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WOMEN AND HIV/AIDS: CHALLENGES AND COPING MECHANISMS OF WOMEN LIVING WITH HIV/AIDS IN UGANDA:
The Case of National Council of Women Living with AIDS (NACWOLA) in Arua District

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Candiru Josphine
(UGANDA)

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Members of the examining committee:

Dr. Bridget O'Laughlin
Drs. Loes Keysers

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Disclaimer:

Inquiries:

Postal address:	Institute of Social Studies P.O. Box 29776 2502 LT The Hague The Netherlands
Location:	Kortenaerkade 12 2518 AX The Hague The Netherlands
Telephone:	+31 70 426 0460
Fax:	+31 70 426 0799

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I dedicate this piece of work to my Dad Rev Dr John Milton Anguyo and Mum Mrs Rose Anguyo for the care, support and love that you gave me from childhood up to now, I will forever be grateful.

TABLE OF CONTENTS

LIST OF TABLES AND FIGURES

LIST OF ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ARVs	Anti -retroviral drugs
BBC	Promote Behaviour Change Communication
CBO	Community Based Organization
CHICC	Community Health Information and Care Centre
DRC	Democratic Republic of Congo
Govt- MOH	Government of Uganda Ministry of Health
HAART	Highly Active Anti-Retroviral Therapy
HIV	Human Immunodeficiency Virus
HSSPP	Health Sector Strategic Plan
IEC	Information Education Communication
IK	Indigenous Knowledge
ILO	International Labour Office
MDGs	Millennium Summit Development Goals
MSF	Medecins Sans Frontiers
MTAC	Micro finance Tools in AIDS Care
NACWOLA	National Community of Women Living With AIDS
NGOs	Non- Governmental organizations
OVCs	Orphans and vulnerable children
PHAs	People Living with HIV/AIDS
PLWA	People Living With HIV/AIDS
PMTC	Prevention to Mother to Child Transmission
ROSCA	Rotating Savings and Credit Association
STDs	Sexual Transmitted Diseases
TASO	The AIDS Support Organization
TAWG	Tanga AIDS Working Group
TB	Tuberculosis
TVAAP	Tivoneleni Vavasati AIDS Awareness Project
UAC	Uganda AIDS commission
UNAIDS	United Nations Joint Programme on AIDS
VCT	Voluntary counselling and Testing
WB	World Bank
WHO	World Health Organization

CHAPTER ONE:

GENERAL INTRODUCTION

1.0 Introduction

AIDS is slowing down development efforts and exacerbating poverty in Sub-Saharan African. According to Miller (1988: xi), "HIV/AIDS is a triple disaster to Africa. First, the tragedy of the disease itself; secondly, the human suffering and thirdly the death", this triple disaster complicates the already "daunting development problems facing the continent and threatens to reverse the hard- won advances" (ibid). HIV/AIDS is a major killer of adults at the peak of their reproductive and economic lives in most African countries (Boyle et. al 2006:1). In Uganda, particularly HIV/AIDS reduced Uganda's economic, political and social development.

People living with AIDS (PLWAs) face many problems due to their ill health. They are prone to income poverty, through loss of jobs. Those that are employed in the informal sector leave their work because of physical weakness.

Women in particular feel the impact of HIV/AIDS, as caregivers, patient's producers and participants. "Epidemiological estimates indicate that women are the most greatly affected by HIV/AIDS epidemic in sub-Saharan Africa, they constitute almost 57% of those who are infected with HIV/AIDS" (ibid:3). Moreover "women are at particular risk of contracting HIV/AIDS for both biological and social reasons, such as gender inequality, economic dependency on men, women marry early, rape and women have no ability to negotiate sex" (Delong 2003:15). Women are the main care providers and some of them are living with HIV/AIDS. They care for the patients, taking care of the orphaned children and of themselves as patients (ibid).Women are more likely to feel more stigmatized when they are known to have HIV/AIDS.

Many mutual help organizations have developed to assist PLWAs to deal with their many burdens. One is the National Council of Women Living with AIDS (NACWOLA) in Arua, Uganda. This research asks how members of NACWOLA deal with their burdens of living with AIDS. It assesses whether/how membership in the organization helps its members to deal with these burdens. It asks whether participation in the organization is itself a burden that only certain women can bear. This is important because these women seem to be coping with their positive sero-status despite many burdens they face as a group and individuals.

1.1 Background

Uganda was the first African country hit by AIDS epidemic in 1982 and the first African country to reduce on prevalence rate (Flynn 2003:5). Adult prevalence declined from 25 percent in early 1990s to around 5 percent in 2001, (Govt-MOH, 2000). This achievement was realized through countrywide mobilization and sensitization on HIV/AIDS, use of condoms, provision of ARVS among other things (ibid: 7). However, there is a current increase in prevalence rate from 6.1 percent - 6.2 percent (Kirugi et. al, 2004:37)[1].

The Joint United Nations Program on HIV/AIDS (UNAIDS 2006) estimates out of 28,816 population around 91,000 deaths due to HIV/AIDS in 2005 in the country, an estimated 1,000,000 number of PLWAs. Women in the age cohort of 15-49 living with AIDS are 520,000. Furthermore, World Health Organization (WHO) estimated that about 6.7 percent of adults were living with the virus in 2005. The country has low life expectancy, as estimated to be 48.3 years (De Waal 2003:9). This led to low education attainment due to high school drop out rate of orphans and high death rate of teachers, ultimately affecting economic growth and income poverty since majority of those who died are breadwinners (ibid). In addition,

> "[t]he impact of HIV/AIDS which has been felt across Uganda, bears both a social and economic cost. HIV/AIDS has reduced the size of labour force and quantity of land under cultivation has diminished, as a consequence, income and food security are threatened" (Musaka et. al, 2001:6).

1.2 HIV/AIDS in Arua

In Arua District, HIV/AIDS pandemic has lasted for more than 20 years just like in other parts of the country. The pandemic is a threat to development in the district. It has led to declining productivity and food shortage especially in affected households. In addition, HIV/AIDS has led to increased number of orphans and vulnerable children, poor health and low education levels (HSSPP 2003: 1). HIV/AIDS prevalence in the district is 2.3 percent, which translates to about 10,563 persons in the population are infected with HIV/AIDS. According to health sector strategic plan

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[1] These prevalence figures have been, contested by Allen (2005) on the bases that the data presented on the prevalence was not accurate. He argued that the prevalence rate for Uganda are, mainly got from antenatal surveillance, first of all the testing is carried out in selected clinics, secondly HIV positive women are unlikely to get pregnant. Another argument is that the prevalence might have dropped in certain parts of the country not all the parts of the country especially the northern part of the country; where there is war, the prevalence is high. Finally, it is hard to get the data from men who are unlikely to go for voluntary testing.

(HSSPP) survey conducted in 2003, 70.1 percent of people in Arua had a relative, friend or colleague with HIV/AIDS (Arua District HIV/AIDS Strategic plan 20006:1-2).

In the district, women are the main caregivers to AIDS patients and some of the women are living with HIV/AIDS. At the same time, they have to provide food and pay medical bills in the hospitals for their sick husbands and children. They provide them with care, love and support during such tough periods, care that involves bathing them, washing their soiled clothes, provision of food and medicine among other things. These infected women face stigma because of their HIV/AIDS status. Again, due to the impact of the pandemic, most of the women living with AIDS are living in poverty situations; some of the women are more vulnerable to poverty than other women, especially those who are not employed.

There are differences among women in the burdens of AIDS. Those that live near the urban centres have better access to hospital facilities like Anti retro Val drugs (ARVs) and antibiotics, while the rural women have poor access to such facilities because of the distance to services. This is a major problem facing rural women living with AIDS in Arua district. The ARVs service that is free is only in urban centre, which is too far for the rural women making issues of accessibility and availability at all times so hard, and impossible (Arua district health survey report 2003:15). Yet ARVs are supposed to be taken on daily basis, if not taken it can complicate ones health. Most women are poor and have low income to use for transport in order to access such services.

Furthermore, women living with HIV/AIDS have major differences in kinship and community support services offered to them. In some communities, support given to such women is weak and at times, no support is offered to them, while other communities are more organized. They give them better support in the form of taking care of them when they are ill, collecting firewood and fetching water for the women.

The NGO, NACWOLA was founded by three women living with AIDS in Uganda in 1992, with the aim of uniting women living with HIV/AIDS. The purpose of this initiative was to improve quality of life by fighting stigma, sharing information among them, prevent further spread and empower women economically by encouraging women to do farm activities, to sell some in the market and engage in income generating activities. Home based care as a support is another strategy for nursing by group members that are not bed ridden, that help their friends that are sick and weak to take care of themselves, for example, collection of water, firewood and preparation of food (NACWOLA 2004 national report).

NACWOLA has more than 50,000 members; it is operating in 23 districts of Uganda (NACWOLA 2002/03:2). The program was, established in Arua District in 1994. Out of 32 sub-counties, it is active in eight sub-counties namely Olli, Pajulu Dadamu, Oluko, Adumi, Vurra, Arua hill and Manibe. Today NACWOLA Arua has 380 women benefiting from the organization.

1.3 Problem Statement and Research Objective

Many believe that, people living with HIV/AIDS cannot cope with the situation. For example, a World Bank report stated that in most cases coping strategies developed by communities affected by HIV/AIDS leads to poverty and increased vulnerability (World Bank 1999:11). Nevertheless, women in NACWOLA seem to cope with the sero-status. This study seeks to establish their story. This study attempts, to find out how mutual help organization such as NACWOLA help women cope with the burdens of living with AIDS. I hope that others might learn from NACWOLA's experience and that it could be replicated in other parts of Arua district in particular and the country as a whole.

1.4 Definition of coping

Different authors, define coping differently, according to Rugalema (2007:538) "coping in every day English is to deal successful with a difficult situation. This means to cope is to overcome a difficult situation" [...] "Coping process is achieved through a strategy [...] is a general plan or set of plans intended to achieve something" (Rugalema, 2007). Other authors define coping as, "Coping is a way of escaping from the challenge of confronting how people's capabilities are stunted and how their entitlements are blocked" (Barnett and Whiteside 2002 quoted in Loevisohn 2003:15).

For the purpose of this study, coping mechanisms refers to activities, values, structures that enable women living with AIDS to live, despite physical and sometimes psychological weakness, building resilience and survival strategies to be happy and move on with life.

Coping further means the support offered to women living with HIV/AIDS from mutual support organizations, friends, relatives, government and community like economical, psychological, nutritional and drug support especially access to ARVs.

This is reflected in the longer period that these women live with AIDS, whereas not coping is manifested through mortality, inadequate food, lack of money and high level of stigmatization hence, shorter duration living with AIDS.

(Ulins 1992 quoted in Bujra et.al 2000:1) notes, "The solidarity of women in rural Africa communities may be their greatest strength for coping with AIDS epidemic" (Bujra et. al 2000). This idea seems to work for NACWOLA members, which is yet to be explored in this paper.

1.5 Research Question

What can be, learned from the experience of NACWOLA, about how support organizations can help women living with HIV/AIDS?

1.5.1 Sub-questions

1. What are the problems that confront different groups of rural Ugandan women living with the burden of AIDS?

2. How do people living with HIV/AIDS cope with the burdens?

3. How does NACWOLA an AIDS Support Organization, help members to deal with the burdens?

4. Does belonging to the organization place an added burden on women living with HIV/AIDS?

1.6 Significance of the Study

This study seeks to assess the lessons that can be drawn from the experience of NACWOLA for support organizations for rural women living with AIDS in Uganda. Understanding coping mechanisms may give a ray of hope to those who are living with HIV/AIDS and are not aware of the importance of being in a group and being open about one's status. This study will help policy makers to put better strategies in place for women living with HIV/AIDS to cope with the situation.

NACWOLA has been chosen as the focus of the study because it is the only women's organization dealing exclusively with women living with AIDS regardless of age and marital status (although the majority of these women are widowed). Other organizations have both women and men living with AIDS.

In addition, Arua district has been chosen because the study data collection was, done by the use of local language in order to assist the researcher administer the questionnaires.

1.7 Limitation

The study focuses on those women living with AIDS, NACWOLA members and some non-NACWOLA members in Arua only; given the financial and time limitations, made it impossible to study the whole country.

Since the study used research assistants who were not supervised, the researcher cannot valid some of the findings with her own observation.

1.8 Methodology

The study used a mix of secondary and primary sources of data. For primary data, the study interviewed 10 non- NACWOLA members and 20 NACWOLA members, out of 380. These members of NACWOLA were selected through purposive sampling, each sub county selected 2 interviewees for in-depth interviews, the women were classified into four categories, 1.married 2.widowed 3 Working 4.unemployed. The category of women interviewed adequately answered my research questions adequately for example the question on how do women living with HIV/AIDS in NACWOLA cope with the burdens despite their sero-status.

Interviews were conducted, by the use of structured questionnaires that were administered to both NACWOLA and non-NACWOLA members. The women who were, interviewed were characteristically HIV positive, in order to compare their lives before and after joining NACWOLA. This enabled the researcher to gage the impact of the organization on the lives of these women. Some life histories have been, compiled to understand the problems faced by women living with AIDS and explore how NACWOLA helps women to deal with their burdens. In addition, a focus group interview was, conducted with NACWOLA officials in order to assess their activities in helping women living with HIV/AIDS to cope with multiple burdens.

For the primary data collection, the study used Mrs Eribo Peace and Ms Aitaru Becky, research assistants in Arua, for interviews using the structured questionnaire. The answers were recorded, transcribed and subjected to content analysis of the questions as perceived, by NACWOLA members and Non- NACWOLA members.

In addition, the study used secondary data, whereby the existing literature of ministry of health, District reports and NGO reports were be consulted. To identify problems of women living with AIDS in Africa and rural mutual group organizations in Africa, that are helping people living with HIV/AIDS to deal with challenges of HIV/AIDS. Identify the different coping mechanisms of dealing with the different challenges in Rural Africa and NACWOLA reports were reviewed to assess the activities that are being, offered to the members to cope with their burdens.

Figure 1: The strategy for answering the research questions

Questions	**Source of information**
1. What are the problems the different groups of rural women in Uganda confront in living with the burdens?	Interviews with members of NACWOLA Review of reports on problems different groups of women confront with the burdens in rural Africa.
2. How do people living with AIDS cope with their burdens?	Review of existing literature on mutual help group that exist in rural Africa.
3. How does NACWOLA's support help members to deal with the burdens?	Interview with members of NACWOLA and staff of NACWOLA
4. Does belonging to the organization place an added burden on women living with HIV/AIDS?	Interview with NACWOLA members

1.9 Structure of the paper

The following chapters aim to answer my research questions, by unpacking the areas of discussions and answering the proposed questions. Chapter 2 develops my main analytical frame. It discusses problems of women affected and infected with AIDS in rural Africa and their coping mechanisms. It looks at mutual support organizations in rural African and government interventions for people living with HIV/AIDS. Chapter 3 discuses quintuple burdens of women living with AIDS in Arua District. Chapter 4 discuses, the difference NACWOLA makes to women coping with AIDS and explores the lessons learnt from NACWOLA experience. Chapter 5 draws conclusions and recommendations from the case.

CHAPTER TWO:

PROBLEM OF RURAL WOMEN INFECTED AND AFFECTED WITH AIDS AND HOW THEY COPE

2.0 Introduction

This chapter develops a framework for analyzing specific problems of women living with HIV/AIDS and their capacity to cope. It particularly looks at whether mutuality enables women to cope. In order to discuss the different problems I used Moser's theory/framework of women's triple roles in the community.

2.1 **Theorizing women: multiple burdens:** Moser (1993:48-49) "developed a triple roles schema to draw planner's attention to the way in which the gender division of labour places a range of demands on women's time and impact on their ability to participate in planned interventions"(ibid). These triple roles are; first, productive roles that comprises of production of goods and services for consumption and trade for example farming, fishing, employment and self-employment, which generates income in kind or cash and have an exchange value. Secondly, reproductive roles which, refer to childbearing / rearing responsibilities and domestic tasks done by women who are required to reproduce and maintain labour force. Lastly, community management roles involve women's activities at the community level, as extension of their reproductive role, in order to ensure the provision and maintenance of collective consumption resources for example, water, health care and education (Miller 1998).

For the purpose of this study, the triple roles shall be expanded to quintuple roles or burden because the gender concerns indicate the burdens of women living with HIV/AIDS, will be heavier than those of other women. These are reproductive roles, productive roles, stigmatization, and participation in an organization that takes a lot of their time to do productive work and own health / illness. The two new burdens missing in Moser's framework are own illness and the stigmatization that women living with HIV/AIDS bear.

Stigmatization is a new burden that has been, put in play by HIV/AIDS, which affects the patients. The stigma is both an inbuilt and community burden that these women face.

Own illness is a cross cutting burden, it cuts across the four burdens, and it is because of own illness that these burdens are faced more by these women living with HIV/AIDS.

Platteau (1991) explains, the issue of risk pooling in order to reduce vulnerabilities. This is how mutual support organizations helps its members to cope, however he noted that there is limitation in risk pooling where co-variance of risks is high. The mutual support organizations face this limitation, because of high co-variance of risk. Every one in the organization faces some risks for example productive, reproductive, participation, stigmatization and own illness burdens.

Belonging to an organization, in itself is a form of burden, in terms of the time spent for participation in the organization for carrying out activities like collection of water and firewood, weeding and other farming activities, taking care of the ill patients in the hospital. However, participation is a form of burden only for women who are in mutual support organizations.

2.2 Impact of HIV/AIDS on Reproductive Roles

HIV/AIDS has affected reproductive role of women negatively, it has increased women care burden. The fact that, care for those affected by HIV/AIDS falls disproportionately on females is a major concern (Danziger 1994; UNAIDS 1998; Latre-Gato 1999; Baden and Wach 1998; Manopaiboonet. al. 1998; Baylies 2002; Marcus 1993; Upton 2003). In line with traditional female roles, women often take up the responsibility of caring for the sick, their children, and orphans from extended families. "This care takes a heavy toll, economically, physically and psychologically, as women may be economically vulnerable themselves and may also be infected with HIV/AIDS" (Nguyen et. al 2004:24). This explains why women face more care burden in the HIV/AIDS era.

According to international Labour Office, "HIV/AIDS is a threat to gender equality. Women are highly vulnerable to HIV/AIDS for both biological and cultural reasons, when a male head of the household falls ill, the burden of caring for orphaned children is borne mainly by women" (ILO; 2000:1). These are challenges that women have to face in every day aspect of life with the pandemic.

Women are faced with burden of caring for ill health because of HIV/AIDS. A focus group discussion carried out by Donahu et. al, (2001:3) in Uganda. Identified five different levels of care giving demands; firstly, the early stages when the first signs of AIDS appears, secondly, frequent hospital visits, thirdly, bedridden either at home or in the hospital, fourthly, death and burial expenses coupled with cooking during burial, finally, care for orphaned children. Some studies noted that, "Women withstand worst of AIDS more than men do; they take on greater share of burden of caring for the sick, when they themselves fall sick/ ill, women living with AIDS face more problem than men" (Panos 1990:37). The society takes it that it is the role of women to provide such care to PLWAs as theorized by Moser in 1993; these roles are done without pay.

Care work for sick and other household activities prevents women from participating in income generating activities that would empower them. This explains why most of the women are more vulnerable to income poverty. As Byanyima (2007) noted, "The more the burden of care falls on women in households and community, the less they are able to engage in activities that have the potential to empower them. In addition, women's care work in the context of HIV/AIDS has, a very high opportunity cost and an un-stainable impact on social and economic level. The extra burden of care and support for those infected and sick often means moving a way from productive agricultural work" (ibid). This leads to food insecurity and poor nutrition.

According to Merrill (1998:173), in Africa, where medical facilities and support services are inadequate, in most cases the responsibility of caring for relatives with AIDS and for the orphans of relative's dead of AIDS falls heavily on women. For example in Zambia nurses played an impersonal role, spend little time with patients, providing only medications, however, the routine nursing care such as bathing and feeding are done by women (Bond 1997:22). In Uganda, just like in Zambia female relatives do the routine nursing care for patients in the hospitals.

HIV/AIDS has in most cases impacted negatively on women's reproductive health decisions. Some have chosen not to bear children, with the argument of having HIV/AIDS positive children is useless. Some opt for abortion in case of unwanted pregnancy but a study done in America indicated that doctors fear carrying out an abortion for women living with HIV/AIDS, hence this affects their right to reproductive health (Squire 1993:31-33).

Women bear HIV/AIDS care burden, even when the children are for foster care in the community the relatives that take such burden are women in most cases. Rugalema (1999:73) said:

> "AIDS has triple effects in the community, firstly fostering of orphans by the relatives like uncles, ants grand parents and extended family members, secondly, providing labour or cash help for a sick person by relatives, neighbours'' children wife and extended family members. The labour for caring for the sick is mainly provided by the women in many cases and lastly provides for the survivors in the afflicted households."…. (ibid: 75).

Despite the impact of HIV/AIDS on reproductive roles, rural African societies have devised some mechanisms in order to cope as follows;

2.2 .1 Coping mechanisms for reproductive role

Coping mechanisms in Zambia according to the health workers is "to train community counsellors, who will work with families in providing care" […] hospital based team can act as a back up" Panos (1990; 67). The support groups offer care and they help to reduce the psychological impact of HIV/AIDS infection on individuals and the communities which, are done as part of reproductive work as recognized by Miller (1998), as community management roles, which is without payment. These coping mechanisms have been, recognized as a major base of coping mechanism for PLWAs in most African countries. However, it reinforces unequal division of labour and making women as main care providers to patients.

According to World Bank report (1997:182) home based care for PLWAs, that are initiated by communities are very effective way of coping with HIV/AIDS and the patients spend less time in the hospital, the amount of money spent in hospital bill are reduced. In addition, home based care programs help to increase the level of knowledge of the community on HIV/AIDS and stigmatization. However, this strategy increases the burden of care for women.

Further-more, Twesigye (1996 : 13-14) emphasized that, support from extended family is the primary source for coping for people affected and infected with HIV/AIDS, while the secondary assistance or help is normally provided by neighbours'' and friends.

> "These coping mechanisms' derived from family and social networks limit the impact of ill-health[…] colleagues may take on the labour or working responsibilities of the sick person, in the expectation of similar help when they need it (ibid: 14).

This strategy of coping has weakened in most African societies because of the increased burden of the pandemic, in almost every household.

Assistance from governments and non- governmental organizations helps rural African societies that are affected and infected with the epidemic to cope, by offering foster care for orphans and the vulnerable children, educational support on home care management and prevention measures, feeding post for OVCs and PLWAs and provision of basic household needs among others. However, the support in most cases does not reach to all the families affected and infected with HIV/AIDS due to inadequate funds, personnel and corruption (Twesigye1996: 220-221).

2.3 Impact of HIV/AIDS on Productive roles

AIDS affects household labour availability. The sick person is, incapacitated by AIDS related illness. His or her labour power is completely lost during death and illness of household member forces women to relocate labour from farm work to care hence reducing their changes of getting farm products and income-generating activities (Rugalema 1999:15). Inadequate labour for production leads to inadequate food in the households.

HIV/AIDS affects households' cash incomes because the sick person is unable to work to earn cash income. Besides, cash is spent on medical care and funerals. This leads to depletion of household income and saving (ibid: 16). These explain why most households that are affected with HIV/AIDS have poor living conditions and are more vulnerable to poverty. For example, in Tanzania,

> "all households in Bukoba village are, affected by the HIV/AIDS pandemic. In this village social life and economy is depressed by frequent deaths and every household has to contribute to every funeral in the village" (Rugalema 1999:73).

Panos (1990:50) recognized that "without the care women provide at home, governments would face vastly increased health costs". The care women offer include looking after the bedridden ill patients, provision of basic needs such as food, water, fuel for cooking and heating and finally the maintenance of a clean and sanitary environment. The study recognized the role of women, in provision of care that helps to cut or reduce the financial burden for governments in provision of health services to people living with AIDS. Yet the care work done by women is not counted in the national accounts of governments.

Moreover, within households, specific groups may be highly vulnerable to the impact of HIV/AIDS; particularly the women take on a "double burden of production and care taking. In most cases, their labour is, reallocated from producing income out side the home to care taking" (Loewenson 1997:31), making them more vulnerable to income poverty than men.

Conversely, rural African societies have put in place some coping mechanisms for the impact of HIV/AIDS on productive roles,

2.3.1 Coping mechanisms for productive role

PLWAs in Uganda and Kenya cope by "increased reliance on informal support such as Rotating Savings and Credit Association and accumulating savings [...]" (Patterson 2005:37). They rely on such credit associations for financial support. As per this position, coping mechanism depends on financial situation of clients in order to cope, those with low finance will not be able to cope.

Additionally, organizations that offer credits/loans are working in some parts of rural Africa to help families affected with AIDS to cope. "Most of these associations were launched and operated by women; many have regular meetings at which members make contributions in cash or in-kind" (Lwihula 1994 quoted in World Bank Report 2003:219). However, in most cases men control the loan money because they are the main decision makers and resource managers in most households, for instance this is a common problem in Uganda.

Dis-savings and sale of assets, thus "drawing down savings and selling of assets is an obvious potential mechanism [...] which is one of the least painful ways of coping, much less than reducing food consumption. For example evidence from Kagera and Rakai suggested that households do draw down savings or liquidate assets in response to a prime-age adult death" (World Bank Report 2003:217). However, this works when one has assets. Such strategy might leave the households in absolute poverty once all the assets are sold.

Another way of coping is to build "household resilience to the economic impact by a prime age adult which helps in society response to the generalized epidemic" and the societies are able to manage to cope with limited resources (World Bank Report 2003:214). In a household where there is an adult in a productive age, the person will use his/her labour to raise money to cope with economic crisis. This implies that if there is no adult in the household, such households will not be able to build resilience to economic impact given that AIDS kills productive age group, leaving skip generations to suffer with the consequences.

2.4 Stigmatization as a burden for people living with HIV/AIDS

Stigmatization and isolation are part of every day aspects of live, for PLWAs, which is a,

> "sign of discrimination and violation of human rights, especially job insecurity in the employment sector, for example screening tests of new entrants, in some agencies or non-governmental organization" (kyomuhedo 2003:17).

Women in general suffer more stigmatization than their male counter parts. "Many studies have shown that women are "blamed for bringing HIV/AIDS in the family" (Maria 2005:10) Women who are living with HIV/AIDS lose custody of children, at times abandoned and suffer violence by family members (ibid). Panos (1990) stated that stigma in Uganda affects particularly women. According to Amyire Byangire in Panos (1990:49) "when a woman is sick with AIDS, she is automatically considered a 'loose' women regardless of how she got the infection" (ibid). For example, in the Democratic Republic of Congo (DRC), "when a woman is positive, she will be sent back to her family, while the husband goes to live with another woman" (opt cit). This shows that women suffer stigmatization more than men's experience. Despite the care and support, they offer to AIDS patients.

Further more, stigmatization "due to HIV/AIDS causes reluctance to divulge individuals HIV/AIDS status even if one was very sick due to HIV/AIDS" (Nanambo, 2005:10). This further complicates the treatment of the disease because if the patients do not test; they are unable to get ARV drugs, hence making such patients more vulnerable to death within a short period.

International labour office (ILO;2000:9) stated that "where a person is known to be HIV positive, he or she is frequently the subject of stigmatization, discrimination, or even hostility in the community and work, particularly where the community members and colleagues have little understanding of HIV/AIDS". As a result, some PLWAs hide their status as long as they can to avoid stigma and discrimination.

In addition, a study carried out in Mukurdi in Nigeria among PLWAs showed high level of stigmatization and discrimination of PLWAs. One respondent noted that elites like health staff, discriminate them in service provision and according to her stigmatization kills faster than the virus (HIV) in Nigeria (Ojoawo 2006:23).

> "According to the respondents, they are discriminated. For example, a widow said, when her husband died and her relatives discovered he died of HIV, they suspected that she had the disease. When the relatives visit her, they refuse to enter her house because of fears of being infected. In fact neighbours' and friends tend to stay away from people like her, knowing they are HIV positive" (ibid: 23).

In Tanzania and Uganda widows of HIV/AIDS have been victims of property grabbing by their husbands families, often these widows are, forced off the property, she is left with no belongings and nowhere to go (Patterson 2005:27). HIV/AIDS worsens women's negotiation positions in households.

Due to the above-discussed stigmatization related to HIV/AIDS faced by PLWAs, in rural Africa, some coping mechanisms are in place, as follows,

2.4.1 *Coping mechanisms for stigmatization*

When people are infected with HIV/AIDS, they feel stigmatized. Counselling is one method of coping with stigmatization, through counselling PLWAs can change their mind set. In order to function well in the community thus a change of mindset from of rejection of having AIDS to acceptance of the sero-status, is necessary, because in most cases PLWAs face a lot of mental torture, since they are made to believe that they are about to die. This affects the way they live which can be reduced by counselling. This gives them more hope and desire to live longer and positively with the virus (Panos 1990).

Loewenson (1997:31) indicates clearly, that,

> "Managing the impact of the epidemic has to be two fold, first transmission of HIV/AIDS needs to be prevented to reduce the level of further spread and secondly the current HIV/AIDS epidemic needs to be managed in a socially sustainable manner".

By sensitizing people against discrimination of PLWAs, rather offer help to them. This helps to reduce the level of community level stigmatization of PLWAs.

In Uganda, PLWAs "speak out and get involved in the fight against the disease. This altitude of openness helps to remove the deadly feelings of guilt, shame and dereliction that often accompany AIDS". (Low-Beer and Stone Burner 2004 quoted in Patterson 2005:46). In the sense that, breaking the silence of ones HIV/AIDS status, helps them to overcome stigmatization from within and by the community.

According to Panos (1990:48) "drug therapy and medication may assist in alleviating physical manifestations of HIV infections but understanding and compassion, love and support are what helps PLWAs to see their future in terms of living with AIDS rather than dying with it". This implies that PLWAs can only cope well with the stigma, when they are given love and support by their spouses, relatives and friends. This helps them to live for a longer period than the medical solution that only helps to alleviate the physical symptoms not the emotional burden that kills the AIDS patients more frequently in most parts of the world. However, this depends; because some people need more than emotional care to cope.

2.5 Participation

The word participation has diverse meanings that have been attached to Participatory Rural Appraisal and participatory research. The "word participation is a route to growth of good practice, a path to iterative, self reflective movement forward" Cornwall (2003:33).

Participation in the organization activities by women living with HIV/AIDS seems to be another form of burden on these women. Given that these women have to care for HIV/AIDS patients, cook food, collect firewood and look for money to pay hospital bill among other things simultaneously they are expected to participate in the organization activities, which increases the burden that these women carry on because of their sero-status.

Carr noted that. "To recommend the introduction of income generating activities is unhelpful when the women have no extra time to indulge in them, almost every aspect of improved nutrition and hygiene has a time consuming element, would require diversion of time from other activities, such as food production, which would have a nutritionally detrimental effect" (Carr, 1979: 28). This is the same burden NACWOLA members have.

Participation in the organizations reinforces gender imbalance in division of labour, women have to work more hours for organization activities and home activities and in most cases these types of work is without pay. However, women have no other option because they also need the support from the organization: They have to continue with the participation burden.

2.5.1 Coping mechanism for participation

Coping strategy for participation in the organization could be by reducing the hours that women take to participate in such organization, so that they can have enough time to do their home activities.

Another strategy for participation is by giving support for these women without having to offer their time and labour to do organization activities. This has some implications, if mutual support organizations depend heavily on women's participation it might break down in the end if women stop to participate.

2.6 Own illness

Own illness is a cross cutting burden, the four burdens are felt more because of own illness, for PLWAs. The disease "makes immune system to collapse, leaving the AIDS patient susceptible to the opportunistic illnesses that are ultimately fatal, available treatments become increasingly expensive and their efficacy less certain" (World Bank 1998). They cannot carry reproductive and productive roles well because of physical weakness. Some of them end up losing their job, due to ill health; they may not perform according to the employer's expectation.

2.6.1 Coping mechanism for own illness

Use of ARVs by PLWAs is a way of coping with the disease, given that ARVs help to prolong lives of HIV/AIDS patients by improving their immunity levels. This gives them a chance to live longer than the expected, hence improved life expectancy with HIV/AIDS (MSF DRC report 2004). According to some patients, ARVs work well and improves their heath status. Getting treatment for HIV/AIDS related sickness on time is a good way of coping with own illness.

2.7 Government interventions for people living with HIV/AIDS in Uganda

Ugandan government managed to have a commission called Uganda AIDS Commission (UAC), which was established in 1992, with the aim of coordinating the implementation of multi-sectoral policy, which was adopted by the government in 1990 as a strategy to combat HIV/AIDS (Uganda AIDS commission report). "UAC exists to provide leadership in coordination of HIV/AIDS programs and activities of all stakeholders in Uganda through advocacy, joint planning, monitoring and evaluation for eventual elimination of AIDS scourge in Uganda" (UAC Annual report 2000:7). UAC has major roles in overseeing, planning and coordination of HIV/AIDS activities in public and private sector.

Giving care to PLWAs is what the government emphasizes by providing sensitization to communities on how to provide care and support to PLWAs. According to KII, AIDS Information Centre, "care requires a hands-on training for caregivers. It prepares them for appropriate action [...] therefore, sensitization is not enough; we need orientation and skills for caretakers" (Kyomuhedo 2003).

In Arua district, HIV/AIDS programs are in place with three major objectives, to prevent further transmission of HIV/AIDS, provide quality care, support to infected and affected, and build and strengthen the capacity of institution to manage HIV/AIDS.

However, most of the above objectives are not implemented due to inadequate resource base and personnel. As a result, many mutual support organizations have come in to play to help and implement HIV/AIDS related programs in the country.

2.8 Discussion on mutual support organizations

Mutual support organizations for HIV/AIDS in Africa for the last 15 years are providing care and support to people affected and infected with HIV/AIDS for example AIDS support organization (TASO). NACWOLA is one of AIDS support organizations that helps women living with AIDS to cope with their multiple burdens. The case study illustrates importance of mutuality in coping with AIDS specifically for women in Arua. HIV/AIDS care and support is defined as "set of interventions whose purpose is to mitigate the impact of the epidemic on individuals, communities and nation" (Girma and schietinger 1998).

The organizations are offering support to women living with AIDS because these women face multiple challenges posed by the pandemic. In Uganda, women are the most marginalized regardless of class, race and religion in aspects of health, education and employment among others, are making them more vulnerable to poverty. Moreover, they are the main caregivers to patients. The help offered in terms of home based care by organizations is to help to reduce the care burden.

According to Holden (2003: 168), many benefits accrue for being in a group and support organization. The benefits include a group purchase of land, which members can farm together so that they no longer have to rent land for growing food as with Action aid Burundi. Secondly, "the group is a source of mutual moral support among members, who provide financial assistance and labour, when one of them is ill" (ibid). Finally, loans/credits- saving from revolving loans help members to pay the daily costs associated with HIV/AIDS like medical bills and food.

Many mutual support organizations in rural Africa help members to cope with their burdens by pooling risks together. Gateway support group in Zimbabwe was formed in 1992 offers productive support by giving credits for women, affected and infected with HIV/AIDS for business and fight stigmatization by offering psychological support. Tanga AIDS Working Group (TAWG) in Tanzania offers herbal treatment to its members and fights stigmatization by offering counselling and community sensitization. Kenya Red Cross offers reproductive support by equipping community members with home based care skills, provides income-generating activities in order to boost the nutritional status of patients, and makes them afford the daily costs of AIDS.

The organization provides a way to the members to obtain external resources that help to reduce their level of vulnerabilities. The organization also ensures its members get treatment, thus leading to accessibility of ARVs to all members. This helps to reduce their vulnerabilities to AIDS related illness. They fight stigmatization in the community and among members by offering them counselling and sensitization respectively.

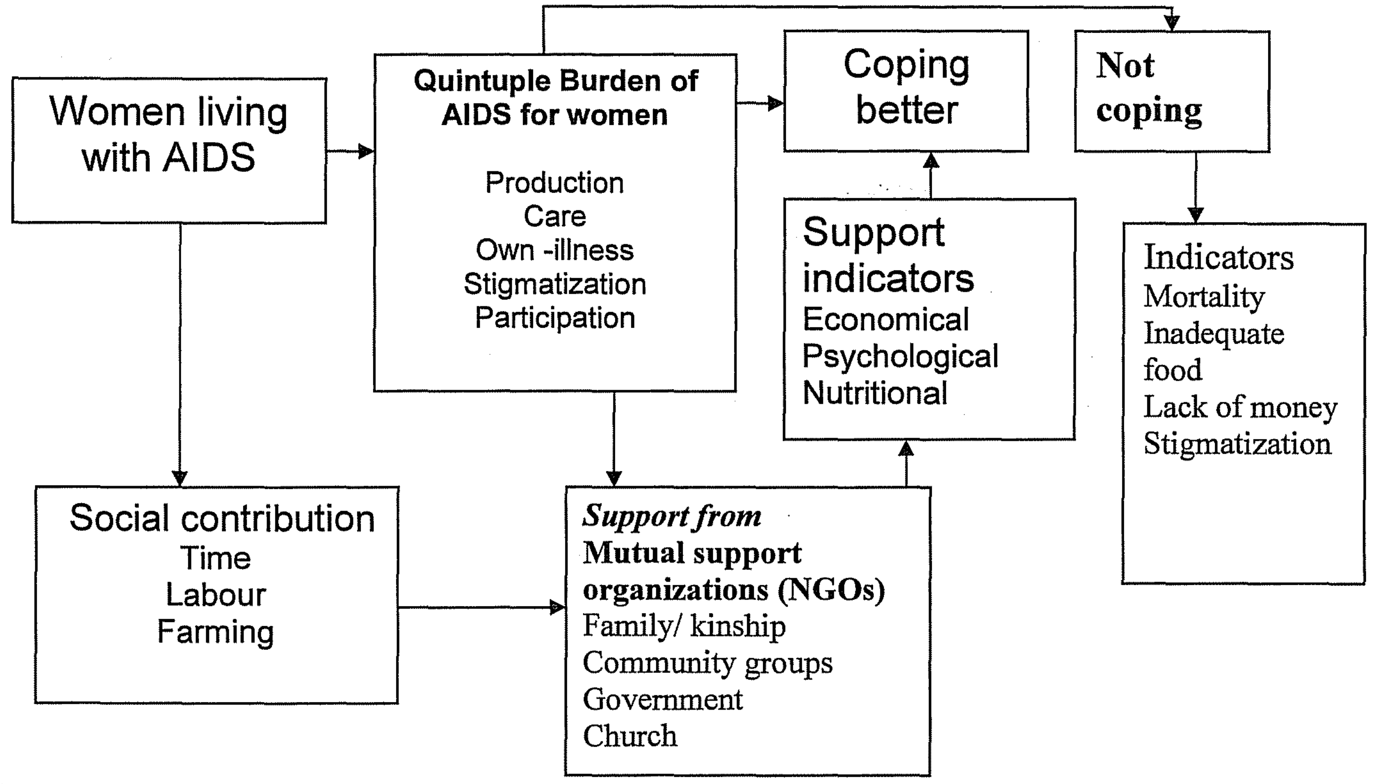
However, there are limitations to these mutual HIV/AIDS support organizations. According to Webb (1997:194), some programs fail due to lack of comprehensiveness within the programs, lack of supportive policies and lack of sustainability plans, given that most of these mutual support programs are on short-term basis.

Campbell (2003) noted many reasons as to why HIV/AIDS programmes fail, includes: lack of technical support for the community outreach coordinators, inadequate accountability of stakeholders to project beneficiaries and communication break down among stake-holders that can lead to withdrawal of technical staffs. For example, a Zimbabwean expert was withdrawn from HIV/AIDS project of Summertown project in South Africa.

These reasons make operations of mutual help organizations for HIV/AIDS programmes to fail, making the PLWAs to suffer the consequence in most countries because donors withdraw their support for such projects for example in Uganda the Global fund for HIV/AIDS was withdrawn based on lack of proper accountability and corruption.

In order to understand the importance of mutuality and what brings in coping for women living with AIDS and what makes the other women unable to cope with their multiple burdens, illustrated in analytical framework in a form of diagram and discussed below;

2. 9 Figure 2, Analytical Framework; shows what brings coping for women living with HIV/AIDS and what makes the other group not to cope.



Source: Own framework

The analytical framework for this paper is based on what makes some women living with HIV/AIDS cope better with quintuple burdens shown by the support indicators, which, they get from family/kinship, community, government, church and mutual support organizations (benefit of being organized in an organization). Indicators showing what makes women unable to cope with their quintuple burdens, are; mortality, inadequate food, lack of money and stigmatization of women living with HIV/AIDs who are not in any support organization.

This mutual help organization helps to meet their social, economical, nutritional and psychological needs, whereas women living with HIV/AIDS, who are not coping with quintuple burden of HIV/AIDS, are not getting the support from mutual organizations or from kin, neighbours and church, this means that being organized helps in coping better, which, is yet to be explored.

The mutual organization helps them cope with quintuple burdens of being patients, taking care of the sick, production roles as well as participation in the organization and stigmatization; this makes them cope better than those women living with HIV/AIDS who are not in the mutual help organizations.

These women have also to invest their time and labour in the organization in order to be part of the organization, by offering home based care for their group members in case they fall ill, so as to make them cope. They are also involved in farming activities, business and others are in formal employment as a way of livelihoods in order to support themselves financially and have access to basic needs. HIV/AIDS comes with high financial costs especially medical bills because of being in and out of the hospital on a regular basis, which needs money. Being involved in livelihood activities will help to have access to funds, which makes women living with AIDS live longer than the expected life expectancy of PLWAs.

In conclusion, mutual organizations enhance member's entitlements and capabilities in order to function well to cope, while women living with AIDS who do not cope have no entitlements and capabilities to function since they are not getting any support to enhance their entitlements and capabilities from these support organization.

CHAPTER THREE

THE QUINTUPLE BURDENS OF WOMEN LIVING WITH HIV/AIDS IN ARUA

3.0 Introduction

This chapter explores quintuple burdens of Arua women living with HIV/AIDS by focusing on the challenges that non- NACWOLA members and NACWOLA members face, discusses the basic information on the rural livelihoods and health facilities in Arua.

3.1 Background and location of Arua district

Arua District lies between latitude 2^0 30'N and 3^0 50'N and longitude 30^0 30'E and 31^0 30'E in the North Western part of Uganda. The Republic of Sudan borders it in the North West, Yumbe District in the North East, Democratic Republic of Congo in the West, Nebbi District in the South, and Gulu District in the East. Arua has 855,055 people, 455,852 are female and 409,203 males according to National population census 2002.

3.2 Rural livelihoods in Arua

Crop farming dominates livelihoods of the rural Arua population. They grow both food and cash crops as an important means of survival for many people in the district. Food cultivation is the most important livelihood strategy in the district. Food crops are mostly grown for subsistence, where the family directly consumes much of the produce and some are sold to purchase household assets. Cassava, millet, sweet potatoes and beans are the main food crops (Uganda participatory poverty assessment process 2001:24-27).

Women are involved more in food production than men because some men have taken to too much drinking and their labour is fully employed in cash crop growing especially tobacco (ibid). Women with the help of children ensure food security in most households. Moreover, women do not own land; men allocate them small land for food production, which is why in some households, food supply is not adequate. Cash crops in Arua are major income monopoly of men. Tobacco is the main cash crop; however, in some parts farm coffee and cotton, bee keeping is gaining popularity even among women.

The division of gender roles in the cultivation of the fields in Arua is so distinctive and biased. Whereby women do most of the works like harrowing, weeding and harvesting which are take a lot of time to do. While men only do digging, worst still they dig together with women and at the same time, women have to cook food and other household activities. After fieldwork, men just go to social places to drink.

Selling of foodstuff, brewing and selling of local alcohol "waragi" is the most important means of cash income for the women, they travel long distances to trade in food produce to earn a living. However, trading in manufactured goods is a major source of livelihoods for some people and men are the main traders (ibid: 29-32).

Sale of labour in agricultural work, care work with pay and jobs that needs unskilled labour is becoming major source of livelihoods for both urban and rural area. The majority of women work for food as a form of payment, while men work for money in addition to money got from cash crops.

Livestock rearing: some people in Arua rear animals like cattle, goats, sheep, rabbit, pigs and chicken. The animals help in payment of bride wealth and meet necessities. Animals sometimes are, used for hiring labour during peak agricultural season. Fishing is source of livelihood for lower madi- county and some parts of the district. Men mainly do fishing, women sell the fish, and money obtained from fishing is in control of men.

3.2.1 Health service delivery in Arua

Arua district has four hospitals, one of which is a government owned Regional Referral Hospital and two are NGO hospitals; four health centres grade IV, 28 health centres grade III, 28 health centres grade II, making a total of 64-health units. With these units, 60 percent of the population lives within 5 kilometres of a health unit. However, there is a high rural urban difference in health service delivery. This places the care burden of women living with HIV/AIDS more on women in rural areas especially care for the sick since they are not getting treatment timely they take a very long period to recover than urban areas whereby most sick people obtain treatment earlier enough, hence shorter time to care for the sick. Rural population have access to few health facilities and health services given that grade 3-2 health centres do not offer all services compared to urban centre that have access to hospital. A limited number of health centres provide HIV/AIDS testing and counselling services and ARVs is provided only in Arua hospital making accessibility for most rural women difficult (Arua district strategic plan 2006:13).

3.3.0 Quintuple burdens faced by women living with AIDS in Arua.

Introduction

In order to establish burdens of women living with HIV/AIDS in Arua, interviews were conducted with (20) NACWOLA members and ten (10) non- NACWOLA members. Of the 10 women interviewed, most of the women are in the age cohort of 30-55 years, while few of them are between 20-29 years. Marital status, four are married and four are widowed; very few are single and divorced. This implies that HIV/AIDS has left most women as widows probably because women live with AIDS longer than their male counterparts because men live in denial making them unable to access ARVs and self-stigma kills them faster.

Majority of the women interviewed are Christians because 85.3 percent of the population in Arua is Christian, while very few are Moslems who form only 2 percent of the population. The majority of the women stopped schooling in primary education, only one has tertiary education given that 64 percent of the women are illiterate in the district. The majorities are traders and farmers; the women's major source of income is trading and sale of produce (Arua District Report 2005).

HIV/AIDS status; most of the women knew their status in 2001-2005, while few knew their status in 2006-2007 and only one knew her status in 1990-1995. This implies that, very few women who are non-NACWOLA members, have lived for 10years with the virus or knew their HIV/AIDS status in 1990s.

Women living with HIV/AIDS in Arua are faced with quintuple burden; all women face some of these burdens. However, HIV/AIDS has made them more difficult for women living with AIDS as discussed below,

3.3.1 Impact of HIV/AIDS on reproductive roles

Table 1

Reproductive roles	Total	Percentage
Bearing children	20	67%
Cleaning	30	100%
Taking care of the sick	30	100%
Fetching water	30	100%
Cooking food	30	100%
Others (home visits)	15	50%

As indicated in the above table, HIV/AIDS has a great impact on reproductive role of women living with AIDS, majority of the women stopped bearing children with the argument that there is no point of producing children when you know you are going to die anytime. One respondent said:

> "I have problems with my in-laws; they want me to produce more children, which I cannot do because of my health conditions; this has led to poor relations with my in-laws".

Others said; giving birth drains a lot and will reduce chance of living longer because of loss of blood during childbirth and most of them have lost their husbands, due to HIV/AIDS, it is hard to remarry when one has the virus.

All the women said, they feel weak and get tired so easily while cleaning, taking care of the sick, cooking food at all times and fetching water and collection of firewood is a major problem to them. On average, the women cannot carry 30 litres of water per day and NACWOLA members said they could not fetch water 40 litres per day and cannot carry enough firewood that can last for one week. Others said:

> "We feel so bad to see our children carry the activities we are supposed to do on our behalf, AIDS has made us to become bad mothers, children are doing heavy work for us, it is such a terrible experience".

This raises the issue of child labour in most households and the girl children are always victims of such more than boys, they end up dropping out of school in order to care for their sick parents.

Taking care of children is a burden; the women have to care of their orphaned children, since most of them are widows. Moreover, some of the children are living with HIV/AIDS; they are ever in and out of the hospital. The majority of the women have children ranging from 3-5 children. In addition, these women have dependants and most of them have dependants ranging from 3-5 people. This forms a big number of dependants for these women. The women have to produce food and other necessities for these dependants, which is a great burden to them considering their health status. Due to their health, they produce inadequate food, yet HIV/AIDS reduces immunity levels. The patients needs to eat a lot of food that increases their immunity levels, however, they have limited access to food and as a result they feel weak and some of the women are malnourished.

Some of the women have to go for home visits and offer reproductive roles for their bed-ridden members like cooking food, collection of water and fire wood that makes them feel weak and tired. A study done in Arua District indicated that women are the most group affected by the HIV/AIDS pandemic:

> "Women are considered the most affected by HIV/AIDS. Women are the caretakers and often times bear the responsibility of taking care of the sick. "Women take all the responsibility to look after the sick and the orphans. Within the household, the woman looks after her husband and children and if orphans come into the home it is the woman to take care of them" (The District Response Initiative on HIV/AIDS Action Research 2003:36).

Inadequate housing: some of the women lost their husbands to due HIV/AIDS; they are unable to construct a good shelter for themselves, given that some are not in any mutual support organization that could help them. They are living in terrible housing conditions that are so pathetic.

3.3.2 Impact of HIV/AIDS on productive roles

Table 2

Productive	Total	Percentage
Farming	19	63%
Business	16	53%
Office work	3	10%
Care work with pay	3	10%
Others (tailoring)	3	10%

As indicated in the table, most of the women have two productive activities that they do. These women said they can no longer farm on large scale let alone farming at all times at the right season, at times when the season for planting comes, we are sick, we cannot plant, example Sabina. P. remarked:

> "I no longer have big fields like those days before I got AIDS, this AIDS has made me to farm on small scale because I have no strength to farm on large scale".

This explains why some of the households have inadequate food.

Business as a source of livelihood is affected by HIV/AIDS, the women who are doing business said; *"we now do business on small scale because our health does not allow us to travel long distances to do business on large scale*". Some respondents said:

> "we have lost our customers in business because we are ever in and out of hospital, some customers have stopped buying our products after getting to know we have AIDS, they do not want to associate with AIDS patients, which is a serious set back to our business".

HIV/AIDS makes it hard and unreliable to depend on business as a livelihood. That is why most of these women have financial problems; they are not operating lucrative business, especially those who were involved in lucrative business.

Office work and care work are affected due to ill health. At times employer are not happy with you for not performing to their expectation since one is always sickly. Therefore, the job security is threatened, most employers would not entrust their children in your hands; they think you will infect them. Much as the women wishes do to work, the opportunity is so minimal for them because of their sero-status. Mandera B. said:

> "I stopped care work with money because my arm and back hurts, which troubles me often, my employer could not understand I hard to stop working. HIV/AIDS is a terrible disease".

Some women who are tailors' said; "we lost our customers" because of our ill health, a customer will want to use their cloths but you cannot make it ready by the expected time, next time the customers will not bring their cloths to you. This makes them vulnerable to poverty not because they are lazy but their health status makes it so hard for them to make a living.

Majority of the women said; they lack money to meet the increasing demands of HIV/AIDS, one needs money to buy drugs, pay hospital bills, buy food and support the family. At the same time take care of the sick ones; some of our children are HIV/AIDS positive, our husbands have HIV/ADS, they are always sickly, we needed money to meet all these demands. We are failing to cope with these various demands.

Some of the women have lost their land, first after losing their husbands to HIV/AIDS, they were chased away by the men's relatives, and secondly at their ancestral home their bothers take way their land for example Ayikoru I. said "*my* *late husbands relatives took a way my land"*. Some of the women have kept their land because the communities they live in are more understandings Driciru.S. Said; "*I have my land that my late husband left for me, my in-laws are very understanding*", such women have more access to land than other communities who grab their land. The situation is pathetic because most of these women livelihoods' depends on farming, taking away land from them minimize their coping skills. This happens because some of them are not in any support organization that would help them negotiate land issues with relatives and educate the community to respect them and to give the women access to land.

3.3.3 Impact of HIV/AIDS on Stigma

Table 3

Impact of stigmatization	Total	Percentage
Yes	7	70%
No	3	30%

As indicated in the above table, majority of women living with HIV/AIDS feel stigmatized within themselves and from the community. Some said we feel so bad that we have HIV/AIDS. Once you have the disease people think you have been a prostitute or unfaithful in your marriage. Since HIV/AIDS is associated with sex, we feel stigmatized; one is not given chance to explain how she or he got the virus and the community views all the patients in the same way. One respondent said:

> "The community laughs at me, they have killed some of animals, they do not want me to own anything, they say your about to die why do you keep animals. This tortures her a lot. In- addition, Eyokia M. said; "I have bad relationship with my brother due to my sickness, he stopped me from digging in the field, when the sickness puts me down nobody brings me to the hospital and they say I am already a dead person I feel traumatized and I am stressed because people laugh at me".

Some of them feel so isolated and lonely at home because nobody cares about them.

In Arua district PLWAs are discriminated against which has been indicated by a study done in the district and the PLWAs said,

> "We PLWAs are the people the world does not want to see at all. People always say that PLWAs should be, collected and dumped together in one place. On world AIDS day, we had a programme where we featured on radio and one listener called in and said that PLWAs should be, collected and taken away from society. She suggested that we should be, dumped in Queen Elizabeth National

> Park so that the wild animals could eat us. PLWAs are treated as lesser human beings compared to those who do not have HIV/AIDS", (The District Response Initiative on HIV/AIDS Action Research 2003:39). The PLWAs revealed that they live in constant fear, waiting for their death.

Some said: we are worried about the future of our children; how will they grow without a father and a mother, our income is not enough to support all their needs now and even we have saved nothing for their future.

This indicates that HIV/AIDS is still highly stigmatized in Arua; the community still views AIDS patients as deviants in the society and offers less care and support to them.

However, NACWOLA members case is a little different, very few felt stigma from within themselves and community. Stigmatization among the NACWOLA members is minimal; it is evident that breaking the silence about one's HIV/AIDS status and the psychosocial support from the organization helps to reduce the level of stigmatization.

3.3.4 Impact of HIV/AIDS on Own illness

This is a burden, which occurs due to ones HIV/AIDS status. These women are always in and out of hospital, because of their health condition. Own illness is a cross cutting burden, it is because of it that these women suffer stigmatization; they have to participate in organization activities, they cannot produce children; perform well their productive and reproductive roles. They feel physical weakness and at times emotional weakness that affects their daily activities.

Own illness is the cause of all the challenges that women living with AIDS suffer. One respondent said:

> "AIDS has made me to become like a child, I cannot do any thing on my own because I am so weak and ill to do anything. It is a terrible experience that I do not wish any one to go through, it is such a painful disease, you soil your cloths with body wastes, you can not clean, someone has to do it for you, where I sleep the room smells bad. I feel a lot of pain all over my body".

From her experience, AIDS has brought with it a lot of pain and challenges that becomes so hard to bear without help from friends, relatives, community and an organization.

3.3.5 Impact of HIV/AIDS on Participation

Participation in the organization is a form of burden that these women living with AIDS face. These women carry on with their reproductive and productive roles in organization activities as Miller (1998) noted women often do reproductive roles in the community or organization without pay that takes a lot of their time.

Most of these women spent between 1-2 hours in the organization activities like home visits whereby they help their friends that are weak to do reproductive and productive roles. Some of the women said they spent between 3-4 hours in the organization activities and other women said, they spent 5-8 hours in the organization activities and yet they have their own burden of productive and reproductive roles as well as being patients. The women said; "they get tired and weary while doing these activities especially those that work for long hours". It seems that the division of labour in this organization is distinctive, some work for more hours than others do. NACWOLA members have proved that participation is a burden that women living with AIDS have to bear.

Some of them said we have to do these activities in order to be part of the organization. This indicates that once a member does not participate in organization activities, one might lose membership of the organization. It is imperative to note that, only women living with HIV/AIDS who are in mutual support organizations face this burden.

However, non-NACWOLA women have some ways of managing these challenges, because the majority depends on ARVs. Very few said they pray to God as a strategy of coping and few get support from relatives and friends but these strategies are not helping them that much to cope like their friends who are in NACWOLA, that is why very few have lived for long and some have died, the majority are not coping.

In conclusion, women living with HIV/AIDS in Arua face many challenges, as discussed. They get minimal support from relatives and friends, which portrays that the traditional/ kinship support in Arua is breaking down, because HIV/AIDS has affected most of the households. The major way of coping for them is ARVs, which they get from the government hospital. These women only get support when they are in mutual support organizations after they break the silence about their status to the society. This will be explored in the next chapter.

CHAPTER FOUR

THE DIFFERENCE NACWOLA MAKES ABOUT WOMEN COPING WITH AIDS.

4.0 Introduction

This section explores how NACWOLA as a case study makes a difference for women coping with HIV/AIDS. The major focus is on how NACWOLA as an organization helps women cope with quintuple burdens and draws lessons that can be learnt from NACWOLA experience for rural African women living with HIV/AIDS.

4.1 Background of NACWOLA Arua

Four women who are living with HIV/AIDS in 1994 founded NACWOLA Arua, three of the founders have since died and Rose Atibuni is the only one living now and she is the coordinator of the organization.

Objectives of NACWOLA

The organization was, formed in order to meet the following objectives;

- To improve the quality of life of women living with HIV/AIDS and their families in Uganda
- To fight stigma and abuse of HIV/AIDS positive women
- To access accurate information on HIV/AIDS and network with other AIDS services organizations so as to reduce fear and isolation among women living with HIV/AIDS
- To empower women living with HIV/ AIDS to act as a strong voice in the fight against HIV/AIDS

The beneficiaries of NACWOLA are women living with HIV/AIDS at a membership fee of 5000 Ugandan shillings renewable annually, in that ones HIV/AIDS status qualifies one to be a beneficiary. This could imply that women living with HIV/AIDS who have not contributed the money might not join the organization. However, individuals who are HIV/AIDS free and have a heart to help NACWOLA pay 25,000 Ugandan shillings annually.

4.1.2 Socio economic background of NACWOLA members

Among the 20 interviewed, the majority of the women are between the age cohorts of 30-45 years and only few women interviewed were in the age cohort of 25-29. This indicates that the majority of women living with HIV/AIDS in NACWOLA are 30 years above; they are in the productive age. In most cases, HIV/AIDS rate among the productive age group is high, evidenced by NACWOLA members. This has implications for Arua's Economy, HIV/AIDS has reduced the level of economic participation of PLWAs, which, has led to high incidence of food insecurity and poverty in the District.

Marital status of NACWOLA members

Table 4

status	Total	Percentage
divorced	0	0
single	1	5%
married	4	20%
widowed	15	75%

As indicted in the table, the majority of the women interviewed are widowed; few are married and are single. This is an indication that women join NACWOLA when their husbands have died. This raises the gender issue on decision making in the households, when husbands are alive, they do not allow women to join NACWOLA since they fear that the community will know that the are living with HIV/AIDS.

Reasons why women do not join NACWOLA

Some non-NACWOLA members said they could not join the organization because their husbands could not allow them to join with the fear that the community will know their status and are worried about stigmatization.

Some of the women had no information about the existence of NACWOLA as an organization, which shows that NACWOLA is not well known in the district, implying that the organization has not done enough district sensitization about its existence. Others have not joined due to the financial aspect of membership hence the exclusion of some women.

All the women interviewed are Christians; this raises the issue of inclusion and exclusion in the organization this is an indication that Non- Christians could be excluded in the organization.

It is important to note that the majority of women interviewed have lived with HIV/AIDS for more than 10 years and very few of the women who knew about their status between the years of 2000-2007have lived less than 10years with the virus. This signifies that NACWOLA members are coping with quintuple burden.

Level of education

The majority of women in NACWOLA have low education level as most of women, the only achieved primary education, very few are secondary school levers and some did not go to school at all. This implies that, most vulnerable groups in the society are more open about their HIV/AIDS status and are willing to look for support than the educated group.

Occupation and source of income

The majority of the women are in informal sector, as traders and farmers. Only few of these women work in an office. This shows that, majority of women interviewed are poor and have limited resources. Most of them are farmers; since Uganda's economy is reliant on agricultural and most women's livelihood in Arua depend on farming.

The major source of income for these women is business; for example, they said they sell fruits, vegetables, local alcohol, clothes among other things. Farming comes second, for example the sale of farm produce. Very few women get financial support from relatives and few of them get monthly salary.

Information on NACWOLA

The information about NACWOLA as an organization for women living with HIV/AIDS is commonly spread through friends, most of the women who are now NACWOLA members got their information through their friends. Very few women knew about NACWOLA through outreaches done by the organization, some got information about the organization through Arua hospital and nobody heard the information through radio programs, probably because these women do not own radios or have no time to listen. Some of the women said their husbands' told them to join NACWOLA, for example, Enzama. M. said:

> "Her husband told her to join NACWOLA before he died so that she can get support and counselling to live longer".

It seems men advise their wives to join an organization, when they are about to die, so that the women get support from such organization for taking longer care of themselves and orphans.

More so, some women joined because their husbands who were breadwinners died, Bako. G. *"I joined NACWOLA because I lost my husband"* in order to get support.

NACWOLA members joined the organization for various reasons, which included getting counselling from the organization, to get support from the organization and be involved in activities of the organization like tailoring and crafts, financial assistance they offer to members. However, most of the women joined NACWOLA to meet their fellow friends in order to get encouragement as Candiru. R. said:

> "I wanted to be encouraged by my fellow members who are living with HIV/AIDS, now I am getting the expected encouragement from members, which makes me to live positively".

In addition, some of the women joined NACWOLA to get peace of mind and fight stigmatization as a member said: "there is a lot of torture from outside communities; the organization helps to reduce the level of stigma".

4.2.0 Life history of NACWOLA members

The three life histories try to depict the life of women living with HIV/AIDS before and after joining NACWOLA, in order to gage the impact on NACWOLA as an organization on these women.

Life history of Dipio Regina

I was born in 1960; I am a senior three drop out. I had two children as a single mother in 1980s, until I joined my present husband in 1993 up to date we are married, I work as a nursing Aid, I got signs and symptoms of HIV/AIDS in 1987. In 1990, I got H/ Zoster and in 1992, I was so weak could not do hard work because of my health condition and I was sickly I decided to tested for HIV/AIDS in AIDS information centre Kampala, since then I have been off and on sick. I joined NACWOLA in1995, I am now on ARV and my husband fell sick in 2003, I had to take care of him, his CD4 was low, now he is on ARV, too. Before joining NACWOLA life in the community was heal, full of stigmatization but joining NACWOLA, has made me feel much better with fellow members and I can now do other activities to run my family. I pray for NACWOLA Arua.

Life history of Ajidiru Betty

First, I thank God for the life he has given me; I am still breathing and seeing. Praise be to His holy name. I was, born in 1965. I am a secondary 2 drop out, I had my first born in 1985 and I brought up my two daughters alone. After some time I got married in 1997.My husband was working with a non-governmental organization up to 1998, one of his work mates called me through radio message that he was sick in Moyo.

I could not believe my eyes. My husband left for work when he was healthy, his weight was 78-kilo grams, he lost weight and we stayed in the hospital until 1999 march when he died. That is when I knew I was HIV/AIDS positive, however, I started falling sick in 2004 and I knew my status when I visited Arua hospital for test and I was positive. I had rashes all over my body, I could not hear properly, I lost appetite and weight from 65-kilo grams to 53-kilo grams. I became very weak, I could not carry water, collect firewood not even cook food, my condition was terrible and I had lost hope for living, I was traumatized.

I was put on ARV treatment and joined NACWOLA in 2004, I am better now, my health has improved I can now do house work. I discovered that staying with NACWOLA members, makes me feel free because these are women who are living with HIV/AIDS, I have gained a lot being a member of NACWOLA, making crafts for making money, sharing testimonies with friends and I thank God for the founders of NACWOLA.

Life history of Immaculate Ayikoru

I thank God for what I am, I was born in 1967 and I went with my studies up to secondary two where, I stopped due to no school fees. After that, I got a child whose father I did not marry, and then I got married to a businessperson in Arua town. I got my second child for him; the baby fell sick at the age of 8 months, all the treatment given to her, could not work, she died. I lost my husband in 2003, which lasted for one month in the hospital.

After his death, his people collected almost everything from my hands. My late husband had a piece of land, which had three buildings; he sold the land with all the buildings before he died. After his death, I could not stay long in their place because of the torture from his relatives. I had to go back to my mother; it was not two years that I started falling sick on and off in the hospital I become so weak, I could not do my reproductive roles as usual[...] I decided to go for HIV/AIDS test; in 2004, I was, found HIV/AIDS positive in Arua hospital. My CD count was very low; I was, put on ARV drugs. I was given food by world food program, for nine months, it stopped , now I am in problems, I have no food, no job. I have no help, not even from my own home, relatives.

Then this year 2007 I decided to join NACWOLA, we meet twice in a week, where we share our problem. This helps me a lot to forget my past and we do other activities that help us a lot. In June this year I have started to learn how to make dresses and craftwork, I am learning I know after getting skills, I will get some money from this activities.

The three life histories depict how women living with AIDS suffer and portray their lives before and after joining NACWOLA to illustrate the importance of mutual support organization in helping women to deal with their challenges. Having joined NACWOLA is their source of joy and hope as they expressed in their life histories. These three women have different challenges. The married woman seems to be coping better than the two widows cope, because she has a job and get some support from her husband in addition to what NACWOLA offers her. The two widows are not working, they have no husbands to support them, the relatives are not offering them support, and they seem to depend only on NACWOLA support for coping with their burdens.

NACWOLA members who joined earlier cope better than the new ones. Like Ayikoru who just joined this year, the living situation is bad, she has no house of her own, no job and payment of school fees is a problem for her children. She lost her land and property to her late husbands relatives. NACWOLA is helping her with income generating skills hopefully if she gains these skills, her situation will change and she will be able to earn some money to afford necessities.

4.3 Determinants of coping for NACWOLA members

What makes coping

Table 5

Item	Total	Percentages
ARV	20	100%
Counseling	15	75%
Sharing with friends	15	75%
NACWOLA	20	100%
Self resilience	10	50%
Good feeding	17	85%
Prayers	4	20%
Help from friends/ relatives	6	30%

Help of coping provided by NACWOLA staff
NACWOLA Activities: Table 6

Activities	Total	Percentage
Cleaning	6	30%
Garden work	20	100%
Tailoring	11	55%
Hand craft	8	40%
Memory book	2	10%
Home visit	10	20%
Out reach	12	60%

The focus group discussions with NACWOLA Arua staff, they said; they have many strategies for helping their members to cope with quintuple challenges through various activities and NACWOLA members reported different mechanisms for coping with their challenges as indicated in table 5 and 6 respectively; discussed as follows:

4.3.1 Coping with reproductive roles

The members said; that home visits by their friends in the organization helps a lot, especially when one is ill or bed ridden. NACWOLA members help to collect water, firewood and clean the household for them. This helps us a lot and we are like a family. When one is ill, other members step in to help with the reproductive role. Some said they still produce children without infecting their children with the virus, by attending prevention of mother to child transmission lessons given in the hospital. We are not, allowed to breast feed our children to avoid mother to child infection. This has helped us to give birth in the hospital, knowing that the child is safe from the virus is a relive.

Home based care; the main activity is care and support for members through home visits to affected households. It is intended to promote psychosocial support, improve care among the affected, enhance adherence to Highly Active Anti-Retroviral Therapy (HAART) and to monitor patients on HAART, TB (Tuberculosis) PMTCT and other vulnerable children benefiting from nutritional support. This project has helped to heal broken hearts through counselling, testimonies of other people that encouraged others. During the home visits, basic counselling is done, material support and physical support is, given to members.

Caring for the patients is done in the hospital. NACWOLA members go and take care of the sick friends who are admitted in the hospital. This makes the sick member's health improve faster knowing that their friends care for them and they are healed physically and emotionally.

Mother's day care; this project takes place twice a week, every Tuesday and Saturdays. The day care provides on going supportive counselling in the centre and at times, the program is, undertaken in the various zones where NACWOLA members reside. The organization has taught and encouraged members to stay clean and be active to help them live longer and it has surely helped the members.

Children activities

In many homes, children affected and infected with HIV/AIDS are discriminated and many are, stigmatized. In order to mitigate the impact of HIV/AIDS and increase the coping capacity of children, NACWOLA offers a day care centre for children once a month; children come and play in the recreation centre. On average seventy children benefit from this activity. To supplement the Universal Primary Education UPE program, scholastic and uniforms are, provided to orphans and vulnerable children. This was, done through donor support to the organization. Many children are not able to go secondary schools due to school fees problem; NACWOLA has helped some children for example train girls in tailoring and hairdressing, boys in carpentry. The training is to equip them with life survival skills.

4.3.2 Coping mechanisms for productive role

According to members, their economic needs are met by the organization through introducing them to handcrafts, tailoring and at times, small allowances that helps in meeting their financial needs. They get an allowance between 5,000- 10,000 Ugandan shillings, while for tailoring an average of 10,000- 20,000 weekly or bi-weekly. Handcrafts money depends on the size and type of the handcraft. This helps in meeting the daily demands of HIV/AIDS costs, although it not adequate.

For nutritional needs, the organization makes members plant greens, fruits and food crops to have access to food, which helps in building their immunity systems and makes them healthy and feel better and stronger.

Very few women said relatives and friends help them to cope by giving them financial assistance and moral support which is essential to cope.

Food provision: After being weakened by HIV/AIDS, not all the PLWAs can engage in labour-intensive activities such as heavy garden work, in order to improve food security World Food Program (WFP) distributes food to the members since they are not strong enough to farm on a large scale with the aim of building their immunity. This has reduced death rates among clients.

Home improvement and renovation; NACWOLA Arua, has built two roomed *mabati* (iron sheet) house for each member in order to improve their shelter.

According to the report, NACWOLA members are, given beehives and goat rearing project in collaboration with other non-governmental organizations with the aim of improving their nutrition and economic benefit by selling the goats and honey which helps to improve household incomes.

Loan revolving funds: Some NACWOLA members have benefited from this loan scheme. The fund is used for financing individual family income generating activities, small-scale business like roadside selling, market vending, produce buying and selling wood fuel and charcoal.

However, NACWOLA members also get some support from outside the organization that helps them in coping with HIV/AIDS because they are NACWOLA members. The organizations that help them includes, AIDS information centre that gave them Jerri cans, water guards for watering fruits and greens and WFP.

4.3.3 Coping mechanisms for stigmatization

Psychological needs (spiritual /stress): the organization offers counselling and encouragement to members. In addition, meeting with women who have HIV/AIDS and sharing with friends is a very good source of encouragement and now majority of NACWOLA members say they are stress free, which is a good sign of coping since having HIV/AIDS is associated with stigmatization, for example Madera. I., said:

> "I reflect on the various testimonies given by fellow members that console me a lot and relieve my fears and stigma".

Some of them believe that prayer is one of the strategies of coping with HIV/AIDS; this helps to reduce the level of fear living with AIDS, knowing that God is in control and he can help them to live long with their situation. This is Christian faith - believe that God can heal all sickness, thus reduced stigmatization and fear.

Memory project; through memory project women are empowered to open up dialogue with their children about their HIV/AIDS situation and document important family information in their children's memory books. This prepares their children to develop coping mechanisms for their future beyond the lives of their parents.

This project provides an opportunity for the women to identify future caregivers for their children. In addition, through this project members have been able to:

- Break the silence to their children, this silence was due to fear that, they would not live for long.
- Build good relationship with their children, relatives and has improved communication with their children.
- Learn how to share confidentiality with their children, that is telling them their status and prepare their children for the future.
- Train their children to take good care of themselves.

All NACWOLA members write a memory book, to each of their children. The main issues in book include; names and date of birth of both parents, name of the child and date of birth. Major information on both parents especially where they went to school; work place thus source of livelihood, their interests and dislike, their happy moments and sad moments, their health story-how they got to know about their status. Family tree, important family culture and important traditional values, location of home, land and other family properties and names of next of kin to the child especially friends and relatives. Lastly their expectation or dream for the child. The women like this project because of its advantages discussed above.

Information, Education and Communication (IEC), involves sensitization and group counselling in communities and health facilities through drama and personal testimonies to targeted audience and local FM radios. This contributes towards control of further spread and reduced stigmatization of PLWAs thus leading to improved community care for the sick HIV/AIDS patients. It also helps to mobilize and sensitize families to support their loved ones to adhere to HIV/AIDS related treatment. NACWOLA has drama group, which is enormously effective at breaking myths associated with HIV/AIDS and conveying essential messages to the community. NACWOLA's drama groups speak from their personal experiences; they encourage community members to test for HIV, to access services for HIV/AIDS. This helps to reduce stigmatization related to HIV/AIDS.

Theatre for development training aims to improve the capacity of trained personnel to carry community sensitization and reduce stigmatization of PLWAs in the community. In addition to training community members on home based care skills and counselling skills to help PLWAs.

4.3.4 Coping mechanism for own illness

All the women said that taking ARVs on daily basis is what makes them cope. ARVs is the main coping mechanism for own illness for NACWOLA members. The organization helps to link all its members free ARVs in Arua hospital. The organization ensures that its members are taking the drugs by going for home visits as a routine check especially for patients who have just begun to take the drugs. The drugs are obtained from the hospital on monthly basis. The organization helps to remind its members to get drugs monthly. NACWOLA members illustrate that being in support organization makes accessibility of ARVs better at all times. In addition, the respondents said feeding well while taking the drug helps in coping with HIV/AIDS.

ARVs are important for coping with AIDS because the drug helps to improve the immunity levels of patients and offers them a better chance of living longer with the disease. Accessibility of the drug is difficult for AIDS patients in Uganda. Not all the patients get the drugs free, it is too expensive and very few can afford them.

More importantly, some of the women took at self-resilience as a form of coping mechanism for example Candiru. R. "*said self-renewal of my strength that is I have learnt to take heart and continue to live*".

Some of the women received help from Ediofe Catholic Mission health centre and the AIDS information centre supplies in form of mosquito nets. All this helps to improve the health status of NACWOLA members.

4.3.5 Coping mechanisms for participation

Participation as a form of burden is a question that I raised in this paper, that getting support from an organization is not free; the members have to give their time and labour to participate in the organization that takes a lot of their time. This does not mean that they do not benefit from the organization; they do benefit, which is the main argument in the paper only that, the participation is another burden; an organization has to deal with and provide coping mechanisms.

I propose that, the organization should reduce the time these women have to spend in the organization activities perhaps one to two hours and not four to eight hours, so that they get some time to do their own productive and reproductive activities.

In conclusion, all the women said, that being members of NACWOLA has made them cope with their situation with the support from the organization meets their economical, nutritional and psychological needs as discussed above. Psychological needs comes first, economic need second and nutritional need is the last. It is imperative to note that the organization does not meet these needs adequately or fully, however, this support helps them to cope better than if they were not getting any support at all from any organization.

4.4 Lessons drawn from the experience of NACWOLA for support organizations for rural women living with HIV/AIDS

4.4.1 What works for coping with HIV/AIDS

NACWOLA as an organization is providing an alternative to traditional/ kinship support that used to exist in Arua. These women now take NACWOLA as their own home, where they can get support to cope with their quintuple burdens.

Memory book writing is an important lesson drawn from NACWOLA as an organization, the memory book helps members to break the silence about HIV/AIDS to their children, which is very difficult thing for AIDS parents and documentation of important family property, relatives and friends the children can look to when the parents have died.

Accessibility of ARVs to all NACWOLA members is an important aspect of the organization. In addition, the organization ensures that all the members are taking the drugs as prescribed by the doctors. Offers support and care for their patients in the hospital, this implies that NACWOLA as an organization is like a home for their members, who rely on it in times of both good and bad times.

Offering psychosocial support and other support to children, is another important lesson learnt from NACWOLA, this makes it easier for the children to cope with what the mothers are going through and stand the stigmatization from their peers. This helps the mothers to cope better because their major concern is their children, how they react to the news of their parents HIV/AIDS status and their future. In addition, training skills given to children helps children to manage their own life, which is a big, relief for their mothers.

The organization helps in reducing level of stigmatization of HIV/AIDS in the community through sensitization about HIV/AIDS. This indicates that the organization deals with member's stigmatization and community stigmatization to reduce overall level of stigmatization. This is important because stigmatization kills the patients faster than the HIV virus if not dealt well. According to the members, psychological support is the best help that they get from NACWOLA that has helped in coping well with their sero-status.

Networking and collaboration of NACWOLA staff is so amazing, NACWOLA networks with many donors, governments organizations and some individuals for financial support. This implies that collaboration of mutual help organization is an important aspect if they are to provide better coping mechanism for their members, which, Campbell (2003) noted that stakeholder's coordination and co-operation for HIV/AIDS activities is very important if HIV/AIDS programmes are to succeed.

Increased level of economic activities through involvement in income generating activities like tailoring, handcrafts, food production, for sale and home consumption leads to improved nutrition status of women. In-addition counselling and psychosocial support coupled with improved care among the infected especially those that are ill, helps to reduce stigma. Finally being able to access drugs like ARVs, antibiotics at all times increases their life expectancy hence reduced mortality rate. This was tested in the field by conducting interviews with the women living with AIDS who are NACWOLA members and NACWOLA staff.

However, it is imperative to note that not all the women living with HIV/AIDS in mutual support organization cope. For example, some of the women in NACWOLA reported the challenges they face living with quintuple burden as lack of money, physical weakness and stigma. More over, some said they are coping well with quintuple burden because of the support the organization offers which implies that some of the women manage quintuple burden better than others in the same organization.

4.4.2 Challenges

Despite the lessons learnt, from the organization for rural support organizations in Africa, the organization has some challenges as follows,

Inadequate funds, NACWOLA depends on donor funds and funds they collect as membership fees. This raises the issue of sustainability; it might be hard to conclude that the organization can sustain activities that help members to cope once the donor funds are unavailable.

Women living with HIV/AIDS who do not have membership fees might not be able to join the organization, since their aspect of contribution to be a member, whether it is only cash or in-kind contributions, needs to established in further research. This has lead to exclusion of some women in the district.

Non-Christians seems to be excluded in the organization because the interviewed women were all Christians, although the sample size so was, it seems to indicate that some women living with HIV/AIDS are excluded based on religious background.

There is a high possibility of the organization not allowing women who are risky in terms of their health status to join the organization. It was not clearly indicated how very ill patients have been accepted as part of the group because they cannot contribute in -terms of labour and time, indicating that, very ill patients might not be accepted in the organization.

Stigmatization: some of the women still felt stigmatized this implies that counselling, care and support need to be done continuously. In addition, stigma associated with HIV/AIDS in the district makes some women not to join the organization because their husbands do not allow them to join the organization with the fear of community level stigmatization.

Poverty; especially in terms of income, most of the women reported that they lack adequate income to meet the increasing financial demands of HIV/AIDS and lack of finance to support for the orphans and vulnerable children in terms of school fees as a result most of these orphans are not accessing higher education. The financial support from the organization is so minimal for all the needs. In the long run this might result into inter- generational poverty.

CHAPTER FIVE:

CONCLUSIONS AND RECOMMENDATIONS

This paper discussed quintuple burden of women living with HIV/AIDS; explored how women cope with these burdens and determined lessons learnt from the experience of NACWOLA, for support organizations for women living with AIDS in rural Africa.

5.1 Conclusion

The study found that, women living with HIV/AIDS in rural Africa, can cope better with quintuple burden of reproductive roles, productive roles, own illness and stigmatization when they are in mutual support organization. This is true even though participation is also a burden, drawing on their time to assist other members. The support organization helps to meet their economical, psychological and nutritional needs as evidenced by NACWOLA Arua, where NACWOLA Arua has given women more hope to live; NACWOLA members proved this hypothesis.

In addition, the mutual organization monitors women while they are undergoing treatment and medication, ensure that they take them on daily basis. When some of the members are sick in the hospital, their friends are always at their service, taking care of them in the hospital. This makes them feel better and they are no longer isolated or discriminated.

External dynamics of the organization helps these women to cope with their sero-staus. The assistance from other organizations to NACWOLA is both financial and material support. The solidarity these women have built among themselves makes them feel as a family hence reduced fear and stigmatization.

The study has expanded Moser's triple role of women- that is reproductive role, productive role, community role/ participation in an organization- to quintuple roles/ burden that women living with HIV/AIDS in rural Africa face which are productive burden, reproductive burden participation, stigmatization and own illness. By illustrating that, women living with HIV/AIDS have more burden than women who are not living with AIDS. This implies that, support organization that needs to support women living with HIV/AIDS has to take in to consideration the quintuple burdens these women face in order to meet their needs.

The study found that participation in the organization is an added burden to women living with AIDS in terms of the time spent and amount of work that makes them feel weak and tired due to their health condition.

Women living with HIV/AIDS who are not in any support organization do not cope with the burdens. Their economical, psychological and nutritional needs are not met. More so, some of them are not taking their ARVs as prescribed by the doctors, since there is nobody that encourages them. Most of them do not live long evidenced by those interviewed. Most of them only discovered their HIV/AIDS status when, they were already weak, fumerized, malnourished and consequently have lost hope for survival. This is a clear indication that they are not coping with the burden.

The findings of the research show that, non-NACWOLA members are not in any support organization because most of the women interviewed were not aware of NACWOLA or any other support organization while few of them said they did not want to join any organization. Moreover, these are married women, their husbands do not allow them to join with the fear that the community will know about their status, and they are worried about stigmatization.

Some of the women do not join mutual support groups like NACWOLA because of the financial obligation of a membership fees, managing of the group, however, pooling and sharing of risk is very important for mutual support organizations, although poor women are excluded on this basis.

5.2 Recommendations

Finally, this paper makes some recommendations that may contribute to improving coping mechanisms for women living with HIV/AIDS in Arua, Uganda and rural Africa at large.

Women living with HIV/AIDS should be encouraged to join support organizations like NACWOLA so that their economical, nutritional and psychological needs can be met by such organizations.

Some of the mutual support organizations that are helping PLWAs should replicate what NACWOLA does for its members, so that PLWAs are able to live for a longer period than their expected life expectancy and live with less stigma and discrimination. The reports of some of the mutual groups show that they only help with one or two of the quintuple burdens, while NACWOLA supports members with the quintuple burden this helps the women cope better with these burdens.

Local governments should budget for some funds to support such organization like NACWOLA, which has improved many lives of women living with HIV/AIDS and the number of women living with HIV/AIDS in the district is increasing. If the district does not step in NACWOLA as an organization may fail to handle the increasing demands of members in the end.

The government of Uganda needs to budget more funds specifically for PLWAs, to support them to cope with their situation and special consideration should be for women living with HIV/AIDS. Given that women are the main caregivers of HIV/AIDS patients at all levels. At the same time when they fall ill or sick, no body seems to care for them and they are disserted, such funds and help will help to give them hope for a better future despite their burdens.

NACWOLA Arua needs to do more advocacy and mobilization for more members, given that many women in Arua who are living with HIV/AIDS do not know about NACWOLA. Since, most NACWOLA members came to know about the organization through their friends. There is need for more mobilization campaign by NACWOLA Staff, in order to give more hope for women living with HIV/AIDS who are not part of NACWOLA.

NACWOLA Arua needs to diversify its activities for income generation for the women, increase the allowances of members and ensure that all the members get this money in order to improve member's economic needs.

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Appendix A

NACWOLA MEMBERS

Bio data of the women interviewed.

Age	Total	Percentage
20-24	0	0
25-19	1	5%
30-34	2	10%
35-39	6	30%
40-45	7	35%
45-49	2	10%
50-55	2	10%

Marital status

status	Total	Percentage
divorced	0	0
single	1	5%
married	4	20%
widowed	15	75

Number of children

No children	Total	Percentage	age
0-2	2	10%	1
3-5	14	70%	1
6-7	4	20%	1
8-9			4
10-11			5
12-13			4
14-16			5
17-20			10
25 and above			

Number of dependants

Number	Total	Percentage
0-2	6	30%

3-5	7	35%
6-8	4	20%
9-12	3	15%
13-14	0	0

Religion

Religion	Total	Percentage
Christian	20	100%
Moslem	0	0

Level of Education

Education level	Total	Percentage
None	2	10%
Primary	12	60%
Secondary	6	30%
Tertiary	0	0
others	0	0

Occupation

Occupation	Total	Percentage
Farming	11	55%
Fishing	1	5%
Trading	12	60%
Paid job	3	15%
Others (tailor)	2	10%

Source of income

Income	Total	Percentage
Farming	8	40%
Self employed	9	45%
Paid job	4	20%
Trading	7	35%
Support from relatives	6	30%

Data of knowing status

Data of status	Total	Percentage
1990-1995	11	55%
1996-2001	5	25%
2002-2007	4	20%

Information about NACWOLA

Information on NACWOLA	Total	Percentage
Out reach activities	5	25%
Friends	10	50%
Radio	0	0
Arua hospital	3	15%
AIDS information center	0	0
Spouse	2	10%

Year of joining NACWOLA

Year	Total	Percentage
1994-1998	9	45%
199-2003	6	30%
2004-2007	5	25%

Reasons for joining NACWOLA

Reasons	Total	Percentage
To get counseling	9	45%
Meet friends/ encouragement	10	50%
To get support	6	30%
Husband advice	10	50%
After death of husband	1	5%
To get peace of mind/ fight stigma	1	5%

Support not covered

Items	Total	Percentage
Money / loan	8	40%
Land	2	10%
Housing	8	40%
School fees	12	60%
Clothing	1	5%

Impact of HIV/AIDS on Reproductive role

Impact reproductive	Total	Percentage
Bearing children	14	70%
Cleaning	20	100%
Taking care of the sick	20	100%
Fetching water	20	100%
Cooking food	20	100%
Others (home visit)	1	5%

Impact of HIV/AIDS on productive roles

Impact on productive	Total	Percentage
Farming	14	70%
Business	10	50%
Office work	2	10%
Care work with pay	1	5%
Others	0	0

Coping mechanisms by NACWOLA

Item	Total	Percentage
Economic needs	14	70%
Nutritional needs	13	65%
Psychological needs	19	95%
Others	0	0

NACWOLA Activities

Activities	Total	Percentage
Cleaning	6	30%
Garden work	20	100%
Tailoring	11	55%
Hand craft	8	40%
Memory book	2	10%
Home visit	10	20%
Out reach	12	60%

Impact of participation

Hours	Total	Percentage
1-2	8	40%
3-4	5	25%
5-8	7	35%

What makes coping

Item	Total	Percentages
ARV	20	100%
Counseling	15	75%
Sharing with friends	15	75%
NACWOLA	20	100%
Self resilience	10	50%
Good feeding	17	85%
Prayers	4	20%
Help from friends/ relatives	6	30%

Support outside NACWOLA

Item	Total	Percentage
AIDS information center	8	40%
World food program	7	35%
Ediofe health center	4	20%
Sub county	1	5%

Stigmatization

Stigma	Frequency	Total
yes	5	25%
No	15	75%

None NACWOLA Members

Bio data

Age	Total	Percentage
20-24	2	20%
25-29	1	10%
30-34	1	10%
35-39	3	30%
40-44	1	10%
45-55	1	10%

Marital status

Status	Total	Percentage
Single	1	10%
Married	4	40%
Widowed	4	40%
Divorced	1	10%

Number of children

Number	Total	Percentage
0-2	3	30%
3-5	7	70%
6-9	0	0
10-13	0	0

Dependants

Number	Total	Percentage
0-2	3	30%
3-5	4	40%

6-9	2	20%
10-13	1	10%

Religion

Denomination	Total	Percentage
Christian	8	80%
Moslem	2	20%
Others	0	0

Education level

Level	Total	Percentage
None	0	0
Primary	7	70%
Secondary	2	20%
Tertiary	1	10%

Occupation

Occupation	Total	Percentage
Farming	2	20%
Fishing	0	0
Trading	4	40%
Paid job	2	20%
Others (tailoring)	2	20%

Source of income

Source	Total	Percentage
Sell of produce	5	50%
Trading	6	60%
Paid job	2	20%

Data of knowing status

Year	Total	Percentage
1990-1995	1	10%
1996-2000	1	10%

2001-2005	6	60%
2006-2007	2	20%

Place of test

Place	Total	Percentage
Arua hospital	8	80%
Kuluva hospital	0	0
Health center	2	20%

Challenges of women living with HIV/AIDS

Challenges	Total	Percentage
Physical weakness	8	80%
Stigma	6	60%
Financial problem	9	90%
Food	6	60%
Loss of land	1	10%
Housing	4	40%
Burden to care for orphans	8	80%

Management of strategies

Strategies	Total	Percentage
ARV	8	80%
Support from business	2	20%
Prayers	4	40%

Any other support

Support	Total	Percentage
Yes	4	40%
No	6	60%

Type of support

Support	Total	Percentage
ARV	8	80%
Prayers/ spiritual support	5	50%

Reasons for not being in an organization

Reasons	Total	Percentage
Lack of information	4	67%
Not interested	2	37%

Impact of HIV/AIDS on reproductive roles

Reproductive roles	Total	Percentage
Bearing children	6	60%
Cleaning	10	100%
Taking care of the sick	10	100%
Fetching water	10	100%
Cooking food	10	100%
Others	0	0

Impact of HIV/AIDS on productive roles

Productive	Total	Percentage
Farming	5	50%
Business	6	60%
Office work	1	10%
Care work with pay	2	20%
Others (tailoring)	3	30%

Stigmatization

Level	Total	Percentage
Yes	7	70%
No	3	30%

Needs that are have not been fulfilled

Educational needs
Love and care
Financial/ economical needs
Spiritual/psychological support
Nutritional needs

Appendix B

QUESTIONNAIRE

Women living with AIDS: The triple Burden and Coping mechanisms NACWOLA ARUA; Uganda.

The questionnaire has been designed to assist in the collection of data, towards writing of a dissertation. It is purely an academic exercise and any information obtained would be treated as confidential. Thank you for your co-operation.

NACWOLA Management Questionnaire

1-When was NACWOLA formed?..

2- Who are the founders?...

3-Why was the organization formed?...

4- How does NACWOLA identify beneficiaries?..................................

5-What programs/ activities do the organization offer to the women?

....

6-What is the funding source of the organizations activities?.........................

7-How do the women participate in these activities? (Time spend for the different activities)

....

8-What challenges does the organization face in meeting member's demands?

....

9-Do you think the organization has contributed to the ways NACWOLA members cope with AIDS? Explain how?..................................

....

10- Do you think there are other areas where the organization could contribute? Or do more?

....

QUESTIONNAIRE

Women living with AIDS: The triple Burden and Coping mechanisms in ARUA; Uganda. For non -NACWOLA members

The questionnaire has been designed to assist in the collection of data, towards writing of a dissertation. It is purely an academic exercise and any information obtained would be treated as confidential. Thank you for your co-operation.

QUESTIONNAIRE FOR THE NACWOLA MEMBERS

1- Age......................

2- Sub-county ....

3- What is your current marital status? Single ☐ married ☐

☐ ☐

Widowed Divorced

4- Have you been married before? If so how did it end?

………………………………………………………………………………………………

5- Number of children if any Girls ☐ Boys ☐

6- Any other people living in the household? Sex and age F ☐ M ☐

7- Religion: Christian ☐ Moslem ☐ Others specify ☐

8- Education: None ☐ Primary ☐ secondary ☐
Tertiary ☐

9-Occupation: Farming ☐ shing Trading ☐ ☐
Paid Job ☐ hers specify ☐

(Can be more than two)

10- What are the sources of household income and who earns the income and how do they earn it?

………………………………………………………………………………………………

………………………………………………………………………………………………

11- When and how did you come know of your status?

………………………………………………………………………………………………

12- Where did you get the test from?…………………………………………

13- What are the challenges are you facing?……………………………………

………………………………………………………………………………………………

………………………………………………………………………………………………

………………………………………………………………………………………………

………………………………………………………………………………………………

14-How do manage the challenges?

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………………………………………………………………………………………………

………………………………………………………………………………………………

………………………………………………………………………………………………

15- Do you get any support from an organization? If yes which organization and what type of support do you get? (e.g. church, village authorities, neighbors')

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……………………………………………………………………………………………

…………………………………………………………………………………………

16-How does the support help you to cope?

……………………………………………………………………………………………

……………………………………………………………………………………………

…………………………………………………………………………………………

17- If no why are you not in any support organization?

……………………………………………………………………………………………

……………………………………………………………………………………………

…………………………………………………………………………………………

18-Do you get any financial support? If yes (from)

…………………………………………………………………………………………..

19- How does the financial support help you cope with AIDS burden?

……………………………………………………………………………………………

……………………………………………………………………………………………

…………………………………………………………………………………………

20-How has HIV/AIDS impacted on your reproductive roles?

- Bearing children
- Cleaning
- Taking care of the sick
- Fetching water
- Cooking food
- Collection of water
- Others specify

21- How has HIV/AIDS impacted on your productive roles?

- Farming
- Business
- Office work
- Care work with pay
- Others specify

22- How do you feel about your situation and how does the community treat you? (Stigmatization)

…………………………………………………………………………………………

23- Any other thing you wish tell me about your situation

QUESTIONNAIRE

Women coping with AIDS: The triple Burden and Coping mechanisms NACWOLA ARUA; Uganda.

The questionnaire has been designed to assist in the collection of data, towards writing of a dissertation. It is purely an academic exercise and any information obtained would be treated as confidential. Thank you for your co-operation.

QUESTIONNAIRE FOR THE NACWOLA MEMBERS

5- Age…………………..
6- Sub-county ………………………………
7- What is your current Marital status: Divorced ☐ngle ☐
Married ☐ widowed ☐

4- Have you been married before? If so how did it end?

5- Number of children if any and their ages: Girls ☐ Boys ☐

6- Any other person in the household? Age and sex: F ☐ ☐

7- Religion: Christian ☐Moslem ☐ Others specify ☐

8- Education: None ☐ Primary ☐ secondary ☐
Tertiary ☐

9-Occupation: Farming ☐shing Tradin☐ ☐
Paid Job ☐hers specify ☐
(Can be more than two)

10- What are the household sources of income? Who earns it and how do they earn it?

………………………………………………………………………………………

………………………………………………………………………………

11- When did you know your status?………………………………

12-Where did get tested for the virus?....................................

13- How did come to know about NACWOLA?.....

....

14-When did you join NACWOLA?.......................

15- What reasons made you join NACWOLA?

....

....

....

....

16- Are there things that you need help with that are not being covered?

17-How has HIV/AIDS impacted on your reproductive roles?

- Bearing children
- Cleaning
- Taking care of the sick
- Fetching water
- Cooking food
- Collection of water
- Others specify

18-How has HIV/AIDS impacted on your productive roles?

- Farming
- Business
- Office work
- Care work with pay
- Others specify

19-Has joining NACWOLA made a difference in your life? Examples

- Economic needs
- Nutritional needs
- Psychological needs(spiritual/stress)
- Others specify

20- What type of activities are you involved in NACWOLA?

……………………………………………………………………………………

……………………………………………………………………………………

……………………………………………………………………………..

21- For how long do you work for the organization activities?

…………………………………………………………………………………

…………………………………………………………………………………

22-What are the ways you cope with your situation?

……………………………………………………………………………………

……………………………………………………………………

…………………………………………………………………………………

…………………………………………………………………………………

23-Is their any other support out side NACWOLA? If yes, state where you get the support from? What kind, how much, when and what is the impact.

……………………………………………………………………………………

……………………………………………………………………………………

……………………………………………………………………………………

………………………………………………………………………

24- Do you feel bad about your situation? And how does the community treat you? (Stigmatization)