

THE KAWEMPE HOME-BASED CARE ALLIANCE: TOGETHER FOR RECOGNITION AND SUPPORT

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Introduction

In the early 1980's Uganda was hit by a "strange disease" and many communities struggled to understand and deal with the difficulties that it brought in. The disease was concentrated in some parts of the country and very little was known about it. So many lives were lost and many families' meager resources dwindled very fast as they tried to care and support the people infected. By the 1990's this strange disease was confirmed to be HIV and AIDS. There were massive sensitization campaigns by government on HIV and AIDS. However, by this time, AIDS had spread everywhere in the country and this posed many political, psychological, social, economic and health challenges to the affected individuals, families and communities.

The infected persons suffered unbearable pain from the illness and also suffered very painful deaths. The existing health facilities were over stretched with the increasing number of patients in the few existing health units which lacked sufficient facilities/equipment and medicinal supplies. Stigma was extremely high due to the high level of ignorance about the disease and the fact that it was associated with promiscuity. Many families became very poor and unable to cope with the situation as most of the bread earners got infected and therefore could not work to provide for their families or even died leaving them unable to meet their basic needs. Many families also spent all their meager resources on the sick members of the family and thus became poorer. The number of orphans and vulnerable children shot up. Traditionally in the African context, such children were taken up by their extended families, however, by this time, this structure had started to collapse as the burden had become too heavy for any family to handle. Further still, due to these difficulties, many young boys and girls moved from the rural areas to the urban areas hoping to find jobs to support their families back home or even move their families to the cities where they could access better facilities. However, this did not solve the problem, it instead created a new problem.

Due to this massive rural to urban migration, many slum areas sprung up. The slum areas continued to rise and expand as more people moved from the rural areas to the urban settings, as a way to forge and live a better life for themselves and their families. This created new and

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unique problems and challenges to the occupants in the slum areas including the high spread of HIV and AIDS and its associated effects/challenges. The situation here was even worse off than in the rural communities due to the extremely poor facilities and living conditions within the slums. Stigma was still very high and the traditional extended-family support structure was totally broken down in the urban setting, making it more difficult for those affected and infected in the slums to cope by themselves.

By this time, the government of Uganda was extremely stretched and could no longer deal with this pandemic by itself. Many non-governmental organizations came in to compliment the efforts of the government and many of these were community based and therefore easily accessible by many infected and affected persons. They provided all sorts of care and support including sensitization campaigns and voluntary counselling and treatment. However, this did not reduce the stress and burden suffered by many individuals and families due to the massive and widespread effects of HIV and AIDS. The government and NGO's were overwhelmed, they could not support all affected individuals and households. As a result, individuals, small community self-help and support groups started to take action to support their neighbours by organising to deal with the pandemic in their own communities.

The concept of home-based care

Individuals who were mainly grassroots women started visiting their infected and affected neighbours. This was mainly to provide care and support to the infected and affected so that they could cope with the effects of HIV and AIDS. It was also because many sick people preferred to stay in the confines of their homes due to the high stigma associated with the disease and also due to the fact that they could not afford to pay for extended stays at the health units. Expenses incurred when someone stayed long at a health unit financially strained many families. A few individuals felt that it was their responsibility to support such individuals and families who often did not even have family relatives to care for them in the city. While making the home visits, the individual volunteers counselled and prayed for the sick and their families; they washed the sick, cleaned their wounds and bed dressing, fed them, cleaned their homes. They also encouraged them to go for HIV and AIDS testing and treatment in specialized health units in the community. They provided them with food, drinks, clothing, soap, water and anything they could manage to provide to make their lives more comfortable.

This greatly improved the lives and health of many sick people who felt loved and cared for and as a result of the support provided by the home-based care volunteers. Many people started living positively and this brought tremendous changes to all aspects of their lives, including psychologically, socially, economically, and health wise. Many individuals, especially those that had been considered terminally ill, and whose health improved due to the home-based care support they received, also became home-based care givers themselves, having experienced the value of such care and support. The numbers of home-based care givers therefore grew everywhere in the communities, both in the rural and urban areas.

However, despite this growth of volunteers, they faced major challenges as care givers in doing their work. For instance, they lacked sufficient information on HIV and AIDS; they lacked sufficient training in HIV and AIDS management; they lacked protective wear to use while

attending to their patients and first aid kits. They were also challenged by having to travel long distances, and most importantly they were and are not recognized or supported by the government for the contribution they are making towards a response to HIV in their community. This lack of recognition for caregivers' work is mainly because they are not integrated into any programme or organization and worked in isolation.

The Home-based Care Alliance

The Home-based Care Alliance is an initiative of GROOTS International, which was initially piloted in Kenya in 2005 and is now being replicated and organized in other countries including Uganda. It aims to bring recognition to the contributions of home based care givers, 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 AIDS.

The goals of the HBC Alliance are to organize a social movement aimed at supporting grassroots women caregivers to have the primary outcome of strengthening the provision of care services and care systems and the secondary outcome of strengthening women's political participation and their position within certain societal structures.

Its objectives are:

- To bring recognition to the contributions of the home-based care givers;
- To influence the shift of resources and decision-making power to care givers;
- To become a voice for the voiceless so that the home-based care givers can be recognized at all levels;
- To bridge the gap between the national and community level;
- To ensure that the resources are effectively flowing to those infected and affected by HIV/AIDS, including OVCs, PLWAs, and HBC givers;
- To ensure that there is no duplication of services and efforts at community level;
- To hold caregivers accountable for their services;
- To form a broad network for peer learning;
- To serve as a platform for advocacy and negotiation with government, donors and decision makers in the field of AIDS.

In Uganda, the Home Based Care Alliance is being coordinated by the Uganda Community Based Association for Child Welfare (UCOBAC), a non- governmental organization and a member of GROOTS International and the Huairou Commission. The Alliance is being organized in different regions in the country including: the Eastern region (Bugiri, Busia and Jinja districts); the Central region (Kampala district including Kampala central and Nakawa, Kawempe and Rubaga divisions); the Southern region (Masaka district) and the Northern region (Kabong district).

Reflections on the experience

The Kawempe Home-based Care Alliance (KHCA) is organized in an urban community of Kampala, which is the capital city of Uganda, in a slum community called Kawempe

Kisalolosalo zone. The KHCA was started in November 2007 and is made up of 452 members (402 women and 50 men.) These are all at Home Based Care givers from 11 parishes of Kawempe division.

Originally this work was mainly dominated by women as care work is traditionally viewed as a domain for women; however, with time we have seen more men getting involved in this work mainly because they have experienced and seen the value of care and support in HIV and AIDS.

Starting to get organized

After realizing that home-based care givers were doing a lot of work in the community but facing a number of challenges as described above, it was considered important for home-based care givers to mobilize themselves to come together so that they could work as a team, and, as a group, be in a stronger position to influence government and other partners for more support and recognition of their contributions to the health sector and the development of the country as a whole.

The KHCA is coordinated by Ms. Masitulla Nakisozi, a grassroots woman leader who has been providing home-based care since 2005. She underwent training in home-based care alliance organizing, facilitated by UCOBAC, and with the skills acquired started mobilizing other home-based care givers in her community and in the neighbouring community.

She is still in the process of mobilizing and enrolling more home-based care givers to the Alliance. She has oriented the members of the Alliance in the concept and this has been very much appreciated by all the members as they have realized that working separately makes them weaker and does not advance their work, whereas working as a team makes them stronger and advances their work in the community.

Alliance activities

- Local to local dialogue sessions: This is a governance methodology used in the alliance where members organize and prioritize their needs and issues in the community and strategically engage with local leadership in a way that influences their local planning, decision-making, local financing, and programming to be responsive to these raised needs and concerns. It's aimed at increasing women's participation in local decision-making and to influence policy. It is also to hold the leaders accountable and encourage political transparency and effective communication between the leaders and the common person at grassroots level. It bridges the gap between local leadership and community members, specifically women, who are traditionally marginalized from such public spaces. Taking advantage of the decentralization processes in the country where decision-making powers and resources have been shifted to local levels closer to the people creates an opportunity for such methodologies to be adopted by women to participate more in these processes and benefit more meaningfully from them. Through the local to local dialogue sessions, the Alliance members have been able to lobby for support and recognition of their contributions to the health sector and the development of the community. Through this, they have been able to get some financial and material support to advance their work

- **Training:** The home-based care alliance members are also trained periodically by support organizations like UCOBAC and Kamwokya Christian Caring community in important aspects required to do their work better. They are trained in issues like concept of HBC, facts about HIV and AIDS, positive living mechanisms, local to local dialogue methodologies, women's rights, children's rights, counselling and communication skills, etc.
- **Home-based care provision:** The home-based care givers also provide care at home using the skills acquired. They provide psycho social support, first aid treatments and referrals for specialized care, home cleaning, etc.
- **Community trainings:** Home-based care givers in the Alliance also mobilize their communities and sensitize them in different topics especially health and human rights issues.
- **Income generation:** They are also involved in group income-generation activities such as making books and handicrafts to raise income for the Alliance activities.
- **Community cleaning:** Members are engaged in community cleaning campaigns where they collect rubbish and sweep their communities to promote good hygiene in their community. Local government donated a rubbish collection truck as a contribution to this work.
- **Immunization and family planning clinic:** The alliance also hold periodic community immunization and family planning mobile clinic campaigns in their community.

Results and changes

- They have been able to lobby government to prioritize and respond to the needs of the community and promote accountability and transparency in the local leadership processes;
- Community awareness on HIV/AIDS, health related issues and human rights specifically women's rights and children's rights has increased;
- Promoted community hygiene and sanitation through the community cleaning drives;
- Promoted good health among people infected and affected by AIDS and others through home-based care giving and immunization and family planning drives, thus reducing unnecessary deaths.

Empowerment of women

- **Recognition in the community:** The home-based care givers and their work are now more recognized and respected and thus supported for their contributions to the community and the country at large.
- **Increased women's participation in decision-making processes:** Through the local-to-local dialogue sessions, women have been able to effectively participate in decision-making processes; influencing policy through such dialogue further encouraged 7 of the members to

participate in elective local politics and 3 made it! These are women who had never thought it could be possible for women to participate in the “men’s political domain” but through this, they have been empowered and know their rights as women.

- **Economic empowerment:** The members of the Alliance are now involved in group income-generating activities (book making and craft making) and also are involved in group savings and loans schemes which allow them to access income or start-up capital to start up personal business activities from which they can derive an income to meet their needs.
- **Participation in National sectoral planning processes:** Members of the Alliance were involved in the drafting of the National Health sector strategic plan where their views and contributions were very much appreciated as they effectively represented issues at the community level especially regarding strengthening community health systems.

Challenges:
 - Burn out of volunteers
 - Lack of resources
- **Government Village Health Team recruitment and health community trainers:** As an outcome of some of the lobbying during the process of drafting the country’s health sector strategic plan, over 20 of the Alliance members have been taken on by government to serve as Village Health Team members. Many members of the Alliance have also been taken on by other organizations working in their communities as community health trainers, which strengthens their skills and provides payment for the services provided.
- **The Alliance is now fully recognized** by other development partners and now Networks and collaborates with other NGOs, health units, besides government.
- **They participate in ongoing National health campaigns** like the stop malaria campaign, 2011 platform campaign, and maternal mortality and HIV and AIDS campaign.
- **They participated for the first time in a Regional research**, called the Compensation for contributions research, which documents the contributions of home based care givers and is a strong global advocacy tool.
- **The Alliance has secured funding from government** (Kampala City Center Authority) to expand their work in their community.