International Labour Organization

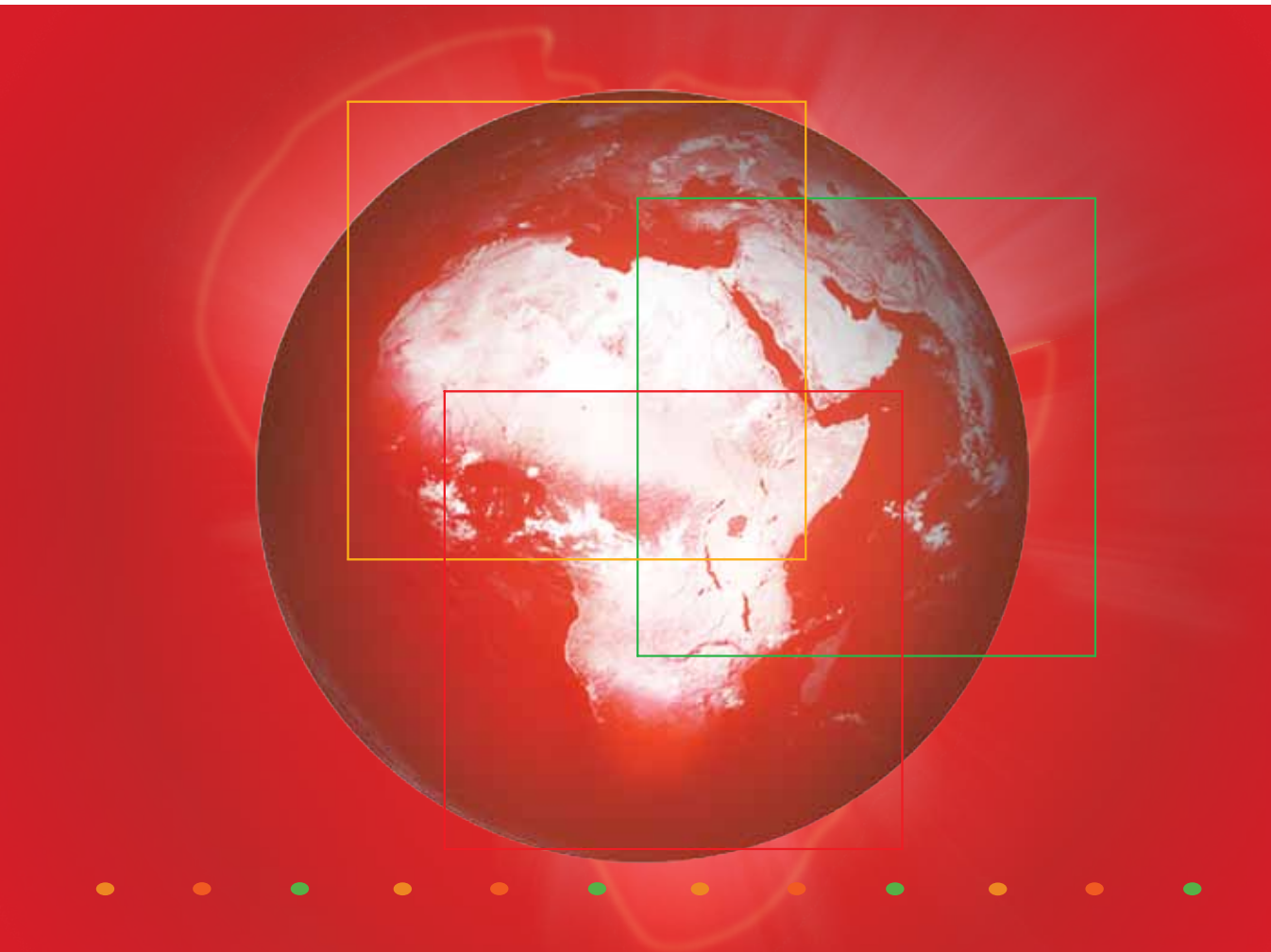
COOP AFRICA

ILO AIDS

Coop[AFRICA] Working Paper No.19 with ILO/AIDS

The cooperative model for the delivery of home based care services for people living with HIV

Sandrine Lo Iacono and Emma Allen



COOP AFRICA

CoopAFRICA contributes to improving the governance, efficiency and performance of primary cooperatives, other social economy organizations and their higher level structures in order to strengthen their capacity to access markets, create jobs, generate income, reduce poverty, provide social protection and give their members a voice and representation in society.

CoopAFRICA'S approach consists of assisting stakeholders to establish a legal and policy environment conducive to the development of cooperatives; providing support services through identified 'Centres of competence'; promoting effective co-coordinating structures (e.g., unions and federations) and establishing and maintaining challenge fund mechanisms, for 'services', 'innovation', and 'training'. These funds are accessible through a competitive demand-driven mechanism and a transparent selection of the best proposals.

CoopAFRICA and its network of 'Centres of competence' provide different types of services: policy and legal advice; studies and publications; training and education; support to field projects; development or adaptation of didactical and methodological material; networking; advocacy; and promotion of innovative cooperative ventures among others.

CoopAFRICA is located in the ILO Office for the United Republic of Tanzania, Kenya, Rwanda and Uganda, and is part of the Cooperative Programme (EMP and COOP) of the Job Creation and Enterprise Development Department of the ILO. The programme works in partnership with the International Cooperative Alliance (ICA), the UK Cooperative College, the Committee for the Promotion and Advancement of Cooperatives (COPAC), the International Trade Union Confederation (ITUC-Africa), the International Organisation of Employers (IOE) and the African Union Secretariat. CoopAFRICA is a multi-donors programme primarily supported by the UK Department for International Development (DfID). It also receives support from the Swedish International Development Cooperation Agency (Sida), the Government of Finland, the Arab Gulf Programme for United Nations Development Organizations (AGFUND) and the German Cooperative and Raiffeisen Confederation (DGRV).

ILO AIDS
www.ilo.org/aids

The ILO Programme on HIV and AIDS in the World of Work (ILO and AIDS) was set up in 2000 to help strengthen the global HIV and AIDS response at and through the workplace. In 2001, the ILO developed the Code of Practice on HIV and AIDS and the world of work and became a cosponsor of UNAIDS. The key objectives of ILO and AIDS are to raise awareness of the social, economic and development impact of HIV and AIDS through its effects on labour and employment; to help governments, employers and workers contribute to universal access to HIV prevention, treatment, care and support; and to eliminate discrimination and stigma related to HIV and AIDS.

The ILO-Sida programme on HIV and AIDS prevention and impact mitigation in the world of work in Sub-Saharan Africa is an innovative programme addressing different dimensions of the HIV and AIDS response through a common strategy led by different ILO departments. The programme aims to reduce the impact of the pandemic in Sub-Saharan Africa by addressing the world of work vulnerabilities and strengthening the application of the policy and legal frameworks for the protection of infected and affected workers. The programme started in December 2005 and is funded by the Swedish Development Cooperation Agency (Sida) over the course of four years and comprises three components; 1) The transport sector through a corridor approach aiming to increase knowledge on HIV and AIDS and minimize risk behaviours; 2) The informal economy and cooperatives to mitigate impact of HIV and AIDS and improve working conditions in informal settings 3) Enhanced legal and policy compliance.

The programme covers 14 countries in the sub-region (Lesotho, South Africa, Mozambique, Malawi, Zimbabwe, Botswana, Ethiopia, Nigeria, Burkina Faso, Mauritius, Togo, Benin, Cameroon, Democratic Republic of Congo) but the main programme countries are Benin, Cameroon, Ethiopia, Malawi, Mozambique, South Africa, and Zimbabwe.

A new phase of the Sida programme has been negotiated and will focus on economic empowerment to reduce the HIV vulnerabilities along transport corridors (Zambia, South Africa, Malawi, Mozambique, Zimbabwe and Tanzania) for a period March 2011-March 2013

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List of abbreviations

ACU	Aids Control Unit
AIDS	Acquired Immunodeficiency Syndrome
CASSs	Constituency AIDS Control Committees
CBO	Community Based Organisation
CHW	Community Health Worker
CHBC	Commumity Home Based Care
CPSD	Cooperative Public Service Delivery
DACCs	District AIDS Control Committees
DHMT	District Health Management Team
FBO	Faith Based Organisation
HBC	Home Based Care
HIV	Human Immunodefiency Virus
IGAs	Income Generating Activities
IMF	International Monetary Fund
ILO	International Labour Organisation
KNASP	Kenya National AIDS Strategic Plan
NACC	National AIDS Control Council
NASCOP	National AIDS Strategic Plan
NGO	Non Governmental Organization
OVC	Orphan and Vulnerable Children
PACCs	Provincial AIDS Control Committees
PLHIV	People Living with HIV/AIDS
PPP	Public-Private Partners
SCC	Swedish Cooperative Centre
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organisation

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Notes on the authors

Sandrine Lo Iacono holds a MSc in "Public health in developing countries" from the London School of Hygiene and Tropical Medicine (LSHTM). She has served as research officer for various agencies of the United Nations system and for non-governmental organizations in Geneva. She also worked as public health consultant in Paris and Singapore.

Emma Allen is completing her PhD in Economics from the University of Newcastle, Australia. She is working for the International Labour Organization (ILO) in areas of cooperative enterprise development and employment intensive investment. Her research interests include employment policy, public works, enterprise development, local economic development, employment impact assessment, spatial analysis and survey research methods. She has worked for ILO in South Africa, Tanzania, Indonesia and Geneva.

Executive summary

In 2008, two million people died from AIDS. Africa remains the hardest hit continent, with 1.4 million deaths and an adult prevalence rate of 5.2 in the Sub-Saharan region alone (UNAIDS, 2009). HIV and AIDS impact on the social and economic spheres of society, including within the world of work. With regards to cooperatives, like other organizations, are directly affected by the pandemic through loss of their members, their workforce and their leaders. This in turn indirectly affects members' revenue and the cooperatives' capacity to address members' needs.

Home-based care (HBC) is an innovative approach to providing a comprehensive continuum of prevention, care, treatment and support services to meet the needs of people living with HIV in settings that have resource limitations. HBC calls for partnership among family members, health care workers, health facilities, local communities, community-based organizations (CBOs), non-governmental organizations (NGOs) and people living with HIV (PLHIV). CBOs are particularly at the forefront of responding to HIV/AIDS. For instance, in Kenya 80 per cent of the country's HIV interventions are implemented through CBOs. Where universal health coverage is not achieved and access to the public health system is compromised, communities have organized themselves and set up self-help initiatives to address their own health needs, including those related to HIV.

Considering the features and values of the cooperative model, the Coop[AFRICA] and the ILO/AIDS programme commissioned this study in 2009 to examine whether this model would be suitable for the delivery of HBC for members and non-members with HIV. The study reviews literature and considers cases in Kenya and Lesotho.

There are several characteristics of the cooperative model that are relevant for HBC programmes that respond to HIV and AIDS. For instance, the governance structure of the cooperative model gives members control over the decision making process, which subsequently ensures that members' priorities and specific needs are at the forefront of the cooperative's activities. Thus, through democratic member control and voluntary membership, members are empowered to take responsibility for satisfying their needs. The cooperative model provides a platform for discussion that can help identify individuals' capacities and strengths, which HBC programmes could use to optimize its services.

Nevertheless, the outcomes of this study found that cooperatives are not yet fully involved in HBC strategies. Members do not have a comprehensive understanding of what HBC is and how it is undertaken in communities. Consideration for HIV is often not included in cooperatives' strategic plans and therefore members often see it as a side issue that diverts them from their key activities. For those that have started HBC activities, the main HBC service in which they seem to be fully involved is the continuum of care through the implementation of income generating activities (IGAs), such as small scale agricultural production and/or animal husbandry. The objective is to enhance the living conditions of affected and infected members. A

second area where cooperatives are active is often linked to IGAs, and involves transport for referrals to health facilities. With funds derived from the proceeds of the IGAs, some cooperatives are able to provide transport – instead of the cost of transport falling onto the individual. Education through awareness-raising activities is the third service in which cooperatives appear as a player, although the study pointed out that stigma and discrimination can still prevent members from disclosing their status, and thus to access treatment and care. Cooperatives seem to be less involved in the provision of care mainly due to the limited training that caregivers (who are often volunteers) receive, the limited access to equipment and general financial limitations.

Even though some cooperatives started to implement some HBC activities, several questions remain. Considering that public health issues tend to be largely addressed by public-private partnership (PPP), can an organization that is legally registered as a cooperative be involved in such a partnership considering the cooperative principles of autonomy and independence? How can a sustainable cooperative HBC programmes operate considering the financial burden that such a programme implies?

1. Introduction

In 2008 two million people died from AIDS. Africa remains the hardest hit continent, with 1.4 million deaths and adult prevalence rate of 5.2 in the sub-Saharan region alone (UNAIDS, 2009).

HIV and AIDS affects the social and economic spheres of society, and thus impacts on the world of work. Enterprises are affected through reduced productivity and through loss of skill. With regard to cooperatives, like other organizations, they are directly affected by the pandemic in that they lose their members, their workforce and their leaders. This in turn affects their members' revenue and the capacity of the cooperative to address their members' needs.

A major consequence of the increasing number of people living with HIV (PLHIV) is also an increasing demand and need for health care. However, poverty and limited capacity of the health infrastructure impedes the access that a large number of PLHIV have on care and social services. Thus, policy measures, such as the Alma Ata Declaration (1978) and the Bamako Initiative (1987), face challenges as they called for community involvement and financial participation in the provision of health care services.

Home-Based Care (HBC) is an innovative approach to provision of a comprehensive continuum of prevention, care, treatment, and support services to meet the needs of PLHIV in resource-limited settings. HBC seeks to bridge the gap between health facilities and home care by allowing PLHIV to receive quality care and dignified services in their homes. Considering that most HIV related care is provided in the home by untrained family, HBC programmes aim to improve access to better quality care. HBC calls for partnership to provide care and support among family members, health care workers, health facilities, local communities, community-based organizations (CBOs), non-governmental organizations (NGOs) and those infected with HIV and AIDS. CBOs have been at the forefront in providing a response to unmet need for HIV and AIDS care and support services. For instance, in Kenya CBOs implement 80 per cent of the country's HIV/AIDS interventions (Ogutu, 2004).

Considering the principles, values and purpose of cooperatives and their connection with local communities, the cooperative model may provide a comparative advantage. For instance, cooperatives are defined as:

> "An autonomous association of persons united voluntarily to meet their comment economic, social and cultural needs and aspirations through a jointly owned and democratically controlled enterprise" (ILO, 2002).

More specifically, cooperatives may be an entry point for providing a response to HIV through HBC due to the scope of their focus, which includes meeting social and cultural needs. The potential of cooperatives to respond to HIV and AIDS was first recognized during a consultative meeting titled, "The Role of Cooperatives in

Fighting HIV/AIDS", held in Swaziland in August 2001 and organized by the ILO in collaboration with international and national coorperative organisations. The cooperative approach was also highlighted as one of the key messages that came out of the 11th ILO African Regional Meeting held in April 2008. It was stated that:

"HIV/AIDS programmes must use all entry points to the informal economy, including informal sector associations, cooperatives**,** business development."

Many activities of cooperatives have been affected by the pandemic. The affects have especially been felt through loss of labour supply, falling remittance transfers, declining participation in savings and credit schemes and poor attendance rates at meetings due to a funeral (Smith, Puga and MacPherson, 2005).

These consequences have made it a necessity for cooperatives to develop and contribute to strategies that address issues related to HIV and AIDS. The first step taken by the cooperative movement in Africa has been to increase awareness among members of cooperatives about the disease through information and education campaigns. A second step has involved thinking about how the cooperative model could be used to augment responses to HIV and AIDS. Particular emphasis has currently been put on the provision of HBC services, and this has seen partnerships develop between ILO/AIDS and ILO/Coop^{AFRICA}.

As there is limited information on existing cooperatives linked to HBC, the purpose of this paper is therefore to provide a better understanding of the potential of the cooperative model in the provision of HBC for HIV and AIDS infected and affected people. Based on literature review and case studies, this paper explores the following questions:

- What type(s) of HBC provided by self-help initiatives currently exist?
- How could the cooperative model strengthen existing self-help initiatives in the provision of HBC?
- What is the current involvement of cooperatives in the provision of HBC for PLHIV?

This paper will first provide an overview of the HIV and AIDS pandemic in Africa. The second part presents HBC as an innovative strategy for responding to HIV and AIDS. The third part examines how the cooperative model could theoretically be applied for the provision of HBC for PLHIV and how cooperatives are currently involved in the provision of HBC. Finally, the paper discusses the various issues raised in order to provide conclusions and recommendations.

2. Methodology

The objective of the study was to examine the potential of the cooperative model for the provision of HBC people living with HIV and AIDS. This is an exploratory study and therefore the data upon which the study is based is mostly qualitative. The

study adopted a mixed methods approach, which included the following aspects:

1. Literature review;
2. In-depth qualitative interviews of national and local authorities in charge of health care, HIV/AIDS and HBC for HIV/AIDS;
3. In-depth qualitative interviews with key informants from the management team of cooperatives offering HBC services to their members or other self-help member-based initiatives involved in HBC for HIV/AIDS;
4. Focus groups discussions with members infected and affected by HIV/AIDS and care givers delivering HBC for HIV/AIDS.

Interviews and focus groups collected data from authorities', providers' and beneficiaries' that were purposively selected due to their involvement with HBC. This gave a multi dimensional assessment of the potential of the cooperative model for the provision of HBC for HIV/AIDS infected and affected people. A total of 163 people were interviewed, including 72 people from two cooperatives and one self-help group in Kenya and 91 people from three cooperatives in Lesotho between July and August 2009.

The study encountered several limitations. Firstly, the literature on self-help initiatives in relation to HIV/AIDS tends to be fragmented due to a body of literature that focuses on selected case studies or on a selection of projects in certain regions. No systematic or standardized evaluation on the effectiveness or efficiency of such initiatives has been undertaken to date. Secondly, many studies have documented the impact of HIV/AIDS on particular types of organizations, but there is little information on the impact of HIV/AIDS on the cooperative movement. Therefore, the study had to adopt an exploratory approach in order to gather baseline data on the involvement of cooperatives in the provision of HBC for HIV/AIDS. Lastly, it was difficult to identify reliable case studies to include as examples in this working paper. Interviews with focus groups encountered difficulty due to participants' level of education, particularly low levels of literacy, and English language skills.

3. Overview of HIV/AIDS pandemic in Africa

3.1 HIV/AIDS situation

The number of people living with HIV was estimated at 33.3 million in 2009, out of which 2.6 million were newly infected. In the same year, 1.8 million people died of AIDS. The Sub-Saharan region, although it contains little more than ten per cent of the world's population, remains most severely affected by HIV. It accounts for over two-thirds of all HIV cases, and some of 75 per cent of deaths. The virus disproportionally affects women and prime-age adults who are at their productive and reproductive peak.

To further illustrate, in Kenya,[1] an estimated 1.3 million adults are currently infected with HIV. Females have a higher infection rate than men, especially young women, with HIV at 4.1 per cent for young women and 1.8 per cent for young men[2]. The urban areas have a higher prevalence of HIV than rural areas. However, HIV prevalence in rural areas has increased from 5.6 per cent in 2003 to 7.4 per cent in 2007, with Nyanza and Rift Valley provinces accounting for more than half of all infected adults in Kenya. On a positive note, antiretroviral therapy (ART) is becoming increasingly available in Kenya, and the number of adults on ART has risen from approximately 10,000 in 2003 to approximately 212,000 in June 2008.

Lesotho, despite its small size, has one of the highest HIV prevalence rate in the world (23.6 per cent in 2009) (UNAIDS, 2010). In 2009, 14,000 people died fromAIDS, and more than 20 per cent of the population are still living with HIV. HIV has had a particular impact on women as there are currently 160,000 women living with HIV in Lesotho. The country is also struggling to cope with 130,000 AIDS orphans (UNAIDS, 2010).

HIV is a critical burden on development because of the number of people and sectors it affects. To put it simply, it has changed demographic trends, such as the population growth rate, across the African continent. Life expectancy is dropping to levels not seen since the 1960s. It is estimated that countries like Botswana, Lesotho, Malawi, Mozambique, Rwanda and Zambia would have had a life expectancy of 50 years or greater without AIDS (UNECA, 2001).

Economic growth and development can be affected by the consequences of HIV and AIDS through the loss of labour from death, sickness, unpaid care and attendance at funerals. According to the United Nations Secretariat (2004) productivity can be reduced for reasons including the following:

- Reduction in land under cultivation;
- Shortage of labour during the harvest seasons;
- Shift to less labour-intensive crops, entailing instable food supplies;
- Reduction of the range and diversity of crops grown;
- Move from cash to food crops;
- Reduction skilled labourers.

These factors subsequently impact upon food security and household income. For instance, many households in Africa rely upon subsistence agriculture for production of their food, and if labour productivity is undermined the household can become more food insecure. Similarly, many households in Africa couple subsistence agriculture with small scale farming activities. However, a household's ability to undertake such work can become constrained if the unpaid care burden increases and household productivity decreases.

[1] Global Report on the HIV Epidemic, UNAIDS 2010.
[2] See Global Report on the HIV Epidemic, UNAIDS 2010.

At the household level, the socio-economic consequences of HIV and AIDS involve loss of assets, decreased income and productive capacity, labour shortage, increased health costs, and changing expenditure patterns (Teljeur, 2002). In some countries, the widows of those who have died from HIV-related or AIDS-related diseases have lost their inheritance, including their house and their spouse's redundancy payments and/or death insurance, due to discriminatory inheritance customs (Keregero and Allen, 2011). Such culture can further damage the social fabric and subsequently discourage investors that could help to create more opportunities within the sustainable business environment.

3.2 Strategies to reduce the transmission of HIV

The impacts of the HIV and AIDS pandemic are felt beyond individuals' illness and death. Households, workplaces, health sectors and the broader economy are also severely affected. Strategies to address this situation have typically included increasing the quality of health care services and awareness-raising. These strategies could be termed prevention strategies and treatment strategies with antiretroviral therapies (summarized below).

Table 1: Prevention strategies against HIV

Target	Prevention Strategy
Prevention of sexual transmission	• Behaviour change programmes • Distribution of condoms • Testing and counselling
Prevention of mother-to-child transmission of HIV	• Antiretroviral drugs • Breastfeeding alternatives • Caesarean delivery
Blood borne transmission	• Harm reduction programs for injection drug users • Blood supply safety • Infection control in health care settings

Source: UNAIDS (http://www.unaids.org/en/PolicyAndPractice/Prevention/default.asp)

However, given the pervasive nature of the pandemic and the fact it is affecting all facets of society; a holistic, multi-dimensional approach is needed. This approach should combine top-down and bottom-up approaches, along with strategies aimed at individuals, families, government as well as both enterprises and their organizations and communities and their organizations.

Support and care for PLHIV provided through HBC services is a key bottom-up response to the pandemic in Africa. HBC gives opportunity for community organizations and enterprises to provide much needed locally based solutions to HIV in their communities that help to address the deficiencies in public health service provision. PLHIV have a wide range of care and support needs. These include psychosocial support, nutrition, economic as well as treatment. However,

the vast majority of those in need do not have access to such health services. The reasons for lack of access to services relate to financial constraints and physical distance, as well as health infrastructure that is inadequate for coping with the increased demand for care. Thus, many are cared for through home based care services.

In sum, HBC has the potential to not only provide direct benefits to PLHIV, but also the potential to reduce the social and economic impact of the pandemic and reinforce strategies to prevent further HIV transmission.

4. An innovation in the HIV and AIDS response

People infected and affected by HIV/AIDS have specific needs. HBC has emerged as an effective method to provide support to individuals and families coping with HIV and AIDS. HBC does not replace hospital care, but is part of a comprehensive continuum of prevention, treatment and support services that include PLHIV and their family, their community and health care providers.

4.1 Needs of PLHIV

PLHIV have physical, social and spiritual needs that must be taken into consideration in order to ensure that the quality and the length of their lives is enhanced. These needs should be identified to ensure that planning of services provision has an adequate and sustainable budget allocation. Some of the most significant needs are listed in the table below.

Table 2: Needs of PLHIV

Needs	Related Services
Physical needs	• Treatment for HIV and for opportunistic infections • Clinical care • Nursing care • Nutrition • Clothing, housing, food • Physiotherapy
Social needs	• Information, education and communication • Respect • A source of income or an income generating activity • Right to own, inherit and bequeath property • Confidentiality regarding their condition
Psychological needs	• Counselling • Support groups

Source: Ministry of Health Kenya (2002)

Importantly, HBC goes beyond the typically medical model. It includes elements that relate to awareness-raising and education, transport, nutrition and empowerment

through income generating activities. HBC focuses on well-being.

4.2 HBC definition and essential elements

A distinction has to be made between Home-Based Care (HBC) and Community Home-Based Care (CHBC). The former is more connected to a medical facility, while the latter is a community response to health care.

HBC can be defined as any form of care given to ill people in their homes (WHO, 2002). It is care that is extended from the health facility to the patient's home through family participation and community involvement within the constraints of available resources and in collaboration with health workers. This care addresses medical, nursing, emotional, spiritual, psychological, social and material needs of PLHIV and their families. HBC services are provided in the home through outreach from a state medical facility. That is health care workers, with the participation of HBC related services, provide care to those in need and in doing so include family and the community in the service delivery.

CHBC includes the above elements, but the service provider is a community member trained in health care, rather than a professional based in a clinic.

According to the World Health Organization (2002), HBC and CHBC require a holistic approach that integrates essential elements for a sustainable and effective service. Those elements that integrate the various needs of PLHIV can be defined into seven main categories, including:

Table 3: Key elements of HBC

Element	Description
Provision of care	Basic physical care, palliative care, psychological support and counselling and care for PLHIV.
Continuum of care	Financial and social access to care and continuity in care provision through referral systems, case management and community coordination.
Education	Individuals, families, health and social professionals, community workers awareness raising for prevention, treatment, care and stigma.
Supplies and equipment	Health centre supplies, home kits, location of HBC team and monitoring.
Staffing	Service providers as well as administrative support.
Financial sustainability	Budget and financial management, technical support, community funding and other resources over time.
Monitor and evaluate	Quality assurance and supervision.

Source: WHO (2002)

HBC is a holistic approach that requires collaborative efforts of various stakeholders including a health facility, a home care team, family and caregivers, the community, PLHIV and the government. Each has a role that might overlap depending on the services provided (see table below).

Table 4: The roles of stakeholders in HBC

Stakeholders	Role and responsibility
National level	Planning, legislation, regulation, allocation of resources, monitoring and evaluation
District/provincial level	Planning, implementation, monitoring and evaluation
Health facility	Provisions of care and management of PLHIV
Community health workers	Provision of care, PLHIV support, counselling, mobilization of community and resources
Community care givers	Continued care, support, networking, education, counselling and advocacy
Family members	Continued care, support, education, counselling and advocacy
PLHIV	As above for family members

Source: WHO (2002)

Roles and responsibilities of different levels of administration may vary from country to country, and also within the country.

4.3 Lessons learnt for HBC provision

In the 1980's and 1990's many African countries were subjected to the economic austere policies that were associated with the structural adjustment plans of the World Bank and the International Monetary Fund (IMF). This approach to governance resulted in the breakdown of most of the health care delivery systems. In the light of governments' lack or inadequate responses to health problems, especially HIV and AIDS, self-help initiatives increasingly emerged in order address to the challenge in many African countries. Self-help initiatives have taken up a range of activities related to HIV prevention, treatment and care, including home based care services. The involvement of communities in health care has been promoted since the Bamako Initiative in 1987.

The literature on these initiatives tends to be fragmented due to a body of literature that focuses on selected case studies or on a selection of projects in certain regions. No systematic and/or standardized evaluations on the effectiveness or efficiency of these initiatives have been undertaken.

Self-help initiatives to address HIV can take different forms: Faith-based organizations (FBOs), women and youth groups, associations and cooperatives. For instance, in some African countries FBOs play a great role in HIV care and treatment. A report on the African Religious Health Assets Programme commissioned by WHO in 2006 estimates that between 30 per cent to 70 per cent of the health infrastructure in Sub-Saharan Africa is driven by FBOs.

HBC seems to be more successful when caregivers are involved in all stages of the design of a programme. However, the quality of services offered is often inadequate (Goma, et al., 2002). Most of the literature identifies that the key problems facing HBC service delivery are associated with 1) the lack of linkages with formal social services; and 2) the lack of financial and human resources. For instance, the main challenge faced by FBOs is the fact that they are often overlooked by public health policy-makers and major international donors. Informal caregivers are often disadvantaged as they tend to be poorly organized and lack visibility. This is often the case for women's groups that volunteer their time, energy and resources for HBC service provision. However, their efforts are often not recognized and their voices not heard in policy circles. The "Home Based Care Alliance in Africa" has been set up to draw recognition to these women grassroots.

Another issue faced by community-based initiatives is their strong link with poverty. The relationship between poverty and ill-health, particularly HIV, is well established. Community groups often do not have sufficient income to access user pay services and/or centralized services. Reducing poverty and fulfilling basic needs are the first priorities of families in Africa. Thus, it is often crucial for HBC programmes to include poverty alleviation strategies, in order to address the low socio-economic status of PLHIV. Therefore, to be more efficient and effective, a HBC service for PLHIV that is operated by a self-help initiative should seek to combine components including:

- Strong government support;
- Comprehensive care including poverty reduction activities;
- Active community participation;
- Awareness-raising to reduce stigma;
- Sufficient management skills;
- Establishment of referral networks;
- Systematic provision of HBC kits[3] to increase the quality and satisfaction of care services;
- Local partnerships and alliances with other organizations;
- Complementary sources of funding (government, donors, community, insurance schemes);
- Development of monitoring and evaluation systems.

[3] HBC kits contain the essential items that a caregiver needs when caring for someone with HIV in order to alleviate symptoms, promote hygienic practices, prevent the spread of disease, administer antiretroviral drugs and monitor and record progress. The ideal contents of each kit vary depending on who the kit is designed for – clinical or non-clinical staff – as well as local needs, resources and guidelines.

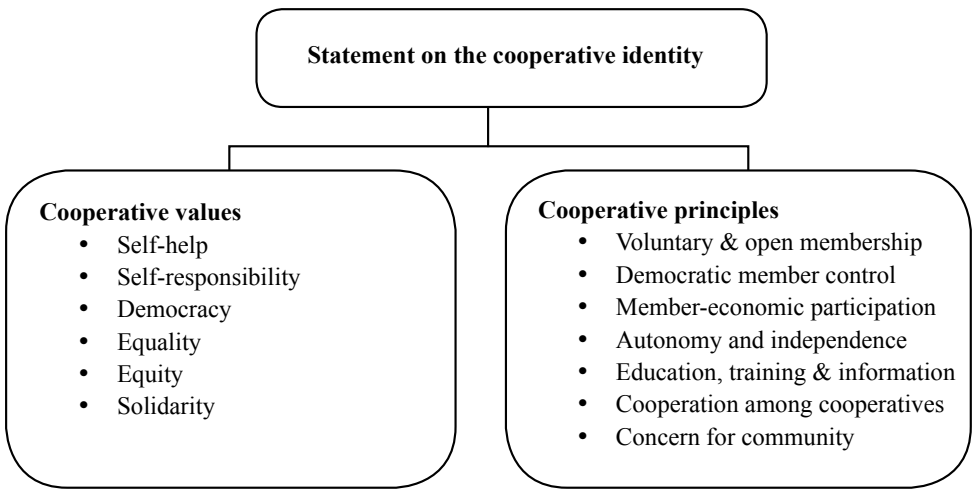
5. The cooperative model and home-based care

5.1 The cooperative model

A cooperative is considered to be an enterprise with broader economic, social and cultural aspirations than other corporate forms. More specifically, a cooperative is an autonomous association of persons united voluntarily to meet their common economic, social and cultural needs and aspirations through a jointly owned and democratically controlled enterprise (ILO, 2002).

Cooperatives are a type of organization that creates opportunity for income generation and employment, while increasing the availability of goods and services. What sets cooperatives apart from other forms of private enterprise is found in their connection to community, underlying values, ethics and democratic principles (see figure below). Decisions taken by cooperatives tend to balance the need for profitability with the broader economic and social development needs of their members. This is because members of cooperatives are also the clients or customers of cooperatives and also because members use cooperatives to increase their bargaining power and to remedy market failures. Cooperatives therefore tend to be motivated by longer term gains, rather than shorter term yields.

Figure 1: The values and principles of cooperatives



Source: ILO (2002)

In order to understand how cooperatives in Africa are involved in provision of HBC, one first needs to understand the current state of cooperative development in Africa – the strengths, weaknesses and challenges that cooperatives face. In Africa cooperatives are most commonly found in the agricultural sector and in financial services. Prevalence varies according to the particular structure of the national economies, though in general agricultural cooperatives represent 40 to 60 per cent of all cooperatives within a given country, and cooperative financial institutions represent 30 to 50 per cent of the

cooperative movements in a given country (Pollet, 2009). Approximately seven per cent of the African population are affiliated to cooperatives. Research also indicates that while cooperatives are large in number and represent an organized movement, the movement suffers constraints that are related to lack of voice and effective representation in society. Moreover, specific social protection mechanisms associated with cooperatives in Africa are limited.

Recently, the cooperative approach has been envisaged as a mechanism to overcome the various economic barriers that reduce one's access to health care services. A United Nations Global Survey (1997) on cooperative enterprises in the health and social sectors found that cooperative health services operated in more than 50 countries and represented or served approximately 100 million households. The survey identified three main types of cooperatives, according to their commitment in the health and social sector, including:

- Cooperatives whose activities are only concerned with health and social care;
- Cooperatives whose activities include, but are not limited to, the health and social care;
- Cooperatives whose activities do not include health and social care, but may include the provision of support to health and social care cooperatives.

The survey revealed that cooperatives tended to adopt either a user-based model or a provider-based model for provision of services in the health and social sector. A *user-based* cooperative is one that is typically set up by community members to help them to meet their health care needs. Users determine the health services provided and the cooperative negotiate contracts with health insurance and health care providers or they run their own services and hospitals. A p*rovider-based* cooperative is one that is typically set up by physicians or by entrepreneurs who wish to offer a wider range of services or to minimize costs through economies of scale. In summary, a cooperative in the health and social sector either provides health care to members or provides self-employment for health care professionals. The cooperative can be used as a platform for collective bargaining and advocacy or for enhancing economies of scale and sharing of costs.

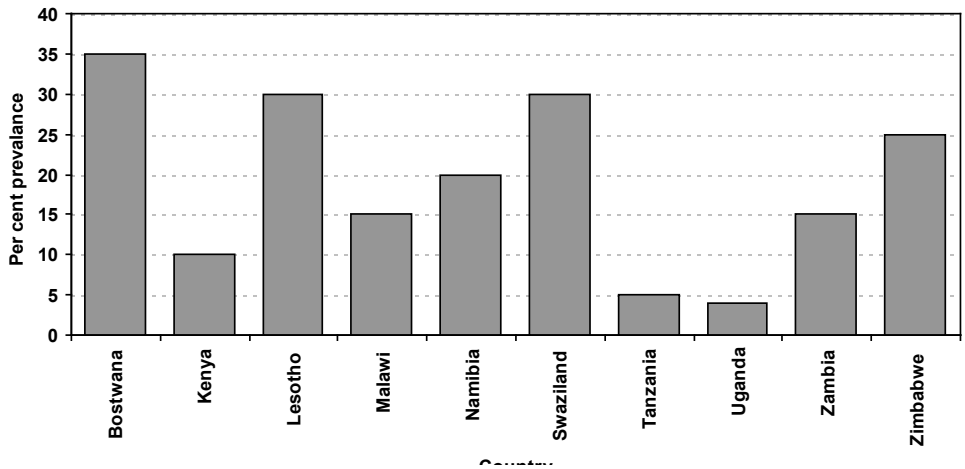
However a cooperative should only be qualified as *health cooperative* if it meets its members health needs. In such cases the cooperative is set up by the community members to help them to meet their health care needs. Members determine the health services needed and the cooperative negotiates contracts with health insurance and health care providers, or they run their own services and hospitals. Cooperatives set up by physicians or by entrepreneurs who wish to offer a wider range of health services, or to contain costs by sharing them should not be considered as *health cooperative* as the cooperative meets the economic needs of its members.

Health cooperatives are well developed in developing countries. For instance, in Brazil USIMED[4] is a user-owned health cooperative that provides extensive coverage to the population and that is complemented by the *Confederação Nacional das Cooperativas Médicas* (Nayar and Razum, 2003). UNIMED[5] is a provider-owned cooperative of physicians.

5.2 The impact of HIV on cooperatives

The impact of HIV on development has been widely documented, but little information on the impact of the pandemic on the cooperatives is available. UNAIDS (2003) estimated that cooperatives can have up to a 35 per cent prevalence rate among members depending on the country of origin (see Figure below).

Figure 2: Estimates of HIV prevalence among cooperative members in 2003



Source: UNAIDS (2003)

In 2001 the International Cooperative Alliance (ICA) and representatives of the national cooperative apex bodies for ten southern African countries acknowledged the impact that HIV was having on their members. They stated that there are no doubts that cooperatives in sub Saharan Africa have been severely affected by the pandemic. With AIDS-induced mortality, membership declines and member participation is depressed due to morbidity. As more members get infected with HIV and develop AIDS, their health status and productivity deteriorate thereby limiting economic performance of their cooperatives. Since HIV/AIDS affects people in their prime ages, it impacts on the most productive workers particularly in the agricultural cooperatives.[6]

[4] http://www.usimedfpolis.com.br/ . Usimed includes 377 cooperatives, owns 79 hospitals, networks with 3,700 hospitals, cares for 50 million patients per year, cares for 1,3 million patients in hospitals per year and has over 14 million of users.

[5] http://www.unimed.com.br/pct/index.jsp?cd_canal=34393

[6] Regional Consultative meeting on the role of Cooperatives in the Fight against HIV/AIDS, Mbabane, Swaziland, 27-29 August 2001.

In 2006, the Kenyan Ministry of Cooperative Development and Marketing identified HIV and AIDS as one of the development challenges likely to negatively affect the cooperative movement in Kenya. Furthermore, a 2009 study undertaken by the Swedish Cooperative Centre (SCC) on the impact of HIV/AIDS on cooperative societies in Kenya found out that the pandemic had a profound effect on the cooperative movement in the country, as it reduced membership, participation and contributions.

5.3 The cooperative model for the provision of HBC for PLHIV

Cooperatives are locally rooted organizations and are guided by principles including concern for community. There are several characteristics of the cooperative model that could make it a suitable provider of HBC for PLHIV. First of all, as cooperatives benefit from a large audience and can reach people in remote areas, they may be able to bring health care services to those who do not often access health facilities, thereby increasing the coverage of the targeted beneficiaries. The governance structure of the cooperative model ensures democratic members' control over the decision-making process, and this type of accountability can also ensure that members' priorities and specific needs are reflected in the cooperative's actions.

As cooperatives are voluntary organizations that are democratically controlled by members, members are empowered to drive the actions and responses taken by their cooperative. Its model can also offer a more sustainable service, as the members have identified the needs for HBC services for HIV/AIDS and have chosen to pay for it. The inclusion of income-generating activities (IGAs) can also improve members' incomes and thus their access to HBC. Through education, training and information, the cooperative model can contribute to the reduction of stigma and discrimination against PLHIV and their caregivers by providing HBC training to volunteers and community members. Within the framework of an integrated HBC, cooperatives can negotiate services with health facilities, and thus influence the quality and cost of care. Depending on their financial resources, cooperatives can also set up their own health units, negotiate for supplies and equipment (e.g. bulk purchasing for home kits) and can also improve caregivers' working conditions, particularly by developing mechanisms to compensate their work. They can also develop insurance schemes or link workers to existing insurance companies. Finally, the cooperative model provides space for discussion that can identify individuals' capacities and strengths that could be made available for the provision of care.

6. Case studies from Kenya and Lesotho on cooperatives on HBC

The case studies selected for analysis included organizations with a focus on economic empowerment of their members that have pursued provision of HBC and related services as a secondary activity. The table below provides a description of the cooperatives and self-help initiatives that were surveyed in Kenya and Lesotho.

Table 5: Description of organizations included in the case study

Organization	Description
Mavindini multipurpose cooperative society - Kenya	This cooperative was established in 2006 and is formally registered as a cooperative. The main purpose of the cooperative is economic empowerment of the community through supporting cotton and sunflower farming. The group currently has 172 members and has 15 known cases of HIV among its members. The cooperative covers Mavindini division of Makueni district. The cooperative has formed a group of caregivers who support each other in caring for orphans and vulnerable children (OVCs).
Kisau Waia multipurpose cooperative society - Kenya	This cooperative was established in 2004 and is formally registered. The main purpose of the cooperative is dairy farming. The group currently has 386 members and has 20 known cases of HIV among its members. The cooperative covers Mbooni East district. The cooperative has a farmers' group - Kisau Farmers' group - within it that carries out fish farming, beekeeping and sale of tree seedlings. The objective of the farmers group is to uplift the living status of their members and the surrounding community. They also use some of their proceeds to support several OVCs in the area.
Wirigiro-Machungulu self-help group – Kenya	This group was established in 2002 and is formally registered. The main purpose of the group is to support widows in the area both socially and economically. The group currently has 350 members and has 65 known cases of HIV among its members. The group covers Machungulu sub location of Igembe South district. They have received financial support from the Maua Methodist Hospital Sacco that has enabled the members to start income generating activities that improve their economic status. The group also has a group of home-based caregivers who support the members living with HIV and their families.
Village Health Workers Cooperative Society – Lesotho	The main purpose of this cooperative is to enhance and sustain village health work by delivering basic primary health care services to all individuals within their designated villages through a savings and credit scheme.
Se Ahe Serobe Phiri Ese E Jele Cooperative Society – Lesotho	The cooperative was established by a group of individuals who have HIV, with the objective of improving their livelihoods within their local community through income generating activities.
Kopanang Filoane Cooperative Society – Lesotho	This cooperative was established with the aim of providing agricultural and base health care support at the village and community level through a savings and credit scheme.

Source: Authors' own data

6.1 Regulatory environment

In Africa the regulatory framework for provision of HBC services ranges from very little regulation to a more formalized framework.

In Kenya HBC services seek to improve the quality of life of PLHIV and are crucial component of the Kenya National AIDS Strategic Plan (KNASP). The government of Kenya sets out the HIV and AIDS control framework within the *National HIV and AIDS Strategic Plan 2000—2005*. The strategy includes a three-tiered system involving a National AIDS Control Council (NACC), Provincial AIDS Control Committees (PACCs) and District AIDS Control Committees (DACCs). The NACC has the overall responsibility for monitoring and supervising HIV and AIDS related activities, while also being responsible for mobilizing resources, formulating policy and strategy, developing information systems, and collaborating with international and local agencies. The PACCs and DACCs coordinate with various government departments, the civil society, and the private sector, as well as PLHIV to carry out their mandate.

The most relevant to the immediate needs of HBC programmes in Kenya are the Constituency AIDS Control Committees (CACCs), whose members are drawn from the same sectors as the district and provincial committees. The committees collaborate closely with District Health Management Teams (DHMTs), District HBC Committees, local and district hospitals, health centres, and NGOs and CBOs that are working in health service delivery. The District HBC Committees have technical assistance and monitoring and evaluation functions. They assist local programmes to design HBC systems and ensure compliance with standards and guidelines. The HBC programmes train community health workers (CHWs) for 11 days to become HBC caregivers. They are supervised by facility health workers who are trained nurses and are overseen by the district HBC coordinator.

Also at national level in Kenya, each ministry has an AIDS Control Unit (ACU) to coordinate the implementation of the Strategic Plan across all sectors of the economy. The national AIDS and STIs Control Programme (NASCOP) is the AIDS Control Unit in the Ministry of Health and the technical arm of the fight against the pandemic. NASCOP also has the overall mandate of providing technical guidance, standards, and direction to all health care services related to HIV. NASCOP is therefore the supervisory body for HBC programmes.

In Lesotho there is no national legislation or policy document that is exclusive to HBC for PLHIV. Therefore, HBC is covered under the 'Treatment, Care and Support' thematic area of the *2007 Government of Lesotho National HIV and AIDS Policy* and the *2006 - 2011 National HIV and AIDS Strategic Plan*. The logical framework of the National HIV and AIDS Strategic Plan states an objective to improve the quality of HBC.

Coordination of HBC in Lesotho is the responsibility of the HIV and AIDS Directorate and the Family Health Division in the Ministry of Health & Social Welfare. National HBC guidelines which integrated HBC for PLHIV were published jointly by the Ministry of Health, Christian Health Association of Lesotho and the World Health Organization in 2002. Plans to establish a formal HBC coordinating body for all national HBC for HIV/AIDS implementers were initiated in 2009 by the Ministry of Health and Social Welfare. The overall aim of the HBC coordinating body is to ensure that HBC service provision adheres to a national standard. HBC services are currently being implemented by 15 different organizations, including ministries, non-governmental organizations and donor partner agencies. The Ministry of Health in partnership with the Christian Health Association of Lesotho is the officially recognized primary trainer of HBC for HIV/AIDS.

Cooperatives in Kenya may establish their own HBC programme and can be assisted by the HBC Committees and the HBC Coordinator. However, they have to request technical assistance and provide the funds needed to cover the training costs of caregivers. Cooperatives in Lesotho may also establish their own HBC programmes and can attend government funded HBC training. The training can be paid by the health facility that serves the community where the cooperative operates.

6.2 Major findings

The main HBC care service in which cooperatives that were studied seem to be fully involved is the *continuum of care,* as almost all of those studies have implemented **income generating activities (IGAs)** to enhance the living conditions of their affected and infected members.

In Kenya, the Mavindini and Kisau Waia cooperatives have been able to start various income generating activities, such as bee keeping and fish farming. They have used the proceeds from these activities to provide some support to HIV/AIDS infected and affected members. In Lesotho, cooperatives have implemented IGAs that benefit both individual households and their community. Vegetable and animal farming are the main IGAs undertaken at the village and community level. The outputs from such activities provide for the nutritional needs of infected individuals. However, in Lesotho, implementation of IGAs at times does not take into consideration the existing infrastructure at the village and community level. Pre-assessments of the capacity at village and community level are mandatory to ensure successful implementation of such activities. For example, in some cases cooperatives have been provided with vegetable seeds to grow produce, only to find that the community does not have the essential irrigation system to enable successful crop production. In another case cooperatives were provided with chicks for breeding into adult chickens without provision for fencing off the breeding area, which left the birds vulnerable to wild animals and vultures.

A second service in which cooperatives are involved and that is often linked to IGAs is **transport for referrals to health facilities.** In Kenya, the Mavindini and Kisau Waia cooperatives are able to provide transport when funds from the IGAs are sufficient. This decreases the burden of transportation costs on the affected family. The same findings have been observed in Lesotho.

Education is the third service in which cooperatives are involved. They appeared to be a main player in increasing HIV awareness. In Kenya, all the interviewed cooperatives had some form of education for their members that raised their awareness on HIV/AIDS. This was organized by the Ministry of Cooperative Development and Marketing in collaboration with the Ministry of Health. The training aimed at essentially training cooperative members to be peer educators for their colleagues and community members. Cooperatives have therefore been active in supporting behaviour change, sensitizing communities to HIV and related issues. One interesting finding was that the *Cooperative College of Kenya* had included HIV and AIDS in its curriculum, in order to raise awareness of the future cooperative officers and empower them with the skills to address HIV and AIDS in the cooperative movement. Nevertheless, the stigma levels in cooperatives were found to be high. In Kenya some respondents even dropped out of the Mavindini Cooperative because of the stigma they faced as PLHIV.

In terms of HBC for HIV/AIDS training, in Kenya most caregivers did not receive any training. However, in Lesotho the Ministry of Health & Social Welfare in partnership with the WHO and the Christian Health Association of Lesotho recently produced a HIV/AIDS HBC training package titled "HIV Prevention, Treatment, Care and Support - A Training Package for Community Based Care Givers". A ten day training course was designed to accompany this package and it is targeted at village health workers and community volunteers. Some cooperatives that provide HBC for HIV/AIDS have undergone training using the package.

Regarding the provision of care, in Kenya, this is one area where the cooperatives have not been able to full excel. This is partly due to a lack of trained staff. Although, it is noted that members are enthusiastic and ready to be trained as home based caregivers. However, it is also noted that cooperatives face basic barriers, including lack of supplies and equipment as they have no kits for treatment and do not have formal offices equipped with the appropriate medical material.

In Lesotho, three cooperatives provided some services related to the provision of care. The Lesotho Red Cross Society, the Lesotho Network of AIDS Service Organization and the Lesotho Network of People living with HIV and AIDS sometimes provide HBC care kits to the cooperatives and community volunteers. However, supplies are not sufficient to meet demand and items, such as gloves and antiseptic ointments, are frequently out of stock due to the demands of HIV/AIDS care at the village and community level. Caregivers that have HBC kits for HIV/AIDS often share its contents with other HBC caregivers, such as traditional birth attendants that provide care that is not specific to HIV. Because of the acknowledged priorities and commitments to HIV/AIDS at all levels, HIV/AIDS HBC caregivers

have wider access to HBC kit supplies and are sometimes exploited within their communities for their kit contents by other non-HIV caregivers . Despite receiving HBC kits from different stakeholder organizations, there is no formal system for supplying and replenishing HBC kits used by cooperatives and community volunteers. Cooperatives and community volunteers therefore receive their HBC kits on an ad hoc basis that is dependent on the stakeholder organizations supply, rather than on the demand of the cooperatives and community volunteers. Similarly, at the health facility level HBC kits are frequently out of stock, due to an erratic procurement, supply and management plan for the district Public Health Nurses.

Despite a commitment to provide HBC for HIV/AIDS, the cooperatives have varied levels of commitment and capacity to implement HBC for HIV/AIDS. Additionally, the quality of HBC provision of care differs between cooperatives. In Lesotho, in households where the village health workers are providing HIV/AIDS HBC, the services are more likely to be comprehensive and applicable to all the six sub-categories for provision of care because the village health workers have been through formal HBC training that adheres to the prescribed national standards. In contrast, cooperative members and community volunteers or support groups have not been formally trained.

Financing and sustainability remain the major challenges for all the interviewed cooperatives, though they have been able to make progress in this area due to funds derived from the income generating activities. Some cooperatives also allow members to contribute some money to meet the needs of the infected members, but this remains limited.

Due to the informal nature of the HBC services provided by the cooperatives, most of them only have an informal monitoring and evaluation system. This involved visiting the beneficiaries and having discussions with them on the support they have received. The approach to monitoring and evaluation is therefore mostly a qualitative and participatory. In Lesotho, as part of the 2006-2011 National HIV and AIDS Monitoring and Evaluation Plan, cooperatives at village and community levels are supposed to complete a form on a monthly basis that is known as the 'Programme Activity Monitoring Form specific for HBC for Community Based Organizations'.[7] However, there is limited understanding of the purpose of monitoring and evaluation at village and community level, so the form is not used routinely by cooperatives.

[7] Reporting is on five indicators which are included in the Core output indicators listed of the 2006-2011 National HIV and AIDS Monitoring and Evaluation Plan:

i. Number of new patients who enrolled for HBC this month
ii. Total number of chronically ill people receiving HBC from your organization in this month
iii. Number of caregivers in your organization that are providing HBC this month
iv. Number of caregivers in your organization that have been trained to provide HBC this month
v. Number of chronically ill people receiving the different types of support of HBC

For each indicator the total number is disaggregated by gender.
Cooperatives forward the completed form to their local Community Council every month. The Community Council then forwards the form the District AIDS Coordination Monitoring and Evaluation (M&E) officer for entry into the Country Response Information Systems (CRIS) electronic database. The District AIDS Coordination Office then forwards the data to the National AIDS Commission.

Most of the individuals who are responsible for completing the form at community level are volunteers with varying levels of commitment to reporting, therefore, it is not unusual to have no reports submitted for certain months. Poor reporting from the village and community level has been noted during the harvest and festive seasons when volunteers are more likely to shift their responsibilities away from monthly completion of forms. Cooperatives report to either their community council or to the local Ministry of Trade focal point, mainly by way of a monthly written report using a non-standardised format. HIV/AIDS HBC information that is included in the monthly report is not regularly communicated to the district AIDS coordination monitoring and evaluation officers.

One major challenge is getting the donors who support HIV initiatives to recognize that cooperatives provide a good opportunity for the provision of HIV related services in the communities where they are located. If well established, cooperatives may have the potential to use their organization and networks to provide such services. If cooperatives were supported to carry out HBC with funds from donors, many communities could be transformed in the way they provide responses to the HIV and AIDS pandemic. However, to ensure the sustainability of these initiatives, it is important to also have funding from within the cooperative movement, such as funds derived through IGAs. However, most IGAs started by cooperatives are on a small scale and require up-scaling. The ability of the cooperative to up-scale should be seen within the context of the broader economy in which it operates, as the economic condition may be a constraining factor for effective up-scaling (e.g., demand deficiency).

At national and community levels there are no clearly defined budget lines for HIV/AIDS HBC. Because HBC is not exclusive to HIV/AIDS management, there is little clarity on the provision or continuum of care for which funding can be disbursed. However, as HBC for HIV has a large public good component, the state should extend funding for such services.

7. Conclusions and recommendations

HBC as a response to HIV is still relatively under-researched in Sub-Saharan Africa. The literature regarding HBC initiated by self-help initiatives tends to focus on one or two projects, and does not allow one to draw objective and evidence-based conclusions and recommendations. From the data that are available, community-based self-help initiatives have addressed needs for HBC of PLHIV that the public health systems have not been able to provide. They all seem to face the same challenges and difficulties associated with both financial and human resource constraints, as well as weak linkages with formal health services. The cooperative model, through its principles and values, may strengthen initiatives that provide HBC for PLHIV. Despite the positive aspects, several questions remain in regard to the legitimacy of the involvement of the cooperatives, particularly cooperatives whose primary objective is not the provision of health services, in the health sector to cope with the failure of the public health system. The partnership with other

organizations and/or the state can also be questionable regarding the autonomy and independence of cooperatives. Therefore, further research needs to be undertaken on the relevance of the cooperative model as vehicle for the provision of HBC for HIV/AIDS.

The participation of organizations such as cooperatives can be questionable according to three points of view. Firstly, access to health care is a fundamental human right, recognized in the Universal Declaration of Human Rights (1948) and the Constitution of the World Health Organization (1946). Therefore, one of the first issues relates to the debate on where the responsibility for ensuring access to health care lies. The Alma Ata Declaration (1978) reminded that primary comprehensive care was a right and stated that it was a responsibility of governments. However, the economic austerity policies of the structural adjustment era substantially reduced the role of the state in the provision of health care services. Privatization through the introduction of "user fees" for health services, the promotion of health insurance schemes increasingly transferred the provision and the control of the health system from African governments to the private sector. The Bamako Initiative (1987) confirmed the application of user fees, and thus the breakdown of free health care. Nevertheless, in 2000 facing the growing criticism related to the negative impact of such policies on the poorest, the World Bank stepped back from the promotion of user pay services. Since then public-private partnerships, (PPP) including cooperative public service delivery (CPSD), have been used increasingly. This trend has seen the public sector utilize civil society and the private sector for the delivery of public goods and services in order to address public health issues, particularly HIV/AIDS.

From an ILO perspective, governments, employers and workers, in both the formal and informal sector, can all be involved in the financing and implementation of initiatives related to HIV and AIDS. The ILO code of practice on HIV and AIDS (2001) clearly states the general rights and responsibilities of governments, employers and their organizations and workers and their organizations. More specifically, governments should estimate the social and economic implications of HIV and mobilise resources to mitigate its impact. They should also seek to include those in the informal economy and make use of locally based solutions where appropriate by ensuring that local communities, local businesses, unions and other organizations are involved.

Employers and their organizations should consider developing preventative and care programmes, particularly for enterprises in the informal economy. Workers and their organizations, particularly those in the informal economy, should support initiatives to prevent the spread of HIV and initiatives that mitigate its impact.

The ILO's 2002 Promotion of Cooperatives Recommendation (No. 193) specifies that:

"Governments should introduce support measures, where appropriate, for the activities of cooperatives that meet specific social and public policy outcomes, such as employment promotion or the development of activities benefiting disadvantaged groups or regions. Such measures could include, among others and in so far as possible, tax benefits, loans, grants, access to public works programmes, and special procurement provisions."

Despite these evolutions, debates remain on the legitimacy of having actors other than the state in the provision of public goods, such as health. Thus the participation of organizations, such as cooperatives, in the provision of health care services including HBC services for PLHIV needs to be well thought out. Services can be contracted out to the private sector through public-private partnerships, but this process should not undermine the autonomy of enterprises involved. In the case of cooperatives, such partnerships should reflect members' needs, the cooperative's capacity to deliver and include strategies to promote the long-term financial and social sustainability of the initiative. Importantly, the state should take initiative in health care by providing the policy and regulatory framework, setting standards for workplace practices and training, and conducting monitoring and evaluation activities.

The cooperative model includes different types of cooperatives, such as a multi-purpose, consumers' or producers' cooperative, all of which can play various roles in the provision of health care services in society. While cooperatives have a mandate to meet their member's social, economic and cultural needs, individual cooperatives still exists for a key purpose. The role of cooperatives whose main purpose is not health oriented in HIV related activities and services needs to be individually determined in light of members' priorities and the overall impact that it could have on the cooperative's sustainability.

Considering the lessons learnt in terms of provision of HBC for PLHIV by organizations registered as cooperative, the following recommendations can be made:

- Cooperatives can act as a focal point for mainstreaming HIV as a critical issue within the cooperative movement and broader civil society. A holistic approach that includes, among others, preventative education as well as healthy living (nutrition) can be promoted;
- Cooperatives should develop linkages with the health sector so that they can get access to training and materials supply and support on technical and logistical matters;
- Meeting economic as well as social and health needs is highly important for PLHIV and initiatives that couple health services with IGA improve the overall situation of PLHIV.

Further research on the comparative advantage of the cooperative model for provision of care and support for HIV/AIDS would be valuable. This should include comparative studies between programmes offered by cooperatives (any type) and programmes offered by other organizations. Such a study should consider the working conditions and status of health workers and volunteers involved in HIV/AIDS HBC care.

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Coop[AFRICA] Working Paper No.19 with ILO/AIDS

The cooperative model for the delivery of home based care services for people living with HIV

Sandrine Lo Iacono and Emma Allen

Cooperatives, like other organizations, are affected by HIV and AIDS through loss of their members, their workforce and their leaders, which indirectly affects members' revenue and the cooperatives' capacity to address members' needs. However, cooperatives can also be thought of as part of the solution. Indeed, many communities in Africa have organized themselves and set up self-help initiatives to address their own health needs, including those related to HIV. This working paper looks at home-based care (HBC) and considers whether the cooperative model could potential add-value to this modality of health care provision.

ILO Country Office for the United Republic of Tanzania, Kenya, Rwanda and Uganda
COOP[AFRICA]
Kazi House, Maktaba Street
P.O. Box 9212
Dar es Salaam
United Republic of Tanzania
Tel: +255.22.2196700
Fax: +255.22.2122597
E-mail: coopafrica@ilo.org
www.ilo.org/coopafrica

International Labour Office
Cooperative Programme (EMP/COOP)
4, route des Morillons
1211 Geneva 22
Switzerland
Tel: + 41.22.7997021
Fax: +41.22.7996570
E-mail: coop@ilo.org
www.ilo.org/coop

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