasions, economic need drives women to engage in transactional sex and to enter or remain in relationships often associated with sexual violence (Republic of Kenya, 2005). For example, when faced with a crisis, women-headed households may find it impossible to continue investing in productive activities, saving, paying insurance premiums, or repaying loans because they do not have equal access to social and economic assets (Bishop-Sambrook, 2003) as compared to men. The poorest women heading households are least able to cope with the impact of AIDS-related adult deaths, and are frequently unable to obtain the most basic needs in the short term. Food production and security is sure to be affected as the active workforce is infected with and dies from AIDS. Moreover, there is the issue of increased household expenditures often related to medical expenses of either the women themselves and/or their household members. With this increase in expenditure, an infected/affected woman is likely to be deeply overwhelmed and impacted by stress, resulting in depression and other serious health implications.

The HIV/AIDS epidemic hits women hardest as compared to men, increasing vulnerable women in slum areas, and women who shoulder the burden of caring for the sick and dying loved ones (Nabila et al, 2001); the consequences of which decrease and de-diversify incomes, degrade human, social and economic assets and thereby bring a bigger burden on their livelihoods. As well, there are consequences of insecurity against crisis, such as HIV/AIDS or a bad harvest, which could easily push them into destitution (Donahue et al, 2001). Africa's HIV/AIDS epidemic therefore has various drivers on different levels: biological, personal-behavioural, politics, education, community and society and the economy in general. This is no exception especially with women who constitute a greater percentage in the epidemic. Intergenerational sexual relations between younger women and older men, one factor fuelling the epidemic, have become an acceptable social norm in most rural areas in some African counties, exacerbated by female poverty (KDHS, 2008-09). These social effects may include stigma, loss of business income, worsening poverty (which may lead to prostitution and survival sex), hopelessness, increased gender inequality, and death. This therefore indicates the inter-relation of social, economic and health impacts on women.

It is often stated that, “like a pebble dropped in a pool, HIV sends ripples to the edges of society, affecting first the family, then the community, then the nation as a whole” (UNAIDS, 2004). The UNAIDS further identifies the extent of how the social, economic and health effects of the epidemic are intertwined especially women-headed households who are infected / affected by HIV/AIDS. The impact of HIV/AIDS on women to be specific is therefore a cyclical process on the health, social and economic wellbeing of both the infected and affected.

1.1.1 HIV/AIDS and Kenya

The HIV/AIDS epidemic in Kenya affects all sectors of the country’s population which continues to have disastrous impact on the nation (WHO, 2005). The 2007 Kenya AIDS Indicators Survey estimated the average HIV prevalence among the general population aged 15-49 at 7.4% while the 2008-09 Kenya Demographic and Health Survey (KDHS) estimated prevalence for the same population at 6.3 percent (KNASP, 2005-2010). The findings show that although Kenya’s epidemic has stabilized in recent years, women still have a higher prevalence compared to men (KDHS 2008-09). An estimated 1.2 million people currently live with HIV/AIDS in Kenya. An estimated 1.5 million people have died from AIDS since 1984. More than 1.6 million children younger than 15 years (3.7% of the total population) have been orphaned. At least 180, 000 people die from AIDS annually in Kenya. The prevalence is still high but appears to be decreasing (WHO, 2005). A strategic approach to control the epidemic, outlined in the Kenya National HIV/AIDS Strategic Plan 2000–2005 established by the government in 1999, consists of prevention of new infections; treatment, care and support for those infected and affected by HIV/AIDS; mitigation of the impact of the epidemic on social and economic development efforts; monitoring and evaluation; and management and coordination (WHO, 2005). In Kenya, women are disproportionately affected by HIV. For instance, in 2008/09, HIV prevalence among women was twice as high as that for men at 8% and 4.3% respectively (UNGASS, 2008). Adult HIV prevalence is greater among urban areas (8.4 percent) than rural areas (6.7 percent) of Kenya (UNGASS, 2010). However, as about 75 percent of people in Kenya live in rural areas, the total number of people living with HIV is higher in rural settings (UNGASS, 2010).

The Kenyan government has and is still undertaking prevention and mitigating steps for HIV/AIDS for her citizens, but with specific reference in women. The following are some exemplary cases of strategies taken. The main prevention strategies outlined in the Kenya National HIV/AIDS Strategic Plan 2005-2010 (KNASP) include: increasing availability and access to counseling and testing, condom promotion, expanding services for Prevention for Mother-To-Child Transmission (PMTCT), ensuring more effective and targeted behavior change communication, promoting abstinence, safe sex and delayed sex debut

among young people, ensure mutually supporting prevention and treatment efforts, among others (WHO, 2005). The government also emphasized the importance of male involvement in PMTCT programs (IRIN, 2009). Government policies helpful include the Abstinence, Be faithful and consistent use of Condoms (ABC) program, national guidelines on Voluntary Counseling and Testing (VCT), guidelines on national home-based care programs, on blood safety, antiretroviral therapy and on PMTCT (IRIN, 2009). In addition, Kenya has adopted a multi-disciplinary approach to the provision of HIV Testing and Counseling (HTC) services. With regards to the health sector, HIV/AIDS is associated with the National AIDS and STDs Control Program (NASCOP) through the Ministry of Health (IRIN, 2009). NASCOP in 2002 established a National Antiretroviral Therapy Task Force to guide the way forward to scaling up the provision of antiretroviral therapy across the country (WHO, 2005). Alongside voluntary testing, Provider Initiated Counseling and Testing² (PCT) have expanded (UNGASS, 2010). However, many Kenyans are still unaware of their HIV status. In the 2007 Kenyan AIDS Indicator Survey, 83 percent of HIV-infected adults aged 15-64 were unaware they were infected, because they had never been tested for HIV, had been tested but did not receive the result, or they thought they were uninfected based on their last test (KAIS Collaborating Institutions 2009). More often than not, women are afraid to reveal their HIV status to husbands and or sexual partners because of fear of stigmatization, abuse and neglect (Human Rights Watch, 2008) and may go to the extreme of not seeking antenatal care from hospitals because of fear of their HIV status being.

In a nut shell, although Kenya has steadily made improvement in healthcare, the health status of Kenyans has suffered major drawbacks including a decline in life expectancy from 60 years in 1990 to 54 years in 2008 (UNICEF, 2008). In addition, include low productivity in the agricultural sector becomes a challenge especially for households who solely depend on the sector for their livelihood. Furthermore, though awareness of HIV /AIDS in the country is high, many people living with the virus still face stigma and discrimination. Studies have shown that although people are aware of the basic facts about HIV/AIDS, many are not informed of the more in-depth knowledge that addresses issues of stigma (ITPC, 2007).

Although much research has been on the impact HIV/AIDS has on the wellbeing of women as seen above, it is however unclear how Self Help Groups (SHGs) could help in mitigating this impact regarding the health, economic and social impacts of the disease. Self Help Groups, also known as support groups,

² PCT is when individuals are offered a HIV test whenever they go to a health facility, rather than patients having to ask for a test (UNGASS, 2008).

are groups of people who provide mutual support for each other. In a self-help group, the members share a common problem, often a common disease or addiction. While Bartalos (1992) has pointed out the contradictory nature of the terms “self-help” and “support,” the former U.S. surgeon general C. Everett Koop stated that SHGs bring together two central but disparate themes of American culture, individualism and cooperation (“Sharing Solutions” 1992). Self Help Groups provide many benefits. With respect to health, SHGs help people process their feelings about difficult experiences thereby decreasing the likelihood of being stressed or depressed through the power of sharing and learning about the HIV/AIDS disease. In some cases, SHGs may be mediators in the acquisition of ARVs for women. In addition, SHGs allow members to vent about their struggles and challenges among other people who know exactly what you're talking about through the power of socialization and creation of social networks. In providing economic benefits, SHGs put much emphasis on the acquisition of credit and savings as safety nets for the women and their households. However, it has not yet been clearly documented how these Self Help Groups assist women who are either infected or affected to cope with the economic, health and social impacts HIV/AIDS has on their wellbeing.

1.2 Problem Statement

HIV/AIDS has caused immense human suffering in the continent of Africa. The most obvious effect of this crisis has been on economic growth and development (DFID, 2004) with emphasis on the increasing decrement on productivity and income levels for the sustenance of the rural poor especially. Next is the stressful burden of illness and death whereby depression rates shoot up, causing psychological problems for a country. In 2008 alone, an estimated 1.4 million adults and children died as a result of AIDS in sub-Saharan Africa (UNAIDS, 2009). The impact of the epidemic has certainly not been confined to only the economic and health sectors, the social sectors have also been affected negatively. As population increases with inadequate sources of income to care for occupants, migration begins to take place as people search for greener pastures. This leads to breakages of social networks of families and friends and leaving being those who are in greater need of support_ infected and affected populations. It is clear how strong these impacts can be on a country. On women and their households however, the potency of the impact is worse as there is a reduction of food security based on the economic impacts. There is increased likelihood of not being able to provide ARVs for themselves because of increasing medical bills and household expenditure as well as the loss of socialization and the ability to belong and be loved. Self Help Groups are being formed all over Kenya and the rationale for these SHGs is in their potentiality in mitigating economic distress for women and their households, addressing the health concerns of people living with HIV/AIDS and providing them a forum to share their personal experience, support and encouragement but whether this is really the way forward for women dealing with the impacts of

HIV/AIDS, remains to be determined. Hence, the aim of this study research is to explore how Self Help Groups as a social support network mitigates these impacts through possible economic, health and social functions in the Kitui District of Kenya.

1.3 Organization of Thesis

This research paper has been organized into five major topics in the form of chapters. Chapter one has shown an introductory background of the research study on the impact of HIV/AIDS specifically on the health, economic and social wellbeing of women. Some review of literature on the dynamics and roles of SHGs and how this may help women deal with the impact is also discussed.

In chapter two, the theoretical frame work which will result in specific research questions and acts as a guide for the research methods is thoroughly discussed.

Chapter three describes the research methods and a description of the study area. It begins with the research design followed by a brief description of the study area to indicate its appropriateness as the area of study. Methods of data collection and analysis are discussed in relation to each of the research questions.

Chapter four presents the results of the research study, taking note of the research questions.

Chapter five focuses on the interpretations and critical reflection of the results in relation to the theoretical framework and literature which has been reviewed and discusses whether or not the problem statement has been solved. The discussion ends with the research limitations, conclusions and recommending steps for research, policy makers and development organizations.

2. A Theoretical Framework on the Mitigating Effects of SHGs for Women Infected/Affected by HIV/AIDS

This chapter begins first with what is meant by defining the research population. This is followed by an elaboration of the impact of HIV/AIDS after which the focus turns to SHGs and how they contribute to mitigating these impacts in three broad parts: health, which is examined from the perspective of physical and emotional wellbeing; economic, encompasses worsening poverty, loss of business income and increased household expenditure and social, which covers aspects of stigma, loss of social networks as well as increased gender disparities.

2.1 'Women Heading Households'

The term “household” has been defined differently by different people and in different development theories and concepts. The most comprehensive definition adopted for this study is that given by the Philippines National Statistics Office (NSO). The NSO defines “household” as: an aggregate of persons, generally but not necessarily bound by ties of kinship, which live together under the same roof and eat together or share in common the household food (Lekan, 2006). Furthermore, a person who lives alone is considered a separate household, as also a person who rents bed space but makes arrangements for his/her own food. Moreover, “a group of persons who share and take their meals together but live on separate but adjacent living quarters for convenience is also considered one household” (Morada et. al, 2001). Baylies (2002) contends that the headship of the household is usually identified with the person who has the greater authority in the family or household. Power and authority in turn may be vested in the member who has control over the general affairs of the family unit, including decision-making concerning its economic, social and political interactions.

The concept of women-headed household is the one given by the Communication and Educational Technology Services, University of Minnesota Extension Service, (2004) as “one headed by female household head/reference person who is not currently married and living with her spouse”. Scholars have subjected women-headed households to much research. Initially, two major generalizations are made about female-headed households. The first is that in almost all countries, they are concentrated among the poorer strata of society and often have lower incomes than male-headed households (Chant, 2007). Women-headed households therefore generally refer to widows, divorced, abandoned, and single women who are generally poor, survivor of violence, discriminated, and excluded from the mainstream. Women are hence forced to play the dual role of being economically productive as well as performing domestic

duties. The emergence of women-headed households is a direct result of the economic and demographic transformations in developing countries. Evidence of these changes includes the monetization of the economy and the growth of commerce, industries, and government employment in major cities. These factors promote rural to urban movements of population, and consequently, have influenced the breakdown of the family structure. As countries continue to undergo socioeconomic development, the number of women-headed households is expected to increase.

It should be noted that in the present study the term 'women heading household' will be used instead of the term 'women-headed household' because the research has focused on the women who are heading the households and not necessarily on the households themselves. Women heads as referred to in this paper as between the age range of 22 – 76 years old and may or may not have children.

2.2 HIV/AIDS: Health, Economic and Social Impact

The impact of the HIV/AIDS epidemic on both national development and household economies has compounded a whole range of challenges surrounding poverty and inequality. Louwenson and Whiteside have summarized the devastating implications of HIV/AIDS for poverty reduction in a paper prepared for the United Nations Development Program (UNDP):

"The devastation caused by HIV/AIDS is unique because it is depriving families, communities and entire nations of their young and most productive people. The epidemic is deepening poverty, reversing human development achievements, worsening gender inequalities, eroding the ability of governments to maintain essential services, reducing labor productivity and supply, and putting a brake on economic growth. The worsening conditions in turn make people and households even more at risk of, or vulnerable to, the epidemic, and sabotages global and national efforts to improve access to treatment and care. This cycle must be broken to ensure a sustainable solution to the HIV/AIDS crisis" (FAO, 2002).

Research on the impact of HIV /AIDS has increased significantly over the past years. Studies on socio-economic impacts have been carried out at various levels employing various methodologies. However, as mentioned already, this paper focuses specifically on the woman as a head of the household and a bit on the dependants in the household. A decade ago, women were considered peripheral to the epidemic of HIV/AIDS. Today, there is acknowledgement that they are at its epicenter. The trajectory of HIV/AIDS is clearly demonstrating that gender inequality fuels the epidemic. The international community has clearly endorsed that "gender equality and the empowerment of women are fundamental elements in the reduction of the vulnerability of women and girls to HIV/AIDS," both at the Millennium Summit held in 2000, as well as the UN General Assembly Special Session (UNGASS) on HIV/AIDS in June 2001. In industrialized countries, the first evidence of the AIDS epidemic was among groups of individuals who

shared a common exposure risk. In developing countries, the AIDS epidemic manifested³ quite differently, both because the signs and symptoms were harder to distinguish from competing causes of morbidity and mortality, and because the epidemic was more generalized, instead of seemingly limited to certain “high-risk” groups. Untreated HIV infection is a chronic illness that progresses through characteristic clinical stages; AIDS is an endpoint of HIV infection, resulting from severe immunologic damage, loss of an effective immune response to specific opportunistic pathogens, and tumors. The follow sub topics intends to highlight key issues surrounding the economic, health and social impact of HIV/AIDS on the wellbeing of women infected/affected with the disease.

2.2.1 Psychological and Physical (Health) Impact

Twenty years after the global emergence of HIV/AIDS as a major disease, Antiretroviral (ARV) treatment remains the primary method used to treat patients. The method involves the prescription of a combination of ARV drugs that must be ingested daily for the rest of a patient’s life. Although the drugs do not cure HIV, they can, if successfully administered, significantly slow the spread of HIV in the body, reduce susceptibility to opportunistic infections, and offer HIV-infected people a much longer and better quality of life. However, for most Africans living with HIV, ARVs are still not available - just under half of those in need of treatment are receiving it (WHO/UNAIDS/UNICEF, 2009). The impact of HIV/AIDS on the lives of women is one of the most critical reproductive health concerns of our times. A number of inter-twined reasons why women are more vulnerable than men to HIV/AIDS include female physiology, women’s lack of power to negotiate sexual relationships with male partners, especially in marriage, and the gendered nature of poverty, with poor women particularly vulnerable (Walker, 2002). Below are some specific points of the impact the disease has on the health of a women who is infected.

Physical Wellbeing

Ever since AIDS was first documented in the early 1980’s one of the scariest and frustrating experiences for people living with HIV has been changes they experience in their body weight, size, and shape. With HIV, drug resistance is caused by changes (mutations) in the virus's genetic structure. These mutations can lead to changes in certain proteins, most commonly enzymes, that help HIV reproduce (replicate). For people infected with HIV, drug resistance can render drugs less effective or even completely ineffective, thus significantly reducing treatment options (IRIN News, 2010).

Like most medicines, antiretroviral drugs can cause side effects. Though often mild, sometimes can be more serious and can lead more quickly to death. Lipodystrophy is one of the side effects of the ARVs which involve losing or gaining body fat, often in ways that can be disfiguring and stigmatizing. One

³ Publication: A guide to the clinical care of women with HIV/AIDS (2005). Assessed July/August, 2010 at: <http://hab.hrsa.gov/publications/womencare05/WG05chap1.htm>

pattern which is losing fat on the face, arms, legs and buttocks, resulting in sunken cheeks and having prominent veins on the limbs can be very stigmatizing already without having to tell others your HIV-positive status (added space) (Angermeyer, 2004). Although lipodystrophy sometimes affects people with HIV who have not taken any antiretroviral drugs, it occurs more often among those receiving treatment.

Opportunistic Infections though often occurring before a person starts treatment could also occur when there is adherence to drugs (when the body becomes immune to ARVs) or when a person is not consistent with taking medications. HIV reproduces itself incredibly quickly. Missing just 5 percent of doses can allow enough time for the virus to develop mutations and build resistance to the ARV drugs (IRIN News, 2010).

Weight loss and wasting syndrome are two AIDS-related complications that, if not adequately treated, can be life threatening. Even though anti-HIV therapies have helped reduce the risk of weight loss and wasting syndrome, both problems still occur (WHO, 2008). Weight loss refers to a loss of body weight. Wasting syndrome refers to a loss of body mass or size, most notably muscle mass (sometimes referred to as "lean body mass"). Very often, both occur at the same time.

Loss of Hope and Feeling of Worthlessness

It is a normal reaction to feel down, or even devastated, after being diagnosed with HIV or during the course of the disease⁴. However, depression is a separate medical condition that requires treatment. Research shows that depression can speed up HIV's progression to AIDS. Feelings of helplessness are common in those who are clinically depressed. A sense of hopelessness reflects a negative view of the future. This includes expectations of personal dissatisfaction, failure, and a continuation of pain and difficulty- a belief that a situation is unchangeable and cannot be improved upon. Feelings of helplessness reflect a negative view of the *self*. Depressed individuals view themselves more negatively, their self-esteem suffers, and they have little or no self-confidence. They do not believe they have any control or that they can help themselves to feel better. They may have an urge to give up and think, "What's the use anyway?"

Hence, it is clearly shown here how inter-related the physical and mental states are and also how health impacts in general share a bond with both the social and economic impacts of HIV/AIDS. An example is how depression can be a cause maybe as a result of the side effects of ARVs taken. These side effects, especially from lipodystrophy, easily give way for stigmatization from others (social) and when one is

⁴ After being infected with HIV, some people might show symptoms of the infection which m include depression and fatigue. This was assessed in August, 2010 at: <http://aids.about.com/od/otherconditions/tp/signs.htm>

stigmatized so much, there is the possibility of a business going bankrupt as people refused to purchase items from the shop or loss of financial support from networks when it is mostly needed.

2.2.2 Economic Impact

“I’m concerned that, a good quarter century later, women continue to bear the brunt of HIV. I work with HIV-infected women who live on less than 50 cents per day in resource-scarce settings. For them, opportunities for economic empowerment are few and far between, leaving them to stare in the eyes of the twin social ills of poverty and disease. In these households, when men – who happen to be the sole breadwinners – pass on, the women are literally left destitute.”

– Asunta Wagura

Executive Director

Kenya Network of Women Living with AIDS

(Wangura, 2006)

The impact of HIV/AIDS on the macro-economic environment takes two dimensions, namely the direct and indirect costs (Balyamujura et al, 2000). The former refers to the costs of treatment associated with HIV related illness, which has serious implications for health care budgets in African countries since sections of the population are poor and would lose out most as pressures on the health budgets increases resulting in higher medical costs. Indirect costs are more difficult to measure as they typically refer to loss of value in production (FAO, 2002).

Household Expenditure

The high cost of antiretroviral drugs and the need for clinical⁵ and laboratory services for monitoring response to and efficacy of these treatments have greatly restricted provision of Highly Active Antiretroviral Treatment (HAART) in the developing world. Thus the reductions in morbidity and gains in survival⁶ in HIV patients that have been demonstrated in many industrialized countries do not consistently extend to developing countries in which the majority of HIV cases occur worldwide. Women are vulnerable not only to HIV/AIDS infection but also to the economic impact of HIV/AIDS. It has been reported that in the case of the death of the husband, the family income goes down by 80%- women are generally ill equipped to handle the additional burden due to gender based inequalities and unequal access and opportunities in education, skills and employment sectors (FAO, 2002). One major problem with ARVs is

⁵ Publication: A guide to the clinical care of women with HIV/AIDS (2005). Assessed July/August, 2010 at: <http://hab.hrsa.gov/publications/womencare05/WG05chap1.htm>

⁶ Assessed in July/August, 2010 at: http://www.reproline.jhu.edu/video/hiv/tutorials/English/tutorials/Women_Care_Guide/womencare/Guide_01_Chpt.pdf
Epidemiology and natural history of HIV infection in women (Ruth M. Greenblatt, MD, and Hessel, N.S, MSPH)

the costs. ARVs are expensive (as stated already) and require not only the pills itself but also regular check-ups and laboratory testing. This means that this treatment is out of reach for many poor people.

Worsening poverty

As stated above, households may experience the immediate impact of HIV/AIDS, because families are the main caregivers for the sick and suffer AIDS-related financial hardships. During the long period of illness caused by AIDS, the loss of income and cost of caring for a dying family member can impoverish households. Poverty can be defined in many different ways. The condition of poverty has been interpreted conventionally as lack of access by households to the assets necessary for a higher standard of income or welfare, whether assets are thought of as human (access to education), natural (access to land), physical (access to infrastructure), social (access to networks of obligations) or financial (access to credit) (World Bank 2000). Without job skills or the opportunity to acquire skills, women may resort to transactional or commercial sex to provide for themselves and their families, greatly heightening the risk of contracting HIV. The presence of HIV/AIDS in a household quickly results in depletion of household income earning capacity and of household savings and assets. Many households quickly move into conditions characterized by poverty: very little income or wealth, debt, reduced access to services, and fewer than ever options for attaining socioeconomic security. Women and girls, in particular, are likely to be most affected (Schubert, 2003).

Loss of Business/productive Income

Similarly related to the point above, business and agriculture have also been seriously affected by HIV/AIDS. The economic viability of small farms and commercial agriculture is also compromised by a loss of farm workers. It is difficult to account for the loss of human capital as children's education, nutrition, and health suffer directly and indirectly due to AIDS. The effects of lower investments in the younger generation could affect economic performance for decades (UNAIDS, 2005). Straining the resources of communities - in hospitals, social services, schools and businesses- health care workers, teachers, business and government leaders have been lost to HIV/AIDS. The impact of diminished productivity is felt not only on household or community level, but on a national scale as well.

2.2.3 Social Impact

Partly due to side effects of some medications for the infected, stigma may arise from family, friends and the community in general. This may lead to loss of these social networks. Below are elaborations of how HIV/AIDS impacts the social wellbeing of a woman who is heading a household.

Stigma

Stigma is associated with a wide variety of health-related conditions. Health-related stigma may result from an obvious functional limitation, such as a limb amputation, or from a concealable disease, such as

asymptomatic HIV infection. How patients respond to illness, including many of the possible consequences of stigma such as depression, anxiety, loss of social support, loneliness, and decreased self-esteem, is at the very heart of nursing. Stigma is a recurring theme in research describing the psychosocial aspects of HIV (Angermeyer, 2004). Concern with stigma is widespread among people with HIV. Being rejected and fearing rejection have often been cited as major stressors of having HIV (Rintamaki, et al, 2006). Dealing with stigma takes energy, especially because the emotional after effects of a stigma experience can be intense and may recur (Donohue, 1991). According to research, most people with HIV have disclosed their HIV status to someone, often with mixed results. Although some people are accepting and supportive, others overtly reject or subtly distance themselves from the person with HIV ((Rintamaki, et al, 2006). As used by Goffman (1974), the term stigma refers both to a trait and to the outcome of being known to possess that trait. As a trait, a stigma is an attribute or characteristic that is viewed negatively by the culture or society, "especially when its discrediting effect is very extensive" (Goffman, p. 3). As an outcome, stigma occurs when the negative social meanings attached to the discrediting attribute become linked to the individual. The nature of the stigmatizing trait can influence the individual's experience of stigma (Goffman, 1974). If the trait is not immediately apparent to others, the individual is "discreditable" rather than automatically discredited. This may make it possible to conceal the trait from others in order to "pass" as "normal." Yet even those who successfully conceal their stigma trait may suffer from their own internal perception of being awed. The person with a more noticeable stigma may avoid or withdraw from social interactions (Goffman, 1974). With that linkage the person's social identity changes, resulting in less than full acceptance of the person in social interaction, identity engulfment (in which the trait becomes the defining aspect of the person, coloring all other information about him or her), and limitation of the opportunities that would otherwise be available.

Some studies indicate that women face severe stigma and discrimination from society (UNIFEM, 2001). Often, others stigmatize women as unworthy and immoral, consequently isolating them from medical care and contributing to inadequate adherence. Often AIDS related stigma and discrimination⁷ can result in being shunned by family, peers and the wider community, poor treatment in healthcare and education settings; an erosion of rights, psychological damage, and can negatively affect the success of testing and treatment (Angermeyer, et al, 2004). Stigma not only makes it more difficult for people trying to come to

⁷ AIDS stigma and discrimination exist worldwide, although they manifest themselves differently across countries, communities, religious groups and individuals. They occur alongside other forms of stigma and discrimination, such as racism and can be directed towards socially unacceptable activities such as prostitution. Information assessed and borrowed in July/August, 2010 at: <http://www.avert.org/hiv-aids-stigma.htm>

terms with HIV and manage their illness on a personal level, but it also interferes with attempts to fight the AIDS epidemic as a whole.

Since HIV/AIDS appeared in the 1980s, it has been associated with fear, stigmatization, and discrimination (Parker and Aggleton, 2003). Daniel and Parker (cited in Aggleton, 2000) describe stigmatization as a kind of 'social death' in which individuals no longer feel part of society and cannot access the services and support they need. Stigma and the secrecy that accompanies HIV/AIDS may also affect decisions about HIV testing and accessing treatment and are therefore important obstacles to reducing further spread of the infection within communities (Aggleton, 2000). Stigma can be described as a social construction of deviation from an ideal or expectation, contributing to a powerful discrediting social label that reduces the way individuals see themselves and are viewed by others (Parker and Aggleton 2003). Stigma is time- and context-specific, and therefore an instrument designed to assess stigma needs to address the specific nature of people's reaction to HIV in the local context (Herek et al. 2002). Prior research conducted in Tanzania, Ethiopia and Zambia identified two essential core elements of HIV-related stigma in Africa: first, the continued fear of casual transmission based on a lack of in-depth knowledge about HIV which results in people keeping a social distance from those with HIV, and second, a moral dimension that creates stigma through judgment, shame and blame (Nyblade and MacQuarrie 2006). UN Secretary-General Ban Ki Moon once stated that,

"Stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world" UNGASS, 2009.

Research by the International Centre for Research on Women⁸ (ICRW) found the inter-twined relationship of the possible consequences of HIV-related stigma to be loss of income (economic implication), loss of marriage & childbearing options as well as loss of reputation (social implications). Within the health sector, possible consequences of stigma include poor care, withdrawal of care giving in the home, loss of hope and feelings of worthlessness.

⁸ The ICRW is a global research institute driven by a passion to alleviate poverty and rectify injustice in the world. ICRW believes that women and girls in developing countries – in collaboration with men and boys – are essential to the solutions. Information assessed in August, 2010 at <http://www.icrw.org/>

Loss of social networks

In addition to the implications of stigma, a person in all disciplines and from all walks of life who is infected/affected by HIV/AIDS is impacted by the loss of social networks. In all these effects that the disease has on the wellbeing of women to be specific, the loss of some family members, friends and other people who one way or the other were associated with a person are often impacted with the entrance of HIV and AIDS in a person's life. As stated earlier on, side effects of some ARVs may lead to stigmatization from neighbors, friends and even some family members therefore making it extremely difficult for an infected person to succeed in keeping networks who may have otherwise been helpful during their struggle against the disease and its numerous opportunistic infections.

Deepening Gender Disparities

Gender refers to societal beliefs about the roles and responsibilities appropriate for men and women. Research has shown that the gender-based imbalance⁹ in power found in the socioeconomic sphere is frequently reflected in sexual relationships (Mitchel, 2007). Beliefs about masculinity and femininity affect the sexuality of both women and men as well as their risk of HIV and other STIs (refer to footnote 8).

Societal expectations of men and women also have an impact on their care and support needs. For example, the burden of AIDS-related care often falls disproportionately on women. Undoubtedly, women's inadequate societal power is a driving force behind most Sub-Saharan African countries' ranging HIV epidemic. Stephen Lewis, formerly the UN's special envoy for HIV/AIDS in Africa, observes that "a legacy of inequality ... drives the virus and leads to the devastation of the women and girls of the continent" (Horizons et al, 2000). Women are at high risk of infection and have few options for providing for their families. Children affected by HIV/AIDS, due to their own infection or parental illness or death, are less likely to receive an education, as they leave school to care for ailing parents and orphaned younger siblings. Adults most of whom are elderly women are also heavily affected by the epidemic; many have to care for their sick children and are often left to look after orphaned grandchildren. These elderly women left caring for the sick face the burden of providing financial, emotional and psychological support at a time when they would usually be expecting to receive more support as their energy levels drop with older age. Due to the amount of time spent caring for dependents, adults and the elderly may become isolated from their peers as they no longer have the time to dedicate to their social networks that need to be fostered to prevent isolation and loneliness. (Horizons et al, 2000).

2.2.4 Summary of Health, Economic and Social Impacts of HIV/AIDS

In summary, over the past 27 years, nearly 25 million people have died from AIDS (UNAIDS/WHO, 2009). HIV/AIDS causes debilitating illness and premature death in people during their prime years of life

⁹ Extra information can be accessed on this website: <http://iussp2005.princeton.edu/download.aspx?submissionId=52508>

and has disastrous results for families and communities. Further, HIV/AIDS has complicated efforts to fight poverty, improve health, and promote overall development (Kaiser Family Foundation, 2007). Though trying to separate impacts according to health, social and economic, HIV/AIDS has inter-twining effects on all of these sectors. Taking care of a person sick with AIDS is not only an emotional strain for household members, but also a major strain on household resources. Loss of income, additional care-related expenses, the reduced ability of caregivers to work, and mounting medical fees push affected households deeper into poverty. Also, diminishing a person's ability to support, work and provide for his or her family. At the same time, treatment and health-care costs related to HIV/AIDS can dip into the pockets of household income. The combined effect of reduced income and increased costs worsens the situations individuals and households already find themselves and may result in broken families and networks thereby creating a more depressed state for the infected woman and a greater burden of care on the affected woman.

Research has found an essential treatment concerning the impact HIV/AIDS has on the health sector. This is translated in the form of ARVs and their effectiveness to contribute to a longer and healthier life for People Living with HIV/AIDS (PLWHA). However, there are inadequacies in addressing the impact the disease has on the economic and social wellbeing of both the infected and affected groups of people, especially women heading households. Self Help Groups could be seen as a potential aspect of contributing to the mitigation of these aspects of wellbeing.

2.3 Self Help Groups and their Health, Economic and Social Benefits

Self-help groups, run by and for people with HIV and their families, are being set up in many countries for a specific purpose such as mitigating the impacts of HIV/AIDS on their wellbeing. People give these groups different names, such as support groups or discussion groups. Self Help Groups are usually composed of peers who share a similar mental, emotional, or physical problem, or who are interested in a focal issue, such as education or parenting (Madara, 1999 and <http://www.minddisorders.com/Py-Z/Self-help-groups.html>). Self Help Groups are not new. People have formally and informally helped each other and worked together since the beginning of time. Historically, people banded together to improve their chances for survival by pooling their social and economic resources; however, contemporary groups are more likely to organize around a theme or problem.

Formed and supported usually by NGOs or (increasingly) by Government agencies, the membership of self help groups is one of the things which make them different from other sorts of groups. Members share a life circumstance and strife together to overcome the difficulties they experience. The difficulties

experienced by self help group members in most cases may represent disadvantage and discrimination (Madara, 1999). Although there are a variety of ways in which SHGs organize themselves, common principles followed as part of their philosophy is that they are generally small groups which emphasize face to face contact. In most cases membership is open and people move freely in and out of groups, when they need support and have the energy to contribute and participate in the group. Self Help Groups have a strong fundamental base on common culture and the way in which members identify themselves and each other. Culture is always present in every communicative event, either implicit or explicit (Hall, 2005). Unveiling the complexity into isolated factors and variables does no justice to trying to understand the whole. For instance, if women's perception on SHGs would be reduced to differences only in perceptions of hierarchy and distance, this would do no justice to the role of gender and educational differences, world views and family life identity which are an important part of every interaction. One way in which cultures function to make sense of the world is through understanding of different identities and what to expect in relation to these identities. Identities are a set of social expectations (connected to verbal and non-verbal communication patterns) related to human interactions that a) are grounded in the interplay between similarities and difference (the very heart of identity) and b) pertain to the personal, relational and communal aspects of life (Hall, 2005). The personal identity is the perception of women as distinct from all others in terms of their HIV status and its impacts thereafter; the relational identity is based on particular relationships they have with others in the community; the communal identities are often discussed as related to roles women play in the SHG and the community in general.

The notion that SHGs serve as a social network with the aim to connect individuals, groups, organizations and societies should not be limited since SHGs may provide financial buffers, forms of material and non-material support thereby affecting mental health and indirect physical health, economic and social wellbeing. The following sub-topics provide a more detailed explanation and examples of economic, health and social benefits SHGs have on the wellbeing of women.

2.3.1 Health Benefits of Self Help Groups

Social relationships¹⁰ as found in SHGs have a great impact on health education and behavior. Closely related to health components of social relationships are social integration, social network and social support. *Social integration* often refers to the existence of social tie whiles *social network* refers to the web of social relationships around individuals (Glantz et al, 2002). *Social support* on the other hand is

¹⁰ Barnes (1954) was the first to describe patterns of social relationships that were not explained by families or work groups. Cassel (1976) found a relationship with health. *Social networks* can be seen as the web of social relationships that surround individuals. Information assessed from July-August, 2010 on:
http://www.utwente.nl/cw/theorieenoverzicht/Theory%20clusters/Health%20Communication/Social_Support.doc/

one of the important functions of social relationships. Social networks are bridges between people that may provide social support and related services (Glantz et al, 2002). Therefore, understanding social relationships and its impact on the health status, behaviors and decision making are essential. Because of the peer-led and informal structure, health professionals consider SHGs for mental or emotional problems to be an add-on to therapy (American Self-Help Clearinghouse, 2003). Though the nature of self-help groups is outside of the medical realm, doctors and therapists see participation as a way to improve the outcome related to either ongoing or future formal treatment (Kropp and Suran, 2002). The social support and mutual aid available in a group may be critical to recovery, rehabilitation, or healthy coping. This is especially true for PLWHA, who may have little or no emotional support (King, 2004). Self-help groups are effective for helping people cope with, and recover from, a wide variety of problems. Participation in self-help groups for mental health is associated with reductions in psychiatric hospitalizations (American Self-Help Clearinghouse, 2003). Members begin to display improved coping skills. The amount of time spent in the programs, and how 'hands-on' members are in them, has also been associated with increased benefits (King, 2004). Participating in a social network of people with similar situations there reduces some aspects of social and emotional segregation and promotes healthy behavior.

2.3.2 Economic Benefits

Based on an economic archetype where poor women save regularly in a group fund, lend savings to members and finally link their fund to a bank for additional credit, SHGs may form the backbone of good communication, authority and problem-solving in a community (Allen, 2002). The principles underlying SHGs are financing the poorest of the poor, and achieving individual and collective holistic empowerment. Women in these groups are often encouraged to make contributions on a regular basis. They use this pooled resource to make small interest bearing loans to their members. The process supports them to imbibe the essentials of financial intermediation including prioritization of needs, setting terms and conditions and accounts keeping. This gradually builds financial discipline and credit history for themselves, as the money involved in the lending operations is their own hard earned money saved over time with great difficulty. This is 'warm money' (Allen, 2002). They also learn to manage resources of a size that is much beyond their individual capacities. The SHG members begin to appreciate the limitations and costs of resources.

Self Help Groups as an intervention in curbing worsening poverty in the lives of HIV/AIDS infected and affected women heading households include its ability to: smooth income flows within households to improve quality of life throughout the year, especially SHGs which undertake farming and irrigation activities all year round and strengthen the economic position of women so that they can take greater

control of decisions and events in their lives just as they learn to do in their various groups (http://megapib.nic.in/mselfhelpgroup_geninf.htm).

2.3.3 Social Benefits of SHGs

While the impetus for forming an SHG is most of the time mainly financial, women soon realize that the social benefits they derive from group membership are as important as the financial ones. SHGs by dint of intrinsic dynamics and the money which accrues to members offer women the chance to make decisions, gain power over local resources, and ultimately build confidence. This confidence is precisely the catalyst needed to move communities forward on social problems. Self-help initiatives develop social support networks – a key ingredient to health for people and communities. Self-help is unique because it is informal and involves sharing experiential knowledge and support with others who are “in the same shoes.” It has been well noted that SHGs are all about wellbeing and so since happiness is of course only one indicator of wellbeing, people’s overall life’s satisfaction is enhanced not only by improved capabilities and freedoms, but also by a stronger sense of relatedness and belonging.

The idea of *social networks* (Van Dijk, 2003) is attributed with coining the concept of social networks. Network analysis (social network theory) is the study of how the social organization of relationships around a person or group affects their beliefs or behaviors (Van Dijk, 2003). Network analysis is a set of methods for measuring the enormity of pressures received. A communication network analysis studies “the interpersonal linkages created by the sharing of information in the interpersonal communication structure” (Van Dijk, 2001-2003), that is, the network.

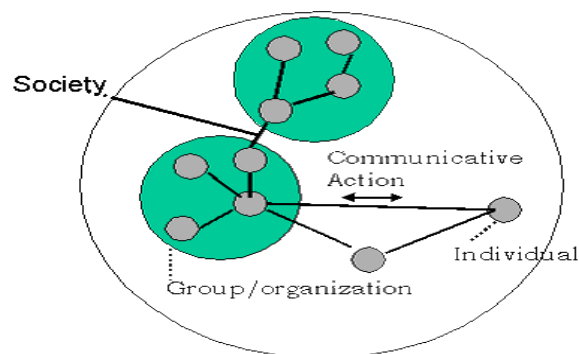


Figure II: Conceptual Model (of a Network Society)

The diagram shows networks connecting individuals, groups, organizations and societies. Source: Van Dijk 2003¹¹

¹¹ Dijk, J.A.G.M.. Van (2003). Outline of a Multilevel Theory of the Network Society, In press .Assessed on the University of Twente website :

Social support served as a “protective” factor to people’s vulnerability on the effects of stress on health. Self Help Groups promote self-esteem and self-respect by encouraging ‘give-and –take’ forms of caring. The belief that one is capable is promoted by reinforcing appropriate behavior and beliefs and sharing germane information regarding the disease or condition (van Dijk, 2003). An example is the passing on of information concerning coping with frustrations, anger and public embarrassment.

2.3.4 Summary of SHG Benefits

Worldwide, SHGs are becoming increasingly popular and are seen as effective tools in the provision of mutual support and information dissemination. Clearly, SHGs contribute to group consciousness among women and a sense of belonging. What a woman cannot achieve as an individual, can be achieved as a group. Becoming a member of a group uplifts her sense of public participation, self-esteem and respect. Economic empowerment of women could help women work their way out of poverty, refuse unwanted sexual advances and gain independence thereby contributing, hopefully to an eventual reduction in HIV transmission. It should however be noted that a family’s ability to cope with the impact of HIV/AIDS depends on the state of the household’s economic resources before, during, and after the disease impacts them.

2.4 Logical Model

The UNAIDS 2004 *Report on the Global AIDS Pandemic* opens: “AIDS is an extraordinary kind of crisis; it is both an emergency *and* a long-term development issue.” The pandemic is the biggest obstacle to the achievement of the development goals agreed to at the UN Millennium Summit in 2000 (Casale& Whiteside, 2006). It works against the objectives of equity, gender equality and poverty eradication. HIV/AIDS has profound impacts on livelihoods in Sub-Saharan Africa. These include the deaths of working-age adults and the diversion of resources to caring and worsening poverty rates (UNAIDS/WHO, 2009). The aggregate impact of AIDS are increasingly visible, and include dramatic reductions in life expectancy (health), the loss of adult workers in every sector (economic), and a striking increase in the number of orphans and other vulnerable children (social) (UNICEF, 2002). The logical model is a summary of the theoretical framework concerning the impact HIV/AIDS has on women heading households who are themselves infected or affected. This is clearly divided into economic, health and social impact. Self Help Groups are then introduced as an intervention, and the model further portrays the benefits and or functions SHGs have in mitigating the economic, health and social impact of HIV/AIDS on women. The model

concludes with a proposed impact of SHGs which is an improved economic, health and social wellbeing for women.

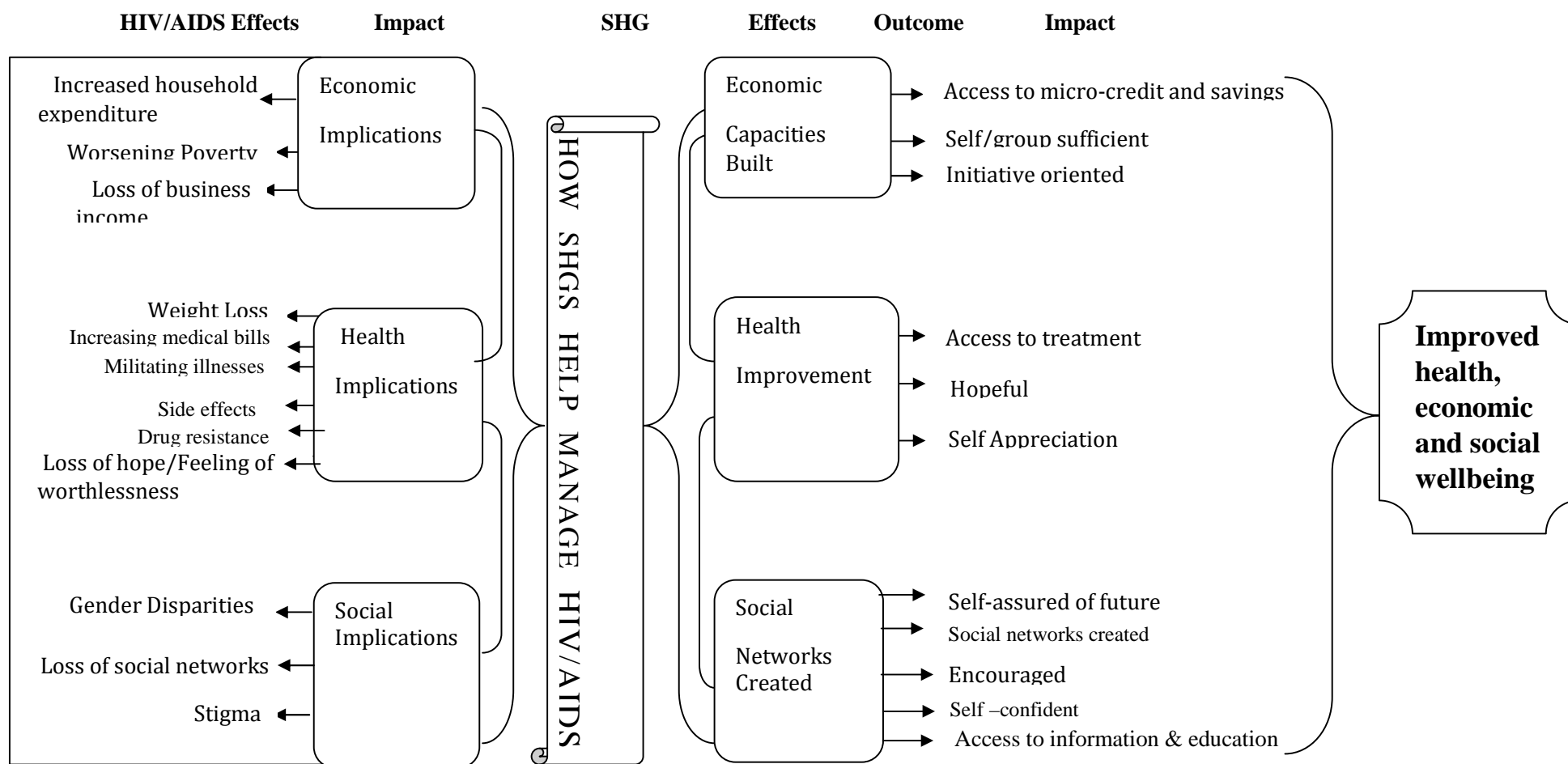


Figure III: Logical Model of Health, Economic and Social Impact of HIV/AIDS and how SHGS Contribute in Addressing the Impacts for a Better Wellbeing of Women

As demonstrated in Figure III, one consequence of being a woman head may be that because women may generally be inadequate in the acquisition of knowledge on resources needed to sustain the production of cash crops which had previously provided a vital source of income, for example, as household expenditure increases, poverty levels may increase as well and may affect the health of the woman as she begins to think of dead-ends for the future. Increasing medical bills could lead to worsening poverty which could then be dissolve some social networks especially as side effects of medications begin to show.

Access to micro-credits and savings reduces the possibility of poverty in the household and gives the woman a sense of hope for the future. Access to information and education can also open a way for treatment options and counselling of how to prevent infectious illnesses and manage side effects or drug resistance. A woman can be encouraged through counselling and learn to appreciate herself as she develops a 'can do' spirit. However, in a group, they are empowered to overcome many of these weaknesses. This is clearly seen in the logical model above. From this logical model, research questions have been derived for the purpose of this paper. These questions which are stated below are the main basis for the results and discussion parts of this paper. It is from these three questions that first, the specific research questions are made, and second, a question list was made and used as tools in collecting data.

2.5 Research Questions

Following from this theoretical framework, specific research questions have been formulated:

1. What health, economic and social impact does HIV/AIDS have on women heading households infected and or affected by the disease in Kitui District, Kenya?
2. What is the contribution of Self Help Groups on the health, social and economic wellbeing of women heading household infected and affected by HIV/AIDS?
3. In what ways does the mitigating function of Self Help Groups depend on the initiatives taken by Self Help Groups?

3. Research Methodology

This chapter describes the methodology used for this research. First, the study area is discussed, followed by the structure and design of the research. Also, the data collection methods in which the case study approach is presented, including literature study (secondary data), focus group discussions, interviews and participant observation (all of which are primary data) are described.

3.1 Study Area

The study was conducted in the Republic of Kenya which lies across the equator in Eastern Africa, on the coast of the Indian Ocean. The country borders¹² Somalia to the east, Ethiopia to the north, Tanzania to the south, Uganda to the west and Sudan to the northwest. It lies between Latitude 4° north to 4° South and Longitude 34° east to 41° east and occupies a surface area of 581, 751 km² of which 2.3 percent is water mass. Only 9 percent of the land is arable while 37 percent is pasture and the remaining 54 percent is semi-arid (FAO 2004). According to UNFPA (2005), Kenya has a population of 34.3 million people within overall annual growth rate of 2.4 percent. With this growth rate the population is expected to rise to 83.1 million by 2050. More than half (61%) of the population is estimated to be living in the rural areas. There are over 70 ethnic groups categorized into: Kikuyu (22%), Luhya (14%), Luo (13%), Kalenjin (12%), Kamba (11%), Kisii (6%), Meru (6%), other African (15 %), non-African (Asian, European, and Arab) (1%). These ethnic groups fall into three linguistic groups; Bantu, Nilotic and Cushitic with Kiswahili as the national language and English as the official language. The majority of the population is Christian (66%), although there is a proportion of traditionalists (22%), and Muslims (7%) (See also footnote 12).

The Kitui District is part of the Eastern Province of Kenya and bordered by the Tana River and Machakos districts. Kitui town is a rural town of Kenya, 170 kilometers south of Nairobi on asphalt road and 75 kilometers East of Machakos. It is the capital of the Kitui district and has a projected population of 588,636 with males accounting for 47% and females, 53% (see source from footnote 12). The population is largely rural-based with only 10% residing in the urban areas. Kitui town itself is a small scale town with a population of less than 10,000 people. With a scarcely populated district, an average household has 5 – 6 persons. Agriculture is the main stay of the district, but one out of three rain seasons tends to fail, thus plunging the inhabitants into periods of drought and hunger. Often such prolonged droughts cause miserable animal and human damage prompting the government and other

¹² This information was assessed and adopted from the website of the Embassy of Kenya in the Netherlands in June, 2010. More information can be seen via the website : <http://www.kenyanembassy-nl.com/about-kenya>

organizations to intervene by providing relief food rations to the most affected families. The district is inhabited by the Kamba people, generally peasant farmers who grow only local food crops namely corn, beans, peas, coco yams, millet, pumpkins, and citrus fruits, among others. The Akambas also keep domestic animals such as local breeds of cattle, goats and sheep which are resistant to the dry conditions in the area. The language spoken by the Akambas is known as Kikamba.

Since the beginning of 2007, a national proposal to increase the number of administrative units especially at the district level is gradually being implemented. The wider Kitui district has now been divided into two autonomous district units: Kitui and Mutomo with the district headquarters being Kitui and Mutomo towns respectively with separate line ministries and departmental offices. Though now two districts, in most research studies and also in this one particularly, Kitui District refers to the combination of the two now autonomous districts.

3.2 Research Procedure and Design

A qualitative descriptive and exploratory research approach by means of a case study design is used to study life experiences. Qualitative research includes virtually any information that can be captured that is not numerical in nature. Some categories of qualitative data include in-depth interviews, direct observation and written documents. Qualitative research refers to the explanation of issues, understanding phenomena and answering questions. Focus groups discussions and in-depth interviews, which have been made use in this study, are among the many formal approaches that are used. In brief, qualitative research attempts to understand what happens and why things happen.

3.3 Research Setting

The setting of the research study begins with the Catholic Diocese of Kitui and its Home Based Care Program and how this program is inter-related with SHGs in the district.

The Home Based Care Program under the Catholic Diocese and the Relationships with SHGs

The Roman Catholic Diocese of Kitui is situated in a semi-arid rural area about 112 miles east of Nairobi, the Capital City of Kenya in East Africa. It covers two administrative districts namely, Kitui and Mwingi with an area of 14,000 square miles and a population of over 1,000,000 people (Mulonzia¹³, 2009/2010). The Diocese collaborates with 2 main hospitals in the districts in which they work mainly the Mutomo Mission and Muthale Mission Hospitals and 11 dispensaries at different locations around the district.

¹³ Vivienne Mawia Mulonzia is both the HIV/AIDS coordinator in the Diocese and an officer under the Home Based Care Program in Kitui.

Home-Based Care Program (HBCP) was introduced into the Diocesan Health program on pilot project basis in Mutomo in 1991, from an initiative of Dr. Frank Engelhard, who was then working in Mutomo Hospital after observing that some patients were dying of AIDS-related Symptoms (Mulonzia, 2009/2010). The program is in four main referral centers: Mutomo Mission Hospital; Kitui District General Hospital; Muthale Mission and Mwingi District Hospital; with outreach stations/ communities/ groups spread all over the diocese. The HBCP's mission there is to create a community that is aware of HIV/AIDS and the prevention, leading to behavioral change through community involvement as well as to provide quality life to people Infected/ affected by HIV/AIDS (Mulonzia, 2009/2010). Some activities the HBCP carries out include administration of ART (at the CCC in hospitals), group therapy/counseling for PLWHAs and those affected, clinical nursing care/ treatment of opportunistic infections, home visits for both the infected and affected, capacity building, income generating activities and of course formation of support groups (Mulonzia, 2009/2010). Major achievements of the HBCP include general reduction in stigma and discrimination; due to increased awareness in the community. This has also made more Persons Living with HIV/ AIDS (PLWHAs) gain confidence, and as a result, they have gone public on their status (Mulonzia, 2009/2010). Kitui District has been nominated as one of the districts in the country with the highest number of PLWHAs who have publicly declared their status. This encourages others to get involved as the program not only supports the infected, but the affected and vulnerable groups as well. Through training in life skills and socio – economic support, the infected and affected persons have developed self-initiative revealed in the income generating activities they establish. Beneficiaries of the HBCP are the PLWHAs and the Orphans and Guardians groups (otherwise known as the affected) with a total population of 9,633, 3555, and 10,856 as at 2006 respectively (Mulonzia, 2009/2010).

Some challenges the HBCP faces are vicious cycle of poverty in this area, where majority percentage live under a dollar in a house hold per day. Also, with low rainfall that is poor distributed, most people, who normally depend on agro – livestock peasantry farming have suffered drought after drought for the last six years. This has left them with virtually no means of getting a decent day's meal. Stigma however, is still evident in the families of infected / affected persons (especially in family property disinheritance), in schools enrolment for the orphans/ vulnerable children, as well as in communities in social activities.

3.4 Sampling Procedures

In this qualitative study, key-informant interviews, though majority being focus group discussions with different, but quite related groups of participants, were undertaken. The first group of participants is the HIV/AIDS infected women who are heads of households, while the second group is individuals who are mostly called the Orphans and Guardian group because they themselves are not HIV positive, but are

somehow affected by the disease. A third group includes organizations which in one way or the other support the wellbeing of these women especially towards coping strategies adopted by these women. Participating women were eligible for this study only if they were either HIV/AIDS infected and or affected. Below is a table showing the number of communities visited to meet with the Self Help Groups and some additional information on the research sample.

Table 1: Information on SHGS and Data Collection Method Used

Community & SHG	No. of women	No. of Infected	No. of affected	Data collection method
Mathima: Mother Theresa Bakery SHG	6	5	1	-FGDs & Interview
Kanyangi: <i>Iyumye</i> SHG	20	20	0	-FGDs
Kavisuni: <i>Mwikiyo(Faith)</i> SHG	17	17	0	-FGDs
Miambani SHG	3	3	0	-Interview
BOMA HALL, Kitui: Katethya SHG	31	0	31	-FGDs
Majengo SHG	23	22	1	-FGDs & Interview
Wii : Community Bakery HIV/AIDS Affected Group	20	0	20	-FGDs
Mulutu: Our Hope HIV/AIDS Infected Group	27	27	0	-FGDs
Kitui: BOMA A1 SHG	15	15	0	-FGDs

Source: Field work

Purposive sampling was used to select women and three other key staff of Kitui Catholic Diocese who work directly in the Home Based Care Program (HBCP) where the focus is on Self Help Groups for PLWHA and for Orphans and Guardians groups. These three staff is the HIV/AIDS Coordinator of the Diocese in Kitui, and two Field/Project Officers for the HBCP who did regular monitoring and evaluation of field activities involving Self Help Groups in the district. This method of sampling was used because it enabled for the selection of key informants within the organization who were knowledgeable about Self Help Groups for the HIV/AIDS infected and affected women. The three staff members have worked directly with the diocese in Kitui for over three years.

With the assistance of the key informants from the Kitui Catholic Diocese and, nine focus groups each consisting of a range from five to 27 people were formed. Short, but very informative meetings were organized with group leaders at various locations to get a general idea of the group's members and how

and when the focus group could be organized. This preparation stage provided an enlightened view on Self Help Groups, as well as ideas on topics to include or omit in this research. A total of 162 women heads participated wither through discussions or interviews, in this research study. The groups were divided into two, mainly those who are infected and those who call themselves the Orphans and Guardians group (the affected). Both the focus group discussion and the interviews were audio-recorded to allow for devotion of full attention to facilitate the discussion. The audio recording was also advantageous as it provided an accurate verbatim record of the interview or discussion

3.5 Data Collection

Focus group discussions and interviews were the main tools used in gathering the data. Interviews were first conducted on specific target groups and through these interviews, discussion points were raised for the focus groups. Interviews were later conducted to gain deeper understanding of issues raised during the discussion.

Focus Group Discussions

Focus group discussions were used as an exploratory tool to discover peoples' thoughts and feelings and to obtain detailed information about the economic, health and social impact HIV/AIDS has on them and what coping strategies they used as a group or as a result of group activities to sustain themselves. Several authors recommend a minimum of four to 10 participants. This ensures that the discussions and the time for participants to contribute are not too limited (Russell 2002; Ritchie 2003). Guided by a facilitator, during which group members talk freely and spontaneously about a certain topic, focus group discussions take place. Its purpose is to obtain in-depth information on concepts, perceptions and ideas of a group. A FGD aims to be more than a question-answer interaction. The intention is for group members to discuss the topic among themselves, with guidance from the facilitator. Implementation of FGDs is an *iterative* process; each focus group discussion builds on the previous one, with a slightly elaborated or better-focused set of themes for discussion (Otsuki & Schipper, 2009). Provided the groups have been well chosen, in terms of composition and number, FGDs can be a powerful research tool which provides valuable spontaneous information in a short period of time and at relatively low cost.

In both the FGDs and interviews, a depression test (list of questions see Appendix 1 F.) was conducted on all the women in each SHG to get a better understanding on whether women in such situations were depressed or not and how that affects them in their daily activities.

Research shows that in case of very sensitive topics, such as sexual behavior or coping with HIV/AIDS, FGDs may also have their limitations, as group members may be uncertain as to whether or not it is 'safe' to declare their feelings as freely as they might want to. Women were therefore given a choice between participating in a focus group discussion or be interviewed. During the administration of the questions, most of the women (with the exception of just a few) in their various groups preferred FGDs to face- to-face interviews.

Interviews

In addition to the focus group discussions, two types of interviews were conducted. To begin with, the in-depth discussions with key informants who have particular or "expert" knowledge about the group or area, the people, their livelihood activities, and HIV/AIDS prevalence and impacts in the SHG and the area as a whole was conducted. One benefit of these first interviews was that they could provide an entry-point for further research and interviewing. These key informants mounted to a total of 14 people. Out of this number, nine are the leaders of each of the nine SHGs in the focus group discussion. In the interviews with respondents from the APHIA II project, Catholic Diocese of Kitui, the Mutomo Mission Hospital as well as the Comprehensive Care Center at the Kitui District Hospital, their insights were highly useful in understanding the Self Help Groups and their impacts of the wellbeing of the women with HIV/AIDS and the impacts it has on the women, the community and country as a whole. Most of the people and especially the leaders of the SHGs also assisted in the selection of individuals to be involved in the various focus groups. Secondly, face-to-face interviews were done with women who preferred such to the focus group discussion held at almost all meetings. A total of seven women preferred this method. Aside from the women themselves, two staff of the Kitui Catholic Diocese were interviewed, one of which was the HIV/AIDS Coordinator who provided key essential information for the study.

As part of the process, interviews were recorded with the permission of the respondents. This was done to ensure that vital information would not be lost, particularly as most of the interviews were conducted in Kikamba, the local language through translation. Interviews are transcribed and then scrutinized for phrases related to the impact of both HIV/AIDS and that of SHGs. In interviews it is assumed that there is a questioner and one or more interviewees. The purpose of the interview is to probe the ideas of the interviewees about the research topic. Phrases with similar meaning were grouped and focused towards answering the research questions. The research data is then interpreted according to the phrases as explained above and then compared with the literature which has been studied.

3.6 Data Analysis

The phases of collecting and analyzing the data usually overlapped and were conducted at the same time. Initial analysis prompted new questions for the next phase of the research. Focus group discussions and interviews were co-conducted by one researcher in English with translation from an assistant in Kikamba when necessary. The content of interviews was recorded in written form and audio taped for later analysis. All data were converted to text and entered into a computer. Verbatim written transcripts were recorded during interviews in English with the assistance of the translator. Data were categorized initially in the general domains that guided data collection (HIV/AIDS impact, role of SHG, activities of groups). In addition, subcategories (economic, health and social impact of HIV/AIDS and roles of SHGs) were generated inductively from the data.

4. Research Results

This chapter is a presentation of the research results. The findings are first presented according to the arrangement of the research questions that guided the study. It thus follows first as health impact of HIV/AIDS on the wellbeing of women heading households who are infected/ affected with the disease. Following the health aspect is the economic and last but not the least, social impacts of HIV/AIDS. A summary is then presented for the impact of HIV/AIDS. Results of the research study concerning the health, economic and social mitigating roles that Self Help Groups play in the lives of these women are demonstrated in the second section. The third section of this chapter draws us into the initiatives SHGs are involved in and how these initiatives differ among each group in playing a role of a coping strategy.

4.1 Background Data on Communities, SHGs and Women

The research was undertaken in nine different locations where self help groups meet on a regular basis. These nine locations are Mathima, Kanyangi, Kavisuni, Miambani, Mulutu, Majengo, Katethya (BOMA HALL), Wii and BOMA A1. With the exception of Katethya and the BOMA A1 who usually gather at BOMA HALL, Kitui Parish, the rest of the groups meet at the various communities as mentioned. The first four communities as listed with the addition of Katethya are rural areas located in the southern part of Kitui District while the rest are located in the northern part of the District. With the exception of Katethya, all the communities are privileged to have a dispensary where PLWHA groups are able to have access monthly medications. The furthest community from the town of Kitui is Mathima which takes no less than five hours *matatu* (bus) trip. The closest location is BOMA A1 SHG with meetings right in Kitui Township. Majengo, Mulutu and Wii are also quite close by for a day return trip.

Although the women meet in these localities, they do not necessarily stay in these same places. For example, it was realized that the Our Hope Mulutu HIV/AIDS Infected Group included members not only from Mulutu town, but also from places such as Tiva, Matinyani, Kwavonza, Ituiani, Kyanwituya and West Kitui, all of which are quite a distance away from the meeting place of Mulutu. When asked the reason, members said,

“The further the meeting place, the less stigmatizing from neighbors and community members.”

The Tables below show the combined respondents of HIV/AIDS infected and affected women heading households. As seen in Table 2, the majority of the respondents (44/162) belong to the age group of 38-

47. This is followed by the age groups of 48-57 (42/162) and 58+ years old group (40/162) respectively. The age of the youngest respondent in all the self help groups combined was a 22 year old girl. The oldest on the other hand, came from one of the HIV/AIDS affected groups with an age of 76 years.

Table 2: Number of Respondents by Age Group

Age Group (years)	Number of women
18 – 27	6
28 - 37	29
38 – 47	44
48 – 57	42
58 +	40

Table 3 below demonstrates the marital status of women in the various self help groups. Although in some groups, a few of the women were still married or had the presence of a man in the household, majority of the respondents were widows whose husbands had died mostly because of AIDS with some exceptions to deceased husbands of some of the affected women. With reference to the women who are currently married, both man and wife were not living in the same household although still married by law. This meant that the 49 divorced or separated women still had to care for the household on their own. The table below shows the distribution of women's marital status. The total numbers of the women in all nine SHGs were widowed and had lost their husbands generally through AIDS; although some had passed away as a result of accidents or old age. Within the self help groups, research showed that although majority of respondents were widowed and had to care for households, generally, the number of household members ranged from a minimum of three children to a maximum of 10 children between the ages of 0- 20 years of age.

Table 3: Number of Respondents by Marital Status

Marital status	Number of women
Never married (single)	11
Currently married	2
Divorced/separated	49
Widowed	100

The research findings showed that majority of the women did not go have any formal education, although few attended primary school to some level but did not finish standard eight¹⁴. Table 4 shows that 84 out of the 162 respondents had no formal education whatsoever. Reasons for this include the illiteracy level of their own parents and a general lack of awareness.

Table 4: Educational Attainment of the Respondents

Educational Level	Number of women
No formal education	84
Primary education & graduated standard 8)	8
Graduated Sec. education	12
Did not graduate primary education	47
Did not graduate Sec. education	11

The study identified that majority of the women depended on agriculture as their main source of livelihood. Followed by this is dependency on petty trading businesses. With regards to the occupation and, or livelihoods of HIV-positive respondents, majority were peasant farmers or had small businesses such as selling staple foods like maize, selling vegetables and fruits. With regards to the affected groups, women are still peasant farmers who struggle to sustain their wellbeing with the little income they get from selling produce from the farms on a seasonal basis. However, a few of the respondents stated that they had no income sources and relied deeply on the SHG and the Catholic Diocese as well as begging for their survival.

4.2 Health, Economic and Social Impact of HIV/AIDS on Infected/Affected Women

This section brings to view first the health impact of HIV/AIDS on the infected and how this may differ from the affected. Economic and social impacts follow in the same manner.

4.2.1 Health Impact

¹⁴ Since 1985, Kenya's education (public) has been based on an 8-4-4 system (University of Nairobi and Jomo Kenyatta University) with eight years of primary education (commonly referred to as standard eight) followed by four years of secondary school and four years of university (http://en.wikipedia.org/wiki/Education_in_Kenya)

Results below will be organized according to psychological and physical health impacts, and separately for infected and affected women in the various SHGs. In answering the question on the impact of HIV/AIDS on their health with emphasis on physical and emotional status, a depression scale of 20 questions was used to gain a deeper understanding of the emotional aspect of the impact on the wellbeing of the women. Some questions asked with reference to feelings and behaviors in the last week were on the loss of appetite, feelings of being depressed, being lonely, the feeling of fear, if they talked less than usual, or felt like people just did not like them.

Madam Harriet*, an infected 43 year old widowed mother of four in the Majengo SHG stated that,

“As for me (touching her chest and shaking her head), I cry everyday... I cry for myself, for my children and for the lack of support from my family and the people I once called friends... I am always crying. I fear that I will just die suddenly and my children, who will take care of them for me...”

Harriet* was both a vegetable farmer farming cabbages, *sukuma wiki*, *pilipili*, carrots and green peppers and selling them in the market on days she had enough produce to sell. Another woman, a 47 year old mother of 4 from the Mulutu SHG stated that,

“...the day I heard that I was HIV-positive, I had no control over myself for the first 5 hours so much that I crapped in my pants right there at my work place and was sacked from work right away. I was so stressed out and found it hard to focus on anything that day...”

The most common psychological challenges among the women in the infected groups of Majengo, Kavisuni, Miambani, Mulutu, Kanyangi, Mathima and BOMA A 1 based on the depression test were that they felt people around them did not like them and would only pretend to when necessary, they talked less for fear of saying too much or for fear of being made fun of or rejected and although they came to group meetings, during the past week, they had felt lonely more than ever. Now, although on ARVs, cannot maintain such a busy schedule and so now relies on a backyard garden to feed the household. For instance, Harriet* continues with,

“... I have lost so much weight that having a schedule like I used to have almost seems impossible. When I leave home, I try to wear ‘big’ clothes to hide my body structure so as not to get much attention from the people around me...”

Health impact of HIV/AIDS on the infected far outweighs that of the affected who though may suffer from loss, depression and some stigma; HIV-positive persons suffer a great deal more. For example, findings of the study show that majority of the infected women especially from Majengo, Mulutu and Kavisuni SHGs got a total score between 50 and 60 each in the depression test (Appendix I F.) which implies that they may be suffering from moderate to severe depression. When asked if they feel depressed even when good things happen to them (question 17), a woman noted (with support from the others) that,

“Of course we know that those good things like the food we get from the Catholic people, is only for today. What about tomorrow...you begin to even understand that people are sometimes pretending to do good to you, but it is not so...”

Two women, one single, the other widowed (Mulutu SHG) made comments on the impact HIV/AIDS has on their psychological wellbeing. The single and never married mother of three said she felt hopeless as her own children were infected through birth, suffered opportunistic infections and finally died at her hands:

“As for me, I always feel like a failure, like unworthy to even be called a mother... maybe that is why I cannot fall asleep at night. I keep on remembering when they (her last set of twins) were here with me... and my inability to save them. I couldn’t even save one...”

The widowed mother, a 63 year old woman also commented that,

“It hurts me every day when I wake up and realize that with the exception of a few friends, I have no one left to call my own. AIDS has carried away three of my children leaving behind 10 grandchildren to care for. Every day I wake up, my first question to God is why me...”

Also, PLWHA sometimes really have no one to go to and have feelings of guilt as children die of AIDS and so begin to have thoughts of suicide or of guilt that never ceases. Often, they lose so much weight and strength and are unable to continue working and getting some income. Militating illnesses such as tuberculosis, diarrhea and elephantiasis and feelings of confusion and feeling of worthlessness, rejection and neglect as well as occasional crying and, fainting and panicking spells then take the opportunity to add more frustration to the person.

Groups such as BOMA A1, Kavisuni and Kanyangi make considerable note of how side effects of the ARVs has affected their physical wellbeing. Comments from these infected women include,

“...after my husband died, I was prompted to also take the test in 2004. It didn’t take long after I was told my HIV-positive status that I began noticing how weak and tired I felt almost daily...I ignored these feelings...did not seek medical help until I could ignore them no more... I had lost so much weight and had become so weak.”

“... My cheeks have sunken like a heavy metal in water... each time I tell the nurse, they say to change medicines, but still like that...”

In Kavisuni, a 57 year old widowed mother who rears chickens as her livelihood made a statement during the life’s story that had all of us laughing, but was a fact clearly put across. She said,

“... Whenever I want to see the other side of my face, I just look through the mirror from one side. The holes in my cheeks are so deep that I could have stored a gallon of water in them during the drought period (laughs)...”

Although lipodystrophy affects HIV-positive person not yet taking ARVs, more often than not, it affects those on medication but are not consistent with taking them at the right time or maybe just be a body reaction to some medications being taken. Seven women from Mulutu SHG agreed to the case of lipodystrophy, but added that it was affecting their butts as well as cheeks.

Although majority of the women in the seven infected groups agreed to and defended Harriet*'s comment, a few (4) especially from Miambani and Majengo SHGs noted that they had not realized any weight loss although, they have had other complications like boils on the upper stomach and painful rashes all over the body. Tabitha*, a 39 year old single woman with a big vegetable farm in Miambani said that,

“I have never experienced this body weight loss I hear people talking about. This is the way I have always been and although I feel tired every once in awhile, it doesn't affect my work in the farm at all. I still go there every day.”

Some women confirmed to the fact that although they had lost weight in the beginning before they were put on the ART, they now look 'normal'. For instance, Madam Florence, a 43 year old divorcee who earns her income through selling second hand clothes in the market center said that,

“ Before I started taking these ARVs, there were days I didn't want to look at myself in the mirror because I reminded myself like a dead walking stick...Now, look at me (turning around so everyone could see her)I am not how I was before, but I have put on some weight... My neighbors don't even know my status...”

Majority of the women in all seven infected groups fell in the group of Florence* since a lot had gained a bit more weight after they started taking the ARVs. This has had a great influence in both their psychological and physical wellbeing.

Health impact for HIV/AIDS affected women were mainly on the fact that they had to take care of many more family members. For instance, women in Katethya and Wii SHGs noted that before they had more members joining the household, they had an average range of 2 -4 children of their own and now has an average of 6-10 members in the household .As a result of increase in household members for the affected groups of women as mentioned above, rooms become crowded and with little ventilation sources, it increases the risk of developing and spreading the various infections among the children and adults who

share the room. An example of such diseases is Cerebra-Spinal Meningitis (CSM) which with dry weather, dusty winds, cold nights, and large populations living in overcrowded conditions, can leave people vulnerable to respiratory infections caused by kissing, sneezing, coughing, and sharing of eating or drinking utensils. In addition, there is the feeling of general helplessness as children may get or were already infected with HIV/AIDS, go through pain, frustration, depression and of the inability to do much and finally die from AIDS.

4.2.2 Economic Impact

The findings of the focus group discussions and interviews held with the women will be shown first concerning the affected groups of women (mainly the Wii and Katethya SHGs), followed by the infected groups of women

Women in both Katethya and Wii groups concluded that the additional household members (AIDS orphans) greatly impact their economic wellbeing through payment of increased school fees. Also stated in both groups was the increasing rate of medical bills in the household especially because both the Wii and Katethya groups call themselves guardians of orphans and may have children or additional household members who are HIV-positive and require medical attention regularly. A 58 year old divorced woman from the Wii group stated that,

“...Look at me (referring to me), I am an old woman with nothing, yet I have to cough up school fees and pay for all medicines for all (emphasized) the children in my house. Where do I go for this...sometimes, I just pretend that everything is ok with us...sometimes I don’t want to even hear the name ‘hospital’ because of the money I have to pay, the same money I don’t even have....”

With regards to the HIV/AIDS infected women (all other groups with the exception of Wii and Katethya), economic impact was described differently from one group to the other. For instance, the SHGs in the rural areas such as the Mathima, Kanyangi and Kavisuni SHGs linked economic impact of HIV/AIDS to not only loss of farming activities which led to low production, but also to small scale business (mainly vegetables and fruits) and the onset of increased household expenditure. For example, during a discussion on what each person understood by economic impact, comments such as these were presented.

“...economic impact means not being able to farm to feed your household...”

“... For me, it is when I could no longer sell my sukuma wiki and pilipili (a type of vegetable and pepper commonly used in making kachumbari respectively) in the market on a daily basis...”

The infected groups closer to Kitui township such as the Majengo, BOMA A1, and Mulutu however associated economic impact to the lost of professional and or formal job positions they had held before

the onset of infectious diseases (losing strength and energy to work) which led to the loss of jobs for them and their inability to deal with stigma from co-workers on their physical appearance, For example, Madam Faith* (Kavisuni SHG) commented that,

“...we are all one here, but when it comes to loss of farming, it is me and my house people who will suffer alone. It was when I was absent from work on so many occasions that I lost my job (in the Ministry of Housing and Settlement). This deadly disease (referring to HIV/AIDS), is not only wasting our bodies, it is also wasting our efforts to build a home for our children. Where will my children be after if I die today... there is no food, no money, no income...?”

In Miambani for instance, where an interview was held for the three infected women present that day, they defined economic impact in terms of health related medical and hospitalization bills which sometimes occurred as a result of side effects of ARVs. This would imply that they would have to pay for the drugs on their own.

Tabitha*, a 39 year old single woman in from the Miambani SHG (see on health impact) noted that,

“...Although I am not as poor as my other members in the group because I have my farm, I lost a lot of money before this group was started, in transportation to Kitui and sometimes would have to sleep there because of long queues and from Kitui back to Miambani just to get the ARVs every month. It took a lot out of the little income I get at the end of each month.”

Furthermore, as a result of HIV/AIDS in their lives, a lot of widowed women from the Muluu group especially, stated that they have lost properties to family in-laws who blame them for the death of their respective husbands. One 45 year old widow's statement caught my attention.

“...after my brothers-in-law heard of my situation, they packed the few things my husband had left behind for me away and left me just like that...up till now, I still receive threats from them that they will kill me if they see me anywhere near the property (starts to shed tears)...” Rachel Nguti* (small business in second hand clothes)

Although a lot of women agreed to Rachel's* story, not all had experienced the snatching away of properties. For instance a woman said that,

“As for me, I have been blessed. Aside from the insults, finger pointing I get regularly, I still have the land and house my husband left behind for me and the children. I weep for you my sister (referring to Rachel)...”*

Before the Catholic Diocese developed the idea of the Home Based Care Program, all the infected women and some of the affected women with orphans who are HIV-positive stated that they spent a lot of money on transportation to Kitui town and back to obtain a month's supply of ARVs. When asked how HIV/AIDS has affected her in terms of economic impact, one HIV-positive woman said,

“My daughter (referring to me), all my money finished just on transportation to Kitui and back every month. And when one of my children (now deceased) needed medicine, I had to travel again to Kitui to get this medicine for her. I didn’t have enough money to care for the third child before he passed away. He was sick all the time and I was only told he suffered from AIDS only after his death. If only I had the money and the strength to continue farming my maize and vegetables, things would have been different for me today....”

4.2.3 Social Impact

For the affected groups of women in Wii and Katethya SHGs, HIV/AIDS has had a social impact on their wellbeing in terms of the creation of the burden of care for small children during their old age when otherwise they would be cared for themselves. In addition, the loss of peers and social networks as priorities are turned from social activities to caring for the sick and young orphans. Often friends, neighbors and community members in general rain abusive statements on orphans and point fingers on care givers. Margret* from the Wii HIV/AIDS Affected SHG stated that she has been suffering from stigma- related comments mostly from the outside Wii Community where people would make comments like,

“...so long as your parents have both died of AIDS, you will follow their footsteps and also die...”
to the orphans staying with her. She feels bad about this and has no alternate action, but to comfort the children as much as she can.

HIV-positive women groups on the other hand had a whole lot more on how HIV/AIDS impacts them socially. For instance below are two exemplary stories from the women. A 53 year old widow and a mother of three in Mulutu SHG:

“In 2007, my husband got very sick and was hospitalized, but later died at the hospital. Because I was so heartbroken, it was only later I was told that he died of AIDS. I was ignorant then about AIDS and everything surrounding it so I did not think it wise to seek medical attention for myself by going for a test. One day, during church service, I fainted and was taken to the hospital. I was later told that I had tested positive for HIV/AIDS. I was so afraid of what to do and who to tell about my situation. Later, after my brothers-in-law got to know my status, I was told to call my father and tell him to come and take me so that I would die at home and not in my husband’s house. When I told him, my father used a proverb I will never forget in life. He said, “when a metal breaks down, the earth is used to cover it right there at its station. It is never moved to another place for the same purpose”. This was the final straw of rejection by my own father saying I should stay and be buried at my husband’s place and not come back home!”

The social impact of HIV/AIDS come in the form of loss of peers and social networks as sickness complications set in and as side effects of disease and ARVs begin to show as seen in the short story above. Also is the loss of friendship and companionship from people who used to be close. Stigmatization and rejection from friends, families and neighbors never ceases. A woman in the Majengo SHG, when asked to explain what she meant by stigma said,

“...sometimes neighbors have moved house just because they don’t want to have anything to do with me in anyway. Of course it hurts me. Am I not human?”

Another woman said,

“Sometimes people just don’t want to even walk close to me in the market. People will only shake your hand if they are not aware of your HIV-positive status even though shaking the hand is part of our culture when people meet. We become like animals to them because they don’t want to shake our hands.”

The women shared issues of rejection and having no or limited support from family and friends.

“I needed so much support when I first got to know my status and none of the people I called friends wanted to have anything to do with me or my household members and yet they once called me their friend”, says Evelien*.

Further still, children may have to drop out of school to escape from insults and being made an outcast at schools. Women related education to good job positions and better income Evelien* continues that,

“... and if my children stop going to school because of the bad things people say to them, they will one day become like me (illiterate) and find it difficult to acquire income for their own families. It will be like a never ending story...”

4.2.4 Summary of Impact of HIV/AIDS

HIV/AIDS has numerous impacts on economic, health and social wellbeing of women heading households either for the infected or for those who are one way or the other affected by the disease. Impact goes from losing agricultural productive items like land, crops to losing professional jobs. It goes from experiencing overbearing increasing household expenditure to increasing risks of developing and spreading infections as a result of crowded rooms. It also goes from feelings of worthlessness, guilt, rejection and suicide to loss of social networks and stigmatization from friends, neighbors and even family members. HIV/AIDS has shown considerable frustration and pessimism on these women’s wellbeing in the society in which they find themselves. Therefore, the promotion of Self Help Groups is warmly welcomed although the expectations of their roles in the lives of the women vary from group to group.

4.3 Health, Economic and Social Roles of SHGs for HIV/AIDS Infected and Affected Women

This section shows results first on the health, then the economic and social roles that women infected and affected have for SHGs. Figure VI communicates the major reasons why women (both infected and affected) joined the SHGs and their expectations of the group for the betterment of their own wellbeing.

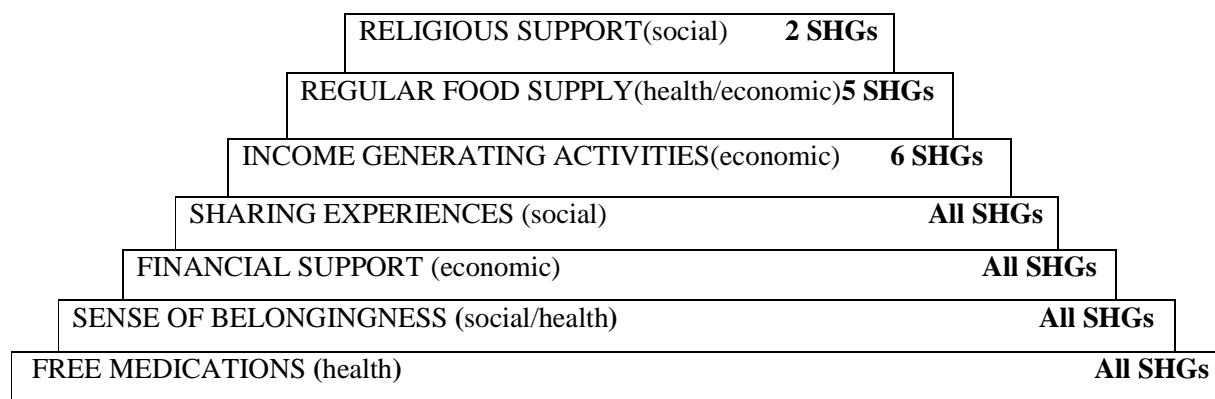


Figure IV: Women's expected roles and functions of SHGs before joining

This section begins with the health roles then economic and social and ends with a summary of all three and how they are inter-related.

4.3.1 Health Role

According to the findings of the study, majority of the women in all the SHGs as seen in figure VI, had expected by joining the group, to have access to regular and free HIV/AIDS medications and have the feeling of belonging or acceptance in the group. Madam Nduku* in a proverb,

“A person can have all the food, money and everything there is to have, but not being allowed to shake hands¹⁵ with others is a bad omen”,

explained the importance of shaking hands in their culture (see footnote 15 below).

The provision of regular nutritious foods was empathized by five SHGs mainly, Katethya (affected), BOMA A1 (infected), Mathima (infected), Wii (affected) and Mulu (infected) as one of the major expectations. The other four groups did not make mention of this role, rather, they put more emphasis on the sense of belonging and acquiring a sense of hopefulness for the future. When asked what expectations had been achieved, a lot of people wanted to share how their story on how being a part of the group has helped them with regards to their health. Below are some examples of women's experiences and comments.

¹⁵ Shaking hands is the most common way of greeting or welcoming a person into the circle. A handshake may be more prolonged when greeting a person you know well and vice versa for a person you do not know. Close friends (mostly females) may hug and kiss on the cheek, although not as common as the handshake (<http://www.kwintessential.co.uk/resources/global-etiquette/kenya.html>)

Woman 1(Majengo):

“...So in December, 2005 after I had joined the group, I started taking the free ARVs I got as a result of this group. Look at me now (referring to me), do I look like I am sick... You can all see how these medicines have helped me look and feel better...without this SHG; I wouldn't have looked this way.”

The census of women regarding health roles that SHGs play was that most of their expectations have been achieved because first, medications are freely given to them, then, there is fact that each member is given at least 4kg of maize and beans with a liter of oil almost every month. Helen, an affected divorced mother from the Wii SHG during a focus group discussion commented that,

“If I am very careful, the food can last me and the 6 children I have in my care for close to one month. I can make so many types of foods with this...ugali¹⁶ and cabbage... some days we eat githari¹⁷ and that is nutritious”.

In addition, the groups are such that each member feels accepted and part of the ‘family’. Although the women had not expected free counseling and psychological support for members, in being a part of the group, they received counseling and psychological support from qualified counselors and nurses from the Kitui District Hospital. It is from joining and being a part of a self help group that women get free regular check up at the Comprehensive Care Center (CCC)¹⁸, of the Kitui District Hospital. The research highlights general improvement of women SHGs provide with health services or facilities. With the provision of free medications and regular supply of food, women are able to balance their weight and strength to work in their farms and small business for the sustenance of their households. A woman from Mulutu SHG commented that,

“... I would never have imagined myself looking as good as I do now without these free medications and food for my body and soul (referring to the prayer sessions with the Catholic Fathers).”

4.3.2 Economic Role of SHGs

Economic roles of SHGs are numerous from the study. More than half of the women had expected financial support from the Catholic Diocese through the SHG. This support, they imagined, would come in the form of providing school materials such as uniforms, books and bags and sponsoring their children who had successfully past their standard eight (primary) examination. They agreed unanimously that such

¹⁶ *Ugali* is a popular food not only in Kenya, in East African countries in general. Made out of ground corn, it is cooked longer than grits and stirred into a thick porridge. *Ugali* can be eaten with *Kachumbari*, *sukuma wiki*, cabbage, *nyama choma*, among others. More information can be accessed via: <http://kenyaconnect.org/wamunyu.htm>

¹⁷ *Githari* is the one of the staple food of the Kamba people. It is the mixture of corn, beans or peas. Because ingredients can be dried and stored, this food is eaten more often during lean seasons. More information can be accessed via: <http://kenyaconnect.org/wamunyu.htm>

¹⁸ The Comprehensive Care Center is the unit in the Kitui District which provides information, care and medications to HIV/AIDS persons

support would help them and encourage children to further their education in the secondary school level and sometimes also to the tertiary level. This support (financial) according to the annual report of the Diocese (Mulozia, 2009/10), is being achieved. For example, a total of 37 students have benefited for secondary school fees, seven in colleges and vocational training. 8436 were followed up for the school performance. For the woman, the support extends further to decrease household expenditure as school fees after standard eight are taken care of and money which would have otherwise been spent on education is now delegated to other needs.

For six of the SHGs (Mathima, Kanyangi, Kavisuni, Miambani, Majengo and Wii), income generating activities such as aloe vera plantations, aloe –vera soap making (Liquid and bar soaps), vegetable farms, tree planting (nurseries) as well as bakeries were one of the roles which they thought was important as a function of a SHG. Therefore, when the Catholic Diocese or other organizations are unable to help support them, they are able to get some small income to sustain their households as a result of the income generating activities they are involved in. Dividend of profits from group income generating activities is now divided equally among members in the groups to spend on needed items for the household. From the sales of group produce, SHGs provide loans to its members with an interest rate of 10% and a maximum amount of Ksh 2000.00 and payable within a month.

“As for me, when I want to borrow the group money, it is possible and you can pay back within two months time... If at night you need small money to buy medicine and you don’t have, I can always send a child to Madam’s (referring to the group leader) house to lend me some money... I think it is very important and I am happy to be a part of this group.”

This helps especially during emergency situations. Then again, decrease in transportation expenses as medications are brought to community dispensaries for pick up now is channeled to other important things for the household.

4.3.3 Social Role

The results of the research study indicated that the participation in a self help group is meaningful to women heading household because of the enormous support they get from it in general. To be more specific, women from all the SHGs stated they get advice and encouragement from nurses from the CCC in Kitui District Hospital, the Catholic Diocese staff, other supporting organizations, each other and some family members. Also, socialization in which networks are created are often formed through seminars, meetings and training workshops organized by the Catholic Diocese and focus on meeting new people with same or similar situations to share experiences.

“...I met so many women even those in my age group with whom I could easily relate to and share my experiences with. Some I took as my own daughters and some as my sisters. They are my family now...”

Francesca* (BOMA A1)

As part of the socialization process, members visit each other as a way to lift each other up on daily or weekly or weekly basis. Women gain knowledge in various group activities such as baking scones (Mathima and Wii) and how to better sell them, more about HIV/AIDS and other diseases and infections and about living positively. A lot of information is passed on about dealing with stigma, neglect and abuse from family, friends and neighbors.

Trainings for improving on business skills of women are provided either by the Catholic Diocese, other organizations or through the initiatives of the SHGs themselves. In general business skills women have learnt are in marketing, book keeping, bee keeping and farm management.

“SASOL Foundation has organized marketing training workshops for the Wii SHG to help them better advertize the scones they bake every week...” SASOL Staff member

Majority of the women in the SHGs mentioned that they gained self-confidence in group meetings and from participatory trainings and some even stated that they had become spokes persons for their communities especially during events and occasions like World AIDS Day when they help create awareness of HIV/AIDS, the importance of VCT and living positive. Mariamme* from Majengo stated that,

“I am generally a shy person... in the beginning when I was living in Mombasa, I had no family so I moved back home (Majengo) with the mindset that my family will help me... I was devastated by the lack of support I received from them, by the finger pointing from my neighbors and friends and the teasing and abusive words sent my way that I crawled right back into my shell...felt I had nothing to share with others...now I voluntarily take part in every year's World AIDS Day here in Kitui with NGOs who are organizing it...”

Findings of the research study shows that women are now able to be self accepting accept who they are as a result of participating in the group and sharing experiences and ideas on how to better support each other come live positively. The groups provided them a sense of belongingness and accorded respect to them as fellow human beings in society. The Catholic Diocese, through the SHGs, provides faith building support in collaboration of learning together and participating in prayer sessions.

4.3.4 Summary of Roles of SHGs

Being a part of the SHG accrues a lot of benefits from the provision of financial support, through income generating activities, provision of medications and personal development, creating a place of

belongingness and according the much needed respect to its members. With the exception of building houses for its members, SHGs through the Catholic Diocese have achieved the physical and psychological, economic and social expectations women had for SHGs.

4.4 Summary of Impact of HIV/AIDS and SHGs

An example of one woman's story is used here to show practically how HIV/AIDS impacted her wellbeing and how being a part of a SHG has given her a sense of hope and a future as she stands strong for her household.

Francesca John, a 57 years old HIV-positive widow is a mother of four children – three daughters of whom two are late and one son. Francesca John was living a happy life until 1998 when her husband died (was told by some nurses in the hospital that he had AIDS) leaving behind nothing, but a piece of farm land. As the years went by and she was not losing weight like she expected a HIV-positive person should look, she decided on her own that she was negative and need not worry. However, between 2002 and 2005 she lost two of her daughters to TB and other militating sicknesses. “When I lost my second daughter, I wanted to also die. Life was too hard for me to bear. Having my own family and then the added burden of my grand children was just too much for me at that age. How could I go on?”

Francesca mourned her daughters' death for years and found it difficult to relate with neighbors whose children were the same age as her deceased daughters. It was after she herself tested positive that same year in 2005 after suffering from TB that she realized the symptoms her daughters experienced and linked them to HIV/AIDS. Her long journey to acceptance of her loss started when she heard of a Self Help Group (BOMA A1) for orphan guardians run by the Catholic Diocese of Kitui Home Based Care Program. She immediately joined and through the overwhelming support from diocese, group members and friends she made through organized seminars and visits in and around her community, she learnt to accept her daughters' death and to 'forgive' herself. As time went on and Francesca got more involved in group meetings and activities, she was made the BOMA A1 group leader and busied herself in the many responsibilities of the group. She says, “Although the road is dark, God provides a lantern on every step of the way so that you do not trip on a stone and break a leg”. Through group economic activities like the vegetable plantation they maintain as a group, she got some seedlings and planted them along with potatoes and maize on the piece of land her husband left behind for her. Although she has lost a great

deal, Francesca now knows to hold tight on what she has now and what she can do and is grateful for the all the support she get from the Kavisuni SHG.

4.5 Group Initiatives among SHGs

From the research, five out of the nine SHGs (Mulutu, Kavisuni, Miambani, Majengo and Mathima) had income generating activities to help sustain the group and their households. These activities range from farming staple foods like maize (Majengo and Kavisuni) and growing vegetables like cabbages and green peppers (Miambani, Kavisuni, Majengo) and nursing seedlings (Majengo and Miambani), rearing animals like chicken and goats (Kavisuni, Miambani, Mulutu) and practicing the merry-go-round system (all groups). Mathima SHG focused just on baking scones for themselves and for sale in the surrounding communities. The other four groups however with the exception of Wii SHG who had a bakery, but baked the scones every 2 or 3 weeks, the rest of the SHGs relied mainly heavily on the Catholic Diocese and on people or other organizations for support.

Also, during weekly meetings, group members in all the SHGs with the exception of that of Kanyangi, Katethya, and Miambani do not contribute any money for the welfare of the group. For those other SHGs who do contribute to group funds, research shows that they each contribute 20 Kenyan shillings each week or during each meeting which then either pooled for members to take loans from, invested in group activities or added to the group savings account for lean seasons. In the seven groups who regularly contribute, findings of the study discovered that group members also contribute a minimum of 10 shillings usually once a month, to be given to one member in what they term their "merry-go-round". Members then draw lots to determine the order of receiving the money. Interesting ways of drawing these lots included putting pieces of sticks (with total number of participants) in a container with one firmly wrapped with a small piece of cloth at the bottom. The person who picks this stick is the one whom the money goes to. In other SHGs, numbers are written on small pieces of paper and folded and each member picks one; the number you get determines your position in the order of receiving the merry-go-round contribution.

“Although some people complain that the contributions are small, I am always happy when it is my turn to receive the money to help my house people. This merry-go-round has helped me to buy chickens and start rearing them for the little income they bring.” Madam Elizabeth* (Mathima)

Elizabeth is a HIV-positive widow who, together with her four children (two of which are infected), lives with her mother because since her husband passed away and the in-laws burnt all her belongings and took away the property she had, she has had nowhere else to go.

During the research, it was discovered that there were some cases where the formation of a group was inspired by the success of other self-help groups active in the locality. Mulu and Katethya SHGs for example, were both started from the bigger group of BOMA A1. As a result of how functional, committed, enthusiastic and successful members were about their economic activities, the Majengo and Kavisuni groups have been blessed abundantly in terms of bounty harvests this year as compared to previous years.

Regarding social development, both the Majengo and Kavisuni SHGs showed a great deal of social-related initiatives the group members had taken upon themselves. For instance, in Kavisuni, the HIV-positive has made an effort to 'preach' to at least one infected person they know whether in the community or elsewhere about the importance of joining a group and about living positive. Other forms of social improvements are practiced by the Kavisuni SHG who has included in their timetable, time for visiting the sick in the community and works towards helping AIDS orphans in the community with food and some provisions for school from group contributions and sales from produce from the farms. It should be noted however that majority of the SHGs who undertake income generating activities are from the rural areas. For instance, groups like that of Wii and Katethya which are closer to Kitui seemed hesitant in undertaking activities which would help sustain them in case of a break or stop of support from the Catholic Diocese or in case of a natural disaster like the drought which occurred a couple of years ago.

In a nut shell, Self Help Groups one way or the other sometimes take their own ingenuity in creating a better world for members in the group which in the long run benefits their household through tripling down effects. However, this is not so for all SHGs studied during this period. It was discovered that majority of those who did take initiatives were from the rural areas while those who did not, waited patiently for support from organizations and individuals to help them and their households.

5. Discussions

This chapter begins with a summary of the HIV/AIDS and its impact in Africa, Kenya and on women touching on the health, economic and social aspects of the impact. Also is how Self Help Groups in Kenya are seen as mitigating tools towards the health, economic and social impacts the disease creates on the wellbeing of infected and affected women. The chapter goes further to integrate literature to results from the research using the theoretical framework. The chapter then ends with the research limitations, concluding remarks and recommendations for further research.

5.1 Summary of Perspectives on HIV/AIDS and SHGs

The number of new HIV infections has yet to decline, though more than 20 into the epidemic. Almost 40 million people around the world are living with HIV and AIDS (UNAIDS, 2009). According to UNDP, the AIDS epidemic has swiftly escalated¹⁹ from a public health challenge into an unparalleled development crisis (UNAIDS, 2009). In Kenya, like most countries in the sub-Saharan Region, the HIV epidemic affects and continues to have devastating impact on all sectors of the population from health to the economy to social amenities (KDHS, 2008-09). Women account for close to half of 40 million infected. The rising feminization of the AIDS epidemic is of crucial trepidation and reveals the imbalance between men and women in accessing information, generating livelihood opportunities, negotiating safe sex and protecting themselves from HIV (UNAIDS/WHO, 2007). Michel Sidibé, Executive Director of *UNAIDS* correctly stated that “*this epidemic unfortunately remains an epidemic of women*” (UNAIDS, 2009). Findings show that although Kenya’s epidemic has stabilized in recent years, women still have a higher prevalence compared to men (KDHS 2008-09). Although the Kenyan government has and is still undertaking strategies in the prevention and mitigation of HIV/AIDS for her citizens and with specific reference to women in terms of increasing availability and access to counseling and testing, promoting

¹⁹ More information can be accessed on the UNDP websites:
[http://www.undp.org/hiv/docs/alldocs/HIV%20Corporate%20Strategy%20\(2006\).pdf](http://www.undp.org/hiv/docs/alldocs/HIV%20Corporate%20Strategy%20(2006).pdf) and
<http://www.undp.org/geneva/hivaids.html>

consistent condom use and expanding services for Prevention for Mother-To-Child Transmission (PMTCT), many more aspects such as the psychological, economic and social wellbeing may need to be considered. Women in East Africa have the indigenous (home-grown) system of coming together to help each other in times of difficulty. Self Help Groups run by and for HIV/AIDS infected/ affected are being encouraged all over Kenya under the assumption that this may have positive outcomes extenuating impacts (mentioned above) HIV/AIDS has wellbeing of the women. However, the full worth of SHGs within this context has not yet been evaluated and accessed. Hence, the objective of this paper was to study how SHGs could be used as a tool in mitigating the health, economic and social impacts HIV/AIDS has on women's wellbeing. The focus of this thesis is on HIV/AIDS infected and affected women heading households. It must be noted that, although all of these women have experienced the impacts of HIV on their lives, findings may be somewhat different for these two groups of women.

5.2 Discussion of Main Findings

Focus group discussions and interviews were used in collecting data. Through these methods, a total of 162 women heads participated and discussed how HIV/AIDS impacted their lives and stated how being a part of the SHG had helped them. Although majority of these women preferred the use of group discussions, four infected women specifically preferred using a face-face interview. Although this gave women freedom (Wimmer and Dominick, 1997)²⁰ to answer at their own pace and paved way for the preparation of the FGDs, it may have been because they were still new to the group and uncertain about completely trusting group members. Although some literature claims that FGDs may not be preferred in certain circumstances by researchers because of the potentiality of one or two members hijacking the discussion, it was not so in this research since the outspoken members seemed to encourage the quiet ones thereby creating a snowball effect.

Educational levels among household heads interviewed showed a low level in general with a slight higher level among SHGs closer to town such as Majengo, Mulutu and Wii. With respect to HIV/AIDS status of respondents and their educational level, the research shows that averagely, there is a higher literacy level for the affected _a total of 50 women from Katethya and Wii groups who have had some formal education_ than the infected with a total of 111 among the rest of the seven groups. SHG leaders are more likely to be better off and have some schooling compared to overall members. According to the definitions women gave to what they understood by social impact of HIV/AIDS first on their wellbeing then that of their household members, women stated *that*,

²⁰ More information on Wimmer and Dominick's literature can be retrieved from:
<http://www.aber.ac.uk/media/Students/aeo9702.html>

“...school drop-out means that a child doesn’t get the education she needs to become someone in future... how will she get a good paying job to support her family?”

Global Campaign for Education (2004) accedes to the fact that education is one of the most effective tools in preventing HIV infections. An estimate from the Global Campaign for Education suggests that if every child received a complete primary education, around 700,000 new HIV infections in young adults could be prevented every year (Global Campaign for Education, 2004).

Although majority of the women (100) were widowed, close to half of them were either divorced or separated (49) and a considerable number were single (11) and had never been married. Two women, though still married, were still the income bearers and so were considered as heads of their households. Majority of all the women (126) fell in the age range of 38 – 57+ years old. There were however 35 women below this age range.

5.2.1 Impact of HIV/AIDS on Infected and the Affected

Research discovered that in all the HIV/AIDS infected SHGs, three groups (Mulutu, Kanyangi and BOMA A1) together had an average age range of 48 – 58+ years old women. Literature states that although most victims of HIV/AIDS are young adults, WHO (2009) agrees with the findings of the study that the pandemic has had major consequences for older people as well and the demands on older care-givers are for the most part burdensome. It is possible that these older women had been infected at an earlier age and had survived with ARVs till now or as the UN Department of Economic and Social Affairs Ageing Units (2010) states may be another possibility. The department points out those early symptoms of HIV infection such as fatigue, poor memory, sleeplessness and weight loss may be mistaken for signs of ageing, thus preventing those infected from looking for early medical assistance such as the medications to enable them stay healthy. Results of the depression scale test for the infected reveals that a greater number of women tend to practice what is often referred to as ‘self-stigmatization’ which is described by Mwala & John (1998) as the avoidance of people, self hatred or the desire for isolation from collective activities. Expressed as low sense of worth or low self-esteem, these women like to play the role of the ‘victim’. This can have a pessimistic blow on the psychological and physical health of a person and could be the reason why majority of the women had an average test results of 50-60 (considered as moderate/severe depression). With the exception of general loss in weight, women complained of side effects(physical) such as experiencing dryness in the mouth, increasing tiredness, headaches, dizziness and the ‘whole in the cheek’ (lipodystrophy). In the case of lipodystrophy for instance, it allows others to see how ‘infected’ with the disease a person is. This way, people are able to detect who is infected and so isolate them or refuse to buy their produce in the market, thereby affecting their economic wellbeing. Other experiences were in the form of painful full body rashes and swelling

in the upper part of the stomach for some women and for others, there were no side effects yet from the medications. A website²¹ with more information of side effects can be sought for more details. One way of reducing the impact of HIV/AIDS on these women, their families and societies in which they hail from is to keep them healthy as long as possible. This could be done through ARV treatment, a healthy diet, and treatment for recurring infections. Sometimes it may be necessary to expand health care services, increase access to counseling and testing facilities, and increase access to care and treatment as well as creating more self sustaining groups.

Wii and Katethya, the two affected women groups on the other hand had majority of members' age higher than 54 years old. This means that majority of these care givers may require some health assistance as they grow old. The women noted that caring for a loved one with AIDS or orphans is no easy task. The health of the "older caregiver" itself has taken a heavy blow. Like widowed 65 year old woman in Wii SHG (HIV/AIDS affected) said,

“Looking after these children is like starting life all over again. I used to think that in my old age, I will just relax. I worry about getting sick and not having enough energy to cope with all this stress and just dying and leaving them behind with no one to care for them...”

Not only does it require physically caring for someone you love at home, but it also implies confronting your own concerns about the diagnosis and ultimate result of the disease. Often partners of AIDS patients, care givers fear for their own health and are hesitant to take in another AIDS orphan. The research shows that many of these affected women may be on the verge of burnout as they struggle with both the psychological and physical brunt of responsibilities on caring for patients and orphans. Kiragu et al (2008) sees eye to eye with these results although relating it to hospital staffs who are themselves care givers. He states that caring for the caregiver encourages the formation of peer support groups where the burden of care is lightened.

Economic impacts for the infected ranged from loss of business or productive income to increase in the expenditure of the household (from medical and related bills) which leads to a worse off poverty situation for them and their households. Schubert et al (2003) agrees that economic impact both for the infected and affected women can have disastrous results on already poor households. He says that the aura of HIV/AIDS in a household rapidly results in exhaustion of household income or earning capacity and savings. Most households quickly progress into situations characterized by poverty. HIV/AIDS affected women also experience increasing household expenditure, though it comes not from medical

²¹ http://www.tibotec-hiv.com/bgdisplay.jhtml?itemname=side_effects_by_category Accessed in August, 2010.

bills, but mainly from increase in household members as there are more mouths to feed with less income because time is taken out to provide care. Because most of these affected women have not lost their jobs or business as a result of inability to work longer or lessened strength as their counterparts would, most are still able to continue with what they were doing to bring in income before joining the group so most did not experience a loss in productive income, just that in most cases nothing is saved or invested again because of the imbalance between the demand from household members and the supply from the farms or businesses.

Results on the social impacts for HIV/AIDS infected women were that there were major issues of disruption in social networks and stigma. The fear of being stigmatized or made fun off is both a resentment of the infected and the affected. With regards to the infected for instance, side effects of ARVs such as lipodystrophy can unveil a person to the persecution of others especially in public. This then impact the mental wellbeing of the woman is trying already to be invisible. Although Schuster et al (2005) suggests that fear of being stigmatized is often associated with high-risk sexual behaviors and inadequate use of HIV services by the infected.

5.2.2 Contributions of SHGs on HIV/AIDS Impact

Although literature suggests that SHGs are formed mainly to provide economic and social benefits, the research shows that this is not limited to only those sectors, but to that of health as well. The American Self-Help Clearinghouse (2003) endorses what this research discovered that health professionals consider SHGs for mental or emotional problems to be an add-on to therapy. Kropp and Suran (2002) agrees by disclosing that although SHGs are really is outside the medical jurisdiction doctors and specialists refer to participation as a way to improve the end result for current and future conduct for both the infected and the affected. Through SHGs, free treatment for the infected are provided at dispensaries nearby. Regular counseling and consultations is given free of charge to infected women to bear their hearts out and talk of how to better deal with side effects or how to live positively.

A remarkable fact is that very few respondents or their households have been members of another similar income- generating enterprise or group. This implies that the changes in the lives of the SHG members, as documented by this study, can be attributed largely to the SHG interventions. Self help groups' assists in broadening women's economic choices especially as members of groups are encouraged to contribute financially to the group's bank account for rainy days and the fact that each group takes the initiative to start some economic activity to help support their families. Another economic benefit of SHGs as seen during the research is the opportunity to diversity household income, to make households less vulnerable

to downturns in the economy or personal or health set-backs but on their own abilities and initiatives sometimes learnt from group activities such as basket weaving. Sometimes, SHGs like that of Kavisuni, Majengo and Kanyangi provide savings which allows group members to accumulate safe but flexible cash accounts to draw on when needed. This is usually done together as a group through the concept of merry-go round.

Sometimes being with people who know from experience how you feel makes all the difference. Crucial for the functioning of a self-help group is that its members are simultaneously givers and receivers of help and as literature states, the bureaucracy and professionalism prevalent in the usual human service organizations is absent (Kropp & Suran, 2002). Both groups of women are empowered through the power of encouragement, sharing, learning and doing things together. While infected women are learning to appreciate their bodies and focus on the 'can do' bit, the affected are gaining hope for the future through collective social capital they may gain as people bond with each other and help each other cope with the burden of a care giver, or with regards to the infected, the stress of worry all day long is washed away as members learn to share burdens and encourage each other to focus on the future, leaving the past behind. Although SHGs have had a great impact on the health, economic and social wellbeing of women both infected and affected, Maria Nzomo, who has written substantially on women and political mobilisation in Kenya, asserts that this is not enough. She states:

"...The last ten years of gender activism in Kenya have clearly shown that mobilization of people is not enough. Social movements must also have sustaining ideas, shared goals and a unifying, ideologically inspired gender vision that transcends respective members' socio-cultural and economic diversities..."

(Nzomo, 2003)

5.2.3 Relationship between SHGs' Functions and Initiatives Taken

The Kenyan "merry-go-round" system of contribution also known to a few Economists as rotating savings and credit associations (ROCAS) shows the interesting and inter-relating aspect of savings and loan development. Forming a merry-go-round therefore is one way to build not only good financial habits (Anderson & Baland, 2002), but the community in general. For the woman who receives the first pot, the merry-go-round resembles a loan; as they are required to still make payments after they receive the pot. For the woman who receives the last pot, the merry-go-round resembles savings without interest. For those that receive the pot sometime in the middle, the merry-go-round is savings up until you receive the pot and is a loan repayment afterward. It should be noted that only about seven of the nine groups were practicing this system of income generation. Excuses given from those two SHGs were either that they were not aware of such a system, they did not think it brought in a significant amount of income to help them start a business or that they were 'too poor' to follow such a system. So although through the SHG,

they were given lots of encouragement to do something for themselves, they preferred waiting with their hands opened for things from others.

From the focus group discussions, research revealed those affected households often have few, if any, resources to organize in the lean season. This could fundamentally be a reason that in many African societies (Kenya not exclusive), the husband's relatives claim all possessions upon his death and leaving the widow without means to earn a living. Community coping responses are set up by informal associations, Self Help Groups, Community-Based Organizations supported by external development agencies and AIDS-specific organizations. Many of these community coping mechanisms to HIV/AIDS are organized and run by women. Although some SHGs had received training on for example marketing scones they baked as a group, those other SHGs who did not get this opportunity were able taking more initiatives as a coping strategy for their situation. The researched revealed that where HIV/AIDS infected women in SHGs like that of Kavisuni, Mulutu, Majengo and Miambani take the lead in developing coping strategies as a response to the epidemic, the effects are far-reaching and more sustainable. However, dependence on others like the Catholic Diocese or SASOL for business training skills, encouragement will not be sustainable for the woman neither will it be for the group. Given that in most cases, such community coping mechanisms are the only viable and sustainable response to AIDS impact research into ways of strengthening household- and community-based coping mechanisms should be allocated top priority. As regards to whether the diverse attitudes and behavior of SHGs greatly influence that of initiatives taken by members in those groups, the study demonstrates that this to some extent is true in that it is the SHG Is established by and for the women so the attitude of each woman towards 'making it better syndrome' should be like a dress they put on every day. There is a saying that goes like: *"it is the people who make the government, and not the other way round"* so although SHGs have the capacity improving the health, economic and social wellbeing of women heading households, it is the responsibility of each woman to contribute her quota in making this work and benefit her and the household.

5.3 Study Limitations

This research raised ethical issues that are worthy of attention. It has been argued that for research in HIV/AIDS issues to be ethical, it must go beyond description and analysis to social responsibility for action. One of the questions that almost every participant in the study asked was:

"How are we going to benefit from all these questions that you are asking us?"

This was despite the fact that the objectives of the study had been clearly explained at the beginning of the interview. In addition, this research study is limited in scope as it is focused on the one hand on just

HIV/AIDS infected women who had either been on Anti-retroviral Treatment (ART) for a longer period of time and have now accepted their HIV-positive status and therefore willing to join a group or those who were considered strong enough to attend group meetings. In other words, since women who are bed-ridden or weak and are unable or unwilling to join a group were otherwise omitted from the study, the correct point representativeness of the sample may be .Lessons learned from the findings should be taken as pointers on how SHGs can be beneficial to HIV/AIDS infected and affected women in general. Literature says that collecting data on entire population would be efficient since each individual characteristic will be identified and taken into consideration during analysis; however, this practice is in most cases impossible considering how large is the population. In almost all surveys, researchers have tried to select a representative sample among the entire population. In Barnett et al. (2001) as an example to buttress the point, is that collecting data representation of a target population is one of the goals of a research. Information gathered from the research is then generalized from the sample back to the total population which is still within the limits random error.

The issue of HIV and AIDS is a very sensitive topic not only in the whole district of Kitui, but in all parts of the world. Although not much difficulty was faced in freely discussing topics such as reasons why women tested for HIV or how they were infected or even the impact HIV/AIDS has on their wellbeing for some women in the focus group discussions, others opted for one-on-one interview. This shows that although women are opening up and learning to accept their situations, it will take time for all to follow the example of others as the fear of stigma and inferiority complex lurks around.

With the exception of the limitations above, the first practical constrain is time. To get a feel for the full round of people's lives, it usually takes at least a year of fieldwork. The research however took a period of 10 weeks in the field. More time spent with either the infected and affected groups of women and on how SHGs function in minimizing the impact of HIV/AIDS over a longer period of time would have been essential in providing a more in-depth view of the topic.

Although, a translator was involved as a method in the acquisition of data, language barrier is something which would needs to be considered. A great deal of information may have been lost especially since the translator herself was not able to express all ideas fluently in English as a second language as good as would have been in own language. This is especially so in the context of sensitive issues like HIV/AIDS which are rarely discussed in the open.

Furthermore, it was expected that all respondents for either the focus group discussions or the interviews would be from within the current Kitui District and it was only during the field work that Mutomo, which was once totally under Kitui District had become a district on its own quite recently. Although with this knowledge, the study still goes by the old Kitui District which includes Mutomo because there are still a lot of things intertwined within the two districts. For instance, the Kitui District still provides administrative functions, educational facilities, and postal addresses, among others to that of Mutomo.

In addition, some of the SHGs (Mulutu, Majengo and Kanyangi) had a total number of 27, 22 and 20 respectively women present for the discussion and because this was too large a number for one person to effectively have a discussion, the group was divided into two and the group leader helped to lead one of the groups while the other was led by the researcher. Although a recorder was used in, it is possible that some vital information may have been lost in the process.

5.4 Concluding Remarks

More than two decades of the HIV/AIDS pandemic has shown that women's issues in all spheres are subsidiary in global response to HIV and AIDS. Yet, it is clear that women are the driving force that sustains the continent. It is among these women that the real heroes and role models of this war against AIDS are to be found. Through its diverse impact, the disease has undermined the structure of the family, and has become a threat to the future of the children. As both the young and old women are faced with the burden of caring for sick or dying family members and friends as well as AIDS orphans women in Kenya are realizing that there's strength in coming together or uniting for a common good and are putting the term '*Harambee*²²' ("let's pull together") into good use. Self Help Groups enable caregivers to share experiences with each other so as to work out feelings of worthlessness, frustration, anger or even guilt. After diagnosis in most life threatening diseases like HIV/AIDS, emotions of people accelerates. As they face changing social supports and financial situations, they can become depressed. HIV support groups often become a major source of love and acceptance as members learn they are not alone and can focus on building a new life. It is also through these groups that women learn new skills to help create a self sustaining income generating activity for themselves and their households. This study used nine Self Help Groups in the Kitui District of Kenya to explore the extent in which HIV/AIDS impacts the economic, health and social wellbeing of infected and affected women heading households in the districts.

²² *Harambee* is a Bantu word which has its origins in the word *Halambee*. Literally, it means 'let's pull together'. The word has also been adopted as a political slogan to symbolize the unity of man to help achieve a worthy end. It encourages Kenyans to give their best in order to complete any task at hand for community development (Chieni, 1998). *Harambee* is used as the motto of almost all SHGs visited during the research. Information accessed in August, 2010 at: <http://boleswa97.tripod.com/chieni.htm>.

The study clearly shows that women infected/affected with HIV/AIDS and who are heads of households can be empowered both psychologically and physically, socially and economically to improve on their wellbeing. Their households then benefit from the triple down effects. However, this 'help me help you' method used by SHGs does not come easy. For instance, Madam Consolator, the leader of the Majengo infected SHG stated that,

"... don't be fooled by how we may look today with happy faces and enjoying each other's company. We are not always like this... there are times when we fight among ourselves on useless issues or because someone thinks they know better than another... we are all learning from each other as we learn to accept our mistakes and appreciate each other on the daily basis... I won't lie to you, sometimes I want to give up on the group (signs and shakes her hands in a way she means 'finish' or 'stop')."

It is therefore a priority that SHGs, networks and organizations of people living with HIV be strengthened to facilitate their full participation in the AIDS response. There is the need to build the capacities of Self Help Groups, which are in need of support not only in marketing skills as SASOL organization has been doing, but in other business development skills to holistically empower women through Self Help Groups. Two strategies in helping mitigate the risk of HIV for older people and lessen the impact of HIV/AIDS on those already infected therefore are: first to identify areas of research specifically looking into the interactions between age and HIV and second, to involve older persons in research on prevention and care. Self sustaining economic activities should be encouraged for all infected and affected households to prevent the imbalance of demand and supply among members and income sources. Stigma continues to have a central function in the fight against the AIDS epidemic, not only because of its effects on the HIV- infected, but also because of the ways in which it plays a part in the spread of the epidemic. Research should be encouraged to provide a greater understanding of stigma and how best to ameliorate its effects on both the infected and affected. Furthermore, in all the SHGs visited for the purpose of this research, it was realized that though they were officially started through the Catholic Diocese of Kitui, it was the initiative of one or a few women who decided to put in action the term '*harambee*' by pulling together other women in the same situation as she and maintaining a group with its members either being HIV/AIDS infected or affected groups of people. Therefore, gender focus in designing and implementing grass root support networks should be patted on the shoulders and promoted towards the fight of development issues such as the HIV/AIDS disease. More in-depth research should be conducted on how development organizations can develop the capabilities of such women through SHGs and how women themselves use the opportunity of membership to develop themselves as they move towards a more holistic development.

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Appendix I: Interview Schedule

A. Question List for the Catholic Diocese, Kitui

1. Could you explain briefly what you do Kitui and why you are motivated in doing that?
2. Could you please elaborate a bit on the types of community groups or Self Help Groups (SHG) that this organization associates with?
3. In what way(s) do you provide support to women infected and affected with HIV/AIDS in rural areas?
4. In what way (s) do you provide support to women infected and affected with HIV/AIDS in rural areas?
5. Could you kindly elaborate on the impact of this organization to the target groups?
 - Challenges:
 - Achievements:

Could you please give me a list of target groups or names of communities benefiting from MF initiatives?
Do we have your permission to contact them?

Thank you for this time and for your cooperation during this interview.

B. Questions for Self Help Group Leaders

- ❖ Introduction: Names (myself and Harriet, the translator). Brief explanation of why I am here and what I am researching into. Briefly state confidentiality process and emphasize of being free to express opinions
- 1) Could you please tell us how the group started?
 - Who started the group?
 - When was it started?
 - Why was it started?
 - For whom was it meant for?
 - 2) What kind of projects is this group involved in and how does it help sustain the group as a whole?
 - 3) What was the source of the capital for these group projects?
 - 4) What are some challenges the group faces in general and how do you cope with the challenges?
 - 5) In your own opinion, what do you think are the advantages and disadvantages of this group?
Please explain
 - 6) What are the future plans for the group? (e.g. expand, improve)

C. Question List for HIV/AIDS Infected Women

Name of community/meeting place:

Name of Self Help Group:

Number of Women:

Number of Women present:

Date:

Personal Details:

- Age:
- Marital status: Never Married() Married/Free Union() Separated/Divorced() Widowed()
- How long have you lived in this community/village?
- What is your highest level of education?
 - a. No formal education (What is/are the reason(s)?)
 - b. Primary education and graduated ()
 - c. Secondary education and graduated()
 - d. Tertiary Education and graduated ()
 - e. Primary education and did not graduate()
 - e. Secondary education and did not graduate()
 - f. Tertiary Education and did not graduate ()
- Who is the head of your household?
- How many members are in your household?

- What do members do for a living?
- What were you doing for a living before you joined this group/association? Why or why not?
- How and why did you come to know this organization/SHG?

Impact of HIV/AIDS:

- ❑ Health Impact
 1. How long have you known your/their HIV/AIDS status?
 2. How has knowing this affected on your physical and emotional status?
- ❑ Financial Impact
 3. What were and are now your income sources?
(Have you had to sell any property/asset in order to pay medical bills for example?)
 4. How has income sources affected you and your household?
- ❑ Social Impact
 5. What things in your life have changed since you has known your status? (Coping strategies: solidarity groups? Reconnecting with family members?)
 6. Are you part of any other community group/ association in this village?
- If yes, which group/association? How does being part of a group help you and your household? If No, why not?

Expectations of the SHG:

7. What were your expectations of this SHG before you joined?
 8. Are your expectations of this SHG being met so far?
 9. How do you foresee this Self Help Group in the future? (Would it still be dependent on the Catholic Diocese if it still is or would it be standing on its own and helping other groups as well?) Why or why not?
- ❑ Health Expectations
 10. In what way(s) has being a part of this group helped improved your emotional and physical status?
 11. In what other way(s) do you expect this association with this group to help your physical status?
 - ❑ Economic Expectations
 12. What do you do to sustain you and the household with the exception of group activities?
 13. How do you think being a part of this group has helped you reduce your poverty level?
 - ❑ Social Expectations
 14. In what way(s) has being a part of this group helped you deal with stigma in the community?
 15. In what way has this group improved on creating social networks for you?
 16. How has your overall status in the community changed since you have been a part of this organization? In terms of the following: Belongingness/acceptability & self appreciation/image
 17. In which ways has the group activities influenced you and your household's wellbeing positively?

Challenges and Coping Strategies:

18. What in your opinion are some of the difficulties in this microfinance initiative?
19. What do you think are the economic benefits of this SHG in you and your household's wellbeing?

This concludes our interview. I would like to thank you very much for helping us. I appreciate the time that you have taken to answer these questions. I realize that some of these questions may have been difficult to answer, but it is only by hearing from women like you about their firsthand experiences that we can understand how to improve the lives of women especially, who are living with HIV. If you have any questions or comments, feel free to ask.

Time of interview:

D. Questions for HIV/AIDS Affected Women

Name of community/meeting place:

Name of Self Help Group:

Number of Women:

Number of Women present:

Date:

Personal Details:

- Age:
- Marital status: Never Married() Married/Free Union() Separated/Divorced() Widowed()
- How long have you lived in this community/village?
- What is your highest level of education?
 - b. No formal education (What is/are the reason(s)?) b. Primary education and graduated ()
 - d. Secondary education and graduated() d. Tertiary Education and graduated ()
 - g. Primary education and did not graduate() e. Secondary education and did not graduate()
 - h. Tertiary Education and did not graduate ()
- Who is the head of your household?
- How many members are in your household?
- What do members do for a living?
- What were you doing for a living before you joined this group/association? Why or why not?
- How and why did you come to know this organization/SHG?

Impact of HIV/AIDS:

- ☐ Health Impact
 - 20. For how long has HIV/AIDS been in your household and who is infected?
 - 21. How has knowing this affected on your physical and emotional status?
- ☐ Financial Impact
 - 22. What were and now are your income sources?
(Have you had to sell any property/asset in order to pay medical bills for example?)
 - 23. How has income sources affected you and your household?
- ☐ Social Impact
 - 24. What things in your life have changed since you has had HIV/AIDS in your household?
(Coping strategies: solidarity groups? Reconnecting with family members?)
 - 25. Are you part of any other community group/ association in this village? If yes, which group/association? How does being part of a group help you and your household? If No, why not?

Expectations of the SHG:

- 26. What were your expectations of this SHG before you joined?
- 27. Are your expectations of this SHG being met so far?
- 28. How do you foresee this Self Help Group in the future? (Would it still be dependent on the Catholic Diocese if it still is or would it be standing on its own and helping other groups as well?) Why or why not?
- ☐ Health Expectations
 - 29. In what way(s) has being a part of this group helped improved your emotional and physical status?
 - 30. In what other way(s) do you expect this association with this group to help your physical status?
- ☐ Economic Expectations
 - 31. What are you doing for yourself excluding group initiatives? How do you think being a part of this group has helped you reduce your poverty level?
- ☐ Social Expectations

32. In what way(s) has being a part of this group helped you deal with stigma in the community?
33. In what way has this group improved on creating social networks for you?
34. How has your overall status in the community changed since you have been a part of this organization? In terms of the following: Belongingness/acceptability:
Self appreciation/image:
35. In which ways has the group activities influenced you and your household's wellbeing positively?

Challenges and Coping Strategies:

36. What in your opinion are some of the difficulties in this microfinance initiative?
37. What do you think are the economic benefits of this SHG in you and your household's wellbeing?

E. Adopted Stigma Related Question List

1. How long ago did you have your first HIV test
2. What was the reason for your having a test? *Mark all that apply. Do not read options.*
 Partner--partner's past sexual behavior () Partner--partner ill or died ()
 Child--child ill or died () Exposure--your own past sexual behavior ()
 Exposure--blood transfusion () Exposure--taking care of people with HIV or AIDS
 Exposure--contaminated instrument () Symptoms/health--hospitalization for a reason ()
 Symptoms/health--giving blood () Future plans—marriage ()
 Future plans--having children () Do not know ()
 Other, please specify... Declined to answer ()
3. Was it hard for you to be tested for the first time?
 Yes, hard () some-what hard () No, not hard () don't remember () Declined to answer ()
 Why / Why not?
4. After giving you your test results, did any health care provider do the following?
 Refer you for medical care? ()
 Talk about getting help from a support group for people living with HIV or AIDS? ()
 Refer you to a support group for people living with HIV or AIDS ()
 Nothing was done () Do not remember () Declined to answer ()
5. Please indicate whether you strongly agree, agree, unsure, disagree or strongly dis-agree with each of the following statements:

	strongly agree	agree	unsure	disagree	disagree strongly	Declined to answer
People with AIDS deserve blame for getting the disease						
Patients with AIDS do not have the right to the same quality of medical care as other patients						
Women who are HIV-positive should be prevented from having children						
People suspected of having HIV should be required to be tested						
AIDS is a punishment for bad behavior						

6. Have you heard of people who have been badly treated because they had HIV?

Yes () Please explain No () Declined to answer ()

7. Do you personally know anyone who has had any of the following experiences in the past twelve months because they had HIV or AIDS?

	Yes, I do	No, I do not	Declined to answer
Excluded from social events?			
Abandoned by spouse/partner?			
Abandoned by other family members?			
Verbally abused or ridiculed?			
Fired from work or lost their job?			
Expelled from their home?			
Had property taken away?			
Denied health services?			

8. Do you know of any other support groups in this area for people living with HIV or AIDS?

Yes () Name of group and its activities: No () Do not know () Declined to answer ()

9. Would you say you generally keep your HIV status a secret from most people?

Yes () No () Unsure () Declined to answer ()

10. Who have you shared your HIV test results with? *Mark all that apply.*

Spouse or partner () Children () Sibling () Parent () other relative () Friend ()

Other, please specify: No one () Why have you chosen not to share your HIV status with anyone?

11. Do any other people in your community know that you are HIV-positive even though you did not tell them?

Yes () No () Do not know () Declined to answer ()

12. Do you intend to tell anyone else your HIV status in the future?

Yes () No () Do not know () Declined to answer

13. How did you expect your family or friends would react when they found out you are HIV positive?

14. Please think of one person whose reaction was the most disappointing to you and say their relation to you (probe: spouse, children, and friends).

- How did they know that you are HIV positive?
- How did this person first react when they found out about your HIV status
- How is this person acting now?

15. Please think of one person whose reaction was more supportive or encouraging and say their relation to you (probe).

- How did they know that you are HIV positive?
- How did this person first react when they found out about your HIV status
- How are they acting now?

16. Just to confirm, are you taking ART to manage your HIV?

Yes () How long ago did you first start taking antiretroviral therapy to manage your HIV? No ()

17. Is it ever difficult for you to take your ART when someone from your family can see you?

Yes () Please explain. No () Declined to answer ()

18. How would you rate your health before starting ART? Please explain

Excellent () Very good () Good () Poor ()

19. Now that you are taking ART how is your health? Please explain

Excellent () Very good () Good () Fair () Poor ()

20. Have you personally ever been made to feel bad because of things people did or said to you on account of your HIV status?

Yes () Can you tell me what happened? No () Declined to answer ()

21. Kindly indicate whether you agree, are unsure or disagree with the following statements:

	Agree	Unsure	disagree	declined to answer
Some people avoid touching me once they know I have HIV				
Some people seem uncomfortable being around me once they learn I have HIV				
Some people act as though it is my fault I have HIV, or say I deserve it for things I have done				
I sometimes feel bad about myself because I am HIV positive I sometimes feel guilty because I have HIV				

F. Depression Testing (by Ivan Goldberg, M.D). Kindly note that this test is not exclusively meant for diagnosing depression without first checking with a medical doctor. The 18 questions refer to your feelings and behavior in the last week. Kindly choose the appropriate item.

	Rarely/none of the time	Some/a little of the time	Occasionally/ moderate amount of time	Most/all of the time
I do things slowly				
My future seems hopeless				
It's hard for me to concentrate on daily chores				
The pleasure and joy has gone out of my life				
I have difficulties making decisions				
I have lost interests in aspects of life that used to be important to me				
I feel sad, blue (let down) and unhappy				

I am agitated and keep moving around (I'm restless)				
I feel fatigued (I'm always tired)				
It takes great effort for me to do simple things				
I feel that I am a guilty person who deserves to be punished				
I feel like a failure				
I feel lifeless_ more dead than alive				
My sleep has been disturbed : too little, too much, or broken sleep				
I spend time thinking about how I might end my life				
I feel trapped or caught (in this life)				
I feel depressed even when good things happen to me				
Without trying to diet, I have lost or gained weight				

24. What have been the most difficult things that have happened in your life since you found out your HIV status?

25. Have there been any good things that have happened in your life as a result of knowing your HIV status?

Yes () kindly explain No () Do not know () Declined to answer ()

26. Since you have known your status, what kind of support have you received from the government or any other AIDS support organization?

Financial () Food () Emotional () other () Please specify

27. Do you think that knowing your HIV-positive status has been good for you overall?

Yes () No () Unsure () Declined to answer () Why / Why not?

28. Do you have any suggestions for ways that microfinance organizations or other NGOs can help improve the lives of people living with HIV in this community?

Scoring the Psychological Questionnaire: for All questions under 23.

If the score is...	You may have...
54 & up	Severe depression
36 – 53	Moderate/severe depression
22 – 35	Mild to moderate

	depression
18 – 21	Borderline depression
10 – 17	Possible mild depression
0 – 9	No depression likely

More information can be accessed on: <http://psychcentral.com/depquiz.htm>

- It should be noted however that the table above is not meant as a diagnosis tool.

This concludes our interview. I would like to thank you very much for helping us. I appreciate the time that you have taken to answer these questions. I realize that some of these Questions may have been difficult to answer, but it is only by hearing from women like you about Their firsthand experiences that we can understand how to improve the lives of women especially, which are living with HIV. If you have any questions or comments, feel free to ask.

Time of interview:

Additional interviewer notes:

Appendix II: Map of Kenya Showing the All Districts including Kitui



Source: http://www.bushdrums.com/news/districts_of_kenya.php

Appendix III: Field Photographs

Impacts of HIV/AIDS here are the death of spouses and children as seen in first picture and the burden of taking care of orphans at an old age.



Groups and interactive processes: Wii Community Bakery HIV/AIDS Affected Group



HIV/AIDS Affected Group by the Catholic Church just before discussion Part of the Katethya



Seeking information in Muthale Mission Hospital and a discussion with a nurse from Kitui District Hospital and one of the HIV/AIDS Groups on living positive



Some examples of Group Initiatives: chicken rearing, vegetable gardens/farms



Appendix IV: Check Your Facts

What is HIV?

The letters 'HIV' stand for Human Immunodeficiency Virus. Viruses are the smallest of all disease-causing organisms. HIV only infects human beings, and attacks the body's immune system. Sometimes HIV is called the AIDS virus, because being infected with HIV can lead to AIDS. But having HIV infection is not the same as having AIDS.

How does HIV affect the body?

The virus destroys a type of white blood cell. These white blood cells have an important role in the immune system which protects the body against illnesses. Soon after being infected, some people may suffer flu - like symptoms for a week or two, but otherwise there are no signs of early HIV infection. Once infected, a person is infected for life and as yet there is no cure, either through traditional or modern medicine. A person infected with HIV (or who has AIDS) can pass on the virus to someone else. The virus may remain inactive for many years, and this is why people who have HIV often stay healthy, and look the same as people who do not have the virus. If the virus becomes more active, it can damage the immune system considerably and the body becomes less able to resist illnesses.

What is AIDS?

AIDS stands for Acquired Immune Deficiency Syndrome. Getting (acquiring) HIV infection leads to a weakened (deficient) immune system. This makes a person with HIV vulnerable to a group of symptoms (syndrome) and illnesses that a person without the virus would be unlikely to be affected by (opportunistic infections). It is the development of these illnesses that leads to a diagnosis of AIDS. They can develop from within a few months to over ten years after initial HIV infection. The time taken depends on the infected person's state of health and other factors, like access to treatment.

What is the HIV test?

The HIV test detects whether someone's blood has developed antibodies to HIV. Although the test does not detect the virus itself, having antibodies to HIV means that the person is HIV-infected (antibody positive, seropositive or HIV-positive). If there are no antibodies, the person is antibody negative (seronegative or HIV-negative). However, the test result can be negative if the person has been infected only recently, because it can take up to six months from the time of infection for antibodies to develop. This is called the 'window period'.

How do you get infected with HIV?

HIV is found in an infected person's body fluids, mainly in blood (including menstrual blood), semen and vaginal secretions. The virus is not that easy to catch. For HIV to be transmitted, it must pass from someone's infected blood, semen or vaginal secretions directly into another person's bloodstream or body tissues, often through the mucous membranes lining the inside of the vagina, penis or rectum. The virus cannot pass through unbroken skin. The virus has also been found in breast milk. There is a risk of transmission from an infected mother to her baby, during pregnancy or delivery, or through breastfeeding. This could apply to about a third of all babies born to mothers who have been infected with the virus, although as yet it is not possible to measure the level of risk in each individual case or to say exactly when or how the virus is passed on. Very small amounts of the virus have been found in saliva, tears, vomit, faeces and urine, but there is no evidence that these fluids transmit infection. HIV has not been found in, and is not transmitted by, sweat.

What is high risk behavior?

High risk behavior means activities that increase the risk of infection for you or someone else. It is not always possible to know who has HIV and who does not, including yourself (unless of course you know

that you and/or your sexual partner are HIV-positive). The following activities are therefore always very risky to other people and yourself:

- Having penetrative vaginal or anal sex (where the penis enters the vagina or anus), without using a condom. This is called unprotected sexual intercourse. The more partners you have unprotected sex with, the higher the risk of infection. Women and men can infect each other through unprotected vaginal or anal sex. The risk of transmission from a man to a woman is higher than from a woman to a man. Men can infect each other through unprotected anal sex.
- Using unsterilized needles and syringes, or cutting instruments, on yourself or someone else, that have been used and therefore are likely to be contaminated by another person's blood.
- Receiving an infected blood transfusion.

How is the virus not transmitted?

The virus can survive only in the body fluids inside a living human body. Once blood and other body fluids are outside the body, HIV survives for only a few hours. Also, HIV cannot pass through unbroken skin. HIV is not spread through casual contact: touching someone who is infected, or something they have used; through sharing eating or drinking utensils, or through using the same toilet seats or washing water.

Can mosquitoes spread HIV?

HIV is not transmitted by mosquitoes or other blood-sucking insects. This is because most insects inject saliva, not blood, when they bite a human. The parasite which causes malaria enters the bloodstream in mosquito saliva. Hepatitis B, which is much more infectious than HIV, is not spread by insects either.

Please write to AIDS Action with any other questions!!!!