MBUYA HOME BASED CARE ALLIANCE: GRASSROOTS WOMEN IN ACTION ON HIV/AIDS IN SLUM COMMUNITY OF MBUYA, UGANDA

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Context and policy environment

In Uganda, the first case of HIV/AIDS was reported in 1982. At the time, neither the government nor Uganda's citizens understood what it was that had befallen those infected by the disease. Several lives were lost while health authorities sought a solution. Many of the victims believed that they were being punished or attacked by evil spirits or witchcraft and so turned to local herbs and traditional herbalists for solace. Others visited medical doctors, though with little hope for recovery.

Towards the 1990s, research revealed that the strange disease was a virus that caused HIV/AIDS. Despite the fact that the disease had already spread to many parts of the country, the Government of Uganda instantly launched massive awareness campaigns on HIV/AIDS.

Challenges ranging from the political to the psychosocial, the economic to health became the order of the day for individuals, families and communities infected and affected by HIV/AIDS. Government endeavored to support the affected population by halting the alarming situation, but its resources were limited and would not last long. Hence, many people continued to suffer and lose lives because the existing health units could not meet the overwhelming needs of the large numbers of patients. Poverty levels shot up because families spent their meager income and savings in medical consultations and treatment. Many children were vulnerable as they contracted the disease from their mothers at birth. Others lost their guardians and parents to HIV/AIDS. The family unit broke down as husbands and in-laws tended to blame their wives for the abominable disease; many abandoned their homes and deserted the wives with children.

While government continued to support research efforts on the virus and the dissemination of information, non-government organizations (NGOs) came on board to compliment government efforts as well as support HIV-positive persons and communities. This was done through awareness campaigns and voluntary counseling because of the high stigma attached to HIV/AIDS infected and affected persons. At the same time, individuals developed self-help support groups to console each other and think together of ways to cope with the pandemic.

The concept of home-based care

Many victims of HIV/AIDS preferred to stay in the confines of their homes because of the high stigma and discrimination from society towards those infected with the disease. The sick persons required medical attention and support but they could hardly afford it due to biting

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poverty. As a result, grassroots women started becoming more and more involved in the lives of HIV/AIDS infected persons and affected families.

Grassroots women volunteered to start visiting infected people. Some did not have relatives left, while others were being ex-communicated by their families. During the visits, the volunteers would counsel people, pray for the victims, help them out with their home chores and, most importantly, encourage them to go for treatment at specialized health centres. This comfort and support brought about positive change in the lives of HIV positive persons; it gave them a will to continue living while accepting their status.

Although home-based care work was causing tremendous change in the lives of infected and affected families, it was not yet recognized because the grassroots women were working without any organization and many still lacked adequate information about HIV/AIDS as well proper training in providing home-based care.

The birth of Home Based Care Alliance

In 2005, GROOTS International came up with an initiative called Home Based Care Alliance (HBCA), which was initially piloted in Kenya before being replicated in other countries globally, Uganda included. The initiative aims to bring recognition to the contributions of home-based caregivers, to shift resources and decision making power to caregivers, to form a broad network for peer learning, and to serve as a platform for advocacy and negotiations with government, donors, and other decision makers in the field of HIV/AIDS.

The primary goal of the HBCA is to organize a social movement aimed at supporting grassroots women caregivers to strengthen the provision of care services and care systems. The secondary goal is to strengthen women's political participation and their position within certain societal structures.

Uganda Community Based Association for Women and Children welfare (UCOBAC) coordinates the HBCA in Uganda. UCOBAC is an NGO and a member of GROOTS International and the Huairou Commission. Since its inception in Uganda, the Alliance has grown to be organized in nine different communities in the country with Mbuya Home Based Care Alliance being the latest to be established. Other existing HBCAs are located in; Kawempe, Masaka, Bugiri, Rubaga, Jinja, Busia, Nakawa and Kaabong.

Mbuya Home Based Care Alliance

Mbuya Home Based Care Alliance (MHBCA) came into existence in 2011 and it is organized in the slum community of Mbuya/Kinawataka – Nakawa division in Kampala district. The alliance began with 10 members from two parishes, with 8 women and 2 men at the time. To date, membership has grown to 100 including 76 women and 24 men from two other parishes: Mbuya I, Mbuya II, Banda and Mutungo.

Before joining MHBCA, many of the home based caregivers were engaged in various activities such as market vending of local food, selling second hand items such as clothes, working in retail shops as shop keepers while others were community volunteers without being recognized as home-based care givers. Some members were housewives without any other sort of employment or engagements outside their homes.

In 2011, UCOBAC, working with Focal Point Persons of older existing HBCAs, started Mbuya Home Based Care Alliance. A need for organized home-based care services had been identified in Mbuya community where UCOBAC secretariat is also situated.

Since its existence MHBCA has been headed by Ms Ndaa Rose, a grassroots woman leader who was initially a community volunteer trained by the Red Cross on water and sanitation. She and several other members have undergone training in home-based caregiving and Home Based Care Alliance organizing, facilitated by UCOBAC.
Rose has used her skills to mobilize, enroll and train more home based caregivers from her community and the surrounding areas. Despite the challenges experienced in volunteering to be home based caregivers, the members have chosen to stick to team work because they believe that as a team they have a stronger voice for advocacy and higher chances of their efforts towards community development being recognized.

MHBCA objectives are:

- To ensure an efficient flow of resources to victims of HIV/AIDS and HBC givers.
- To develop a collective advocacy platform for stakeholders concerned about HIV/AIDS.
- To bring HBC services closer to clients in areas of Mbuya and the surrounding.
- To increase MHBCA income to sustain HBC activities.
- To bring recognition to the contributions of the HBC givers.
- To promote proper hygiene and sanitation.

Women in action: MHBCA activities

1. Provision of Home-Based Care (HBC) services.
   HBC was and still is the core activity of MHBCA. Through HBC, the women reach out to persons infected with HIV/AIDS by providing support and care which involves regular visits to HIV/AIDS patients, helping out with home chores, cleaning and feeding patients, encouraging patients to adhere to ARV therapy and for voluntary counseling and testing (VCT).

2. Income Generating Activities (IGAs)
   Grassroots members of MHBCA earn income to sustain the Alliance activities as well as their families through IGAs such as mushroom growing, poultry keeping, making of crafts and making of liquid soap. The idea of IGAs was embraced because it was becoming quite challenging to sustain the alliance activities and members' families without any reliable source of income. Members of MHBCA in 2012 decided to each contribute 1000 shillings (0.35 USD) as savings for the alliance on a daily basis. When the amount totaled 84,000 shillings (29.5 USD) they approached UCOBAC with the idea of starting a mushroom growing project and they requested 150,000 shillings (52.5 USD) from the organization. They chose to start with this idea because it was cost friendly and fairly easy to sustain. Profits made are ploughed back into the business for expansion and occasionally, the women borrow from the business savings.

   Currently the women are actively involved in more IGAs including; poultry keeping, liquid soap making and crafts making. The alliance also relies on membership fees as a source of income.

Women making crafts as part of their IGAs.

3. Local to local dialogues

Using this governance tool, MHBCA grassroots women discuss and air out their most pressing needs and concerns with their local leaders to solicit their support and ensure gender sensitivity in decision-making. It has helped them to promote healthy working relationships among leaders and the grassroots community.

4. Training

UCOBAC periodically trains the grassroots women on home-based care, advocacy, human rights, women's rights and HIV/AIDS facts. The organization also facilitates capacity building for project management.

5. Community cleaning

In a bid to improve community health and mitigate the rampant spread of diseases such as diarrhea, cholera and malaria, MHBCA promotes proper hygiene and sanitation by mobilizing their members along with the rest of the community for communal cleaning. They encourage community members to clear bushes from their homes, clear garbage from water source points (wells) and trenches.

6. Community sensitizations

The grassroots women work with local council chairpersons to organize village meetings to sensitize citizens on facts about HIV/AIDS, women and children's rights, hygiene, and sanitation. They are also involved in music, dance and drama activities that are educational, informative and entertaining for the community.

Members of MHBCA during a community cleaning activity

7. Women and child rights activism
   Members of the alliance also attend to the rights of women and children by reporting cases of abuse to local leaders and police, as well mediating at times.

8. Peer exchange visits
   Women network with fellow home-based caregivers mobilized under UCOBAC's umbrella to learn from their experiences and share best practices as well as to collectively troubleshoot challenges facing the alliance.

MHBCA impact

Lobbying of local authorities like the Kampala City Council Authority (KCCA), police and local council chairpersons to prioritize and respond to the needs of the community, thus linking local communities to local leadership and promoting accountability and transparency in local leadership processes.

Improved knowledge levels that is; creation of community awareness on HIV/AIDS, health related issues and human rights – particularly women and children's rights

Promotion of community hygiene and sanitation through community cleaning drives.

Home Based Caregivers have also benefitted in important ways from being part of an alliance:

Recognition in the community

Six home-based caregivers have been recognized for their hard work and contribution to the communities and have been appointed as Village Health Team (VHT) representatives in their respective parishes.

Economic empowerment
The group's IGAs have enabled the women to gain skills, build new networks, and earn some income to sustain their families. They are inspired by the alliance's IGAs and are aiming to replicate those ideas as personal income generating activities.

Increased women's participation in decision-making processes
Using the local-to-local dialogue strategy, the women have been able to access political space to air their concerns and thus influence local decision making. Two female members of the alliance ran for positions in local government. While they were not elected, this has not discouraged the women because they have been empowered with knowledge concerning their rights and they are looking out for upcoming opportunities.

Members of MHBCA in the shop where they sell the crafts they make.

New supportive partnerships
Establishment of working relationships with the public, private and civil society sectors; Recognition of MHBCA by local authorities such as Kampala City Council Authority, National Water and Sewerage Corporation, local health units and other NGOs like Mbuya Outreach is advantageous because their issues are prioritized when these entities hold major community campaigns. Members of MHBCA are invited as partners to participate in activities such as training workshops, community sensitizations and clean ups.

Challenges and future plans

Notwithstanding the good achievements that have come about through the alliance, there are some challenges faced. These are;

- High volunteer burn out because of limited or no payment.

- Low financial base for supporting alliance activities.
- High expectations of beneficiaries of home-based care services and sometimes, rude patients that think that they are above home-based care.
- Lack of office premises which would create more visibility for the alliance.
- Limited space/land for carrying out income generating activities.

To address them, the grassroots women are planning to take new actions. For example, expanding existing IGAs of the Alliance to earn enough profits to start IGAs at a personal level and venture into new ones such as tailoring. Linked to that is a plan to establish a savings and loans scheme, recruitment and training of more grassroots women and leaders and organizing peer-exchange visits, to share experience and learn from others.