Building Bridges

Home-based care model for supporting older carers of people living with HIV/AIDS in Tanzania

Rapid Funding Envelope

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Since 1987, HelpAge International in Tanzania is seeking to create a wider understanding and recognition of the ageing issues, and particularly poverty in old age, within the civil society and the government, by supporting a strong movement of older people through actions that empower them, by strengthening age care organizations, by facilitating their interaction with government structures and access to resources and by seeking to mainstream ageing issues into development agenda of the country so that these actions can lead to alleviation of poverty and improvement in the quality of their lives. HelpAge International maintains active links with a range of civil society organizations, national NGOs, government agencies and departments, and academic and research institutions to take forward its development agenda and policy dialogues.

Acknowledgements

This model of home-based care for supporting older carers of people living with HIV/AIDS (PLWHA) was developed from a pilot project coordinated by HelpAge International, in collaboration with its partners, district and community leaders, and older women and men carers in 57 communities within Tanga, Arusha, Dar Es Salaam, Iringa and the Coastal regions in mainland Tanzania. The project was implemented by, and received valuable support from, the Good Samaritan Social Services Tanzania (GSSST), Tanga Elderly Women Resource Centre, (TEWOREC), Southern Highlands Senility Organization (SHISO), Walio katika Mapambano na UKIMWI Tanzania (WAMATA) and Arusha Retired People's Association CHAWAMA).

We are very grateful to the support and encouragement of the leadership of District Councils, Regional and Districts AIDS Control Coordinators in the pilot areas, and many others who have facilitated the processes for this model. We would also like to acknowledge the invaluable contributions of HAI colleagues in London and at the Africa Regional Development Centre in Nairobi. We especially appreciate the active participation of all the older carers of people living with HIV/AIDS and PLWHA themselves.

Finally, we are most grateful to the support and advice we received from the RFE Grant Managers, Deloitte and Touché, from National AIDS Control Programme and (NACP) and Tanzania Commission for HIV/AIDS (TACAIDS).

The project and this model were made possible through the generous funding provided by the Rapid Funding Envelop (RFE).

Registered British Charity number 288180

Front cover photograph: CHAWAMA
Back cover photograph: TEWOREC/CHAWAMA

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1. Background

Government HIV/AIDS care and treatment policies
The Government of Tanzania has developed various policies and guidelines to address the HIV/AIDS pandemic, including Tanzania's National HIV/AIDS Care and Treatment Plan 2003-08 approved by the cabinet in October 2003 and committing the government to reach up to 500,000 HIV positive Tanzanians with Anti-Retroviral Therapy (ART) over the five year period of the plan as well as the delivery of ART in Public Health Facilities in October 2004.

Although the above programme is more than three years into its implementation, it is facing a number of challenges and constraints. These include slow take-off leading to failure to reach targets; low uptake of ART among paediatric patients due to lack of awareness of existing facilities in the communities and inadequate linkage with community home-based carers.

Home based carers have not been trained on issues related to ART and there is an overall lack of human resources to support its delivery. The care and treatment training provided by the plan usually takes 6 days and tends to be medically oriented hence focusing on medical personnel such as clinicians, pharmacists, laboratory personnel, nurses, counsellors and HBC providers with medical backgrounds. Up to August 2006 the total number of people living with HIV/AIDS (PLWHA) reached with ARV drugs is 43,800 with only 30 reported cases of adverse side effects due to the drugs[1].

National Guidelines for Home-based Care Service Providers
Moreover, the Ministry of Health and Social Welfare has developed National Guidelines for Home-based Care Service Providers (February 2005) to guide the implementation of home-based care in the country. The guidelines stress, among other things, the importance of provision of comprehensive care and linking services within the continuum of care from relevant health facilities to the community levels. Realizing the diversity of needs of individuals and families affected by HIV/AIDS, and that no single organization or sector can meet all the needs of the affected families, the national guidelines call for effective networking and appropriate referrals to ensure that the social, psychological, legal and economic needs of patients and their families are met through timely and effective interventions.

Specific needs of older carers
Research in 2006 by HelpAge International and partners in three regions of Tanzania shows that 20-45 per cent of PLWHA and 25-75 per cent of vulnerable children are cared for in older headed households. Older people's role of caring for their dependents is difficult in a complex environment. They are unprepared due to the little knowledge or skills to assist them in their unfamiliar but everyday caring role. They face stigma and discrimination when accessing services. Their burden of care is made even more difficult by their isolation because no formal support structure exists in the communities where they live. The traditional safety nets – weakening as a result of more generalized poverty and economic hardships – are not always available. Further compounding the scenario are the high cost of transport and cost of treatment. Often, therefore, these circumstances force older carers to redirect their meagre resources from their own needs to the needs of those under their care.

[1] The National AIDS Control Programme, Ministry of Health and Social Welfare

As much as the national guidelines for home-based care service providers are comprehensive, they lack an understanding of the specific needs and role of older people or those of younger carers such as children. The guidelines are very generally referring to the family as the care providing unit and there is an underlying assumption that all carers are mobile adults, literate, energetic and productive and that the family has the necessary economic means to pay for medication, water, adequate food and shelter. As a result, the urgent needs of older carers - physical, medical, financial and emotional – arising from caring for PLWHA and surviving grandchildren have not been targeted by local, provincial or national service providers. Older carers continue to be excluded from HIV/AIDS programmes.

"There is an underlying assumption that all carers are mobile adults, literate, energetic and productive."

2. Home-based Care Model

The development of the home-based care model for supporting older carers of PLWHA in Tanzania was the result of a pilot project implemented during 2005/2007 in 57 communities in the following areas in Tanzania - Kinondoni, Kibaha, Bagamoyo and Muheza districts; Iringa and Arumeru Municipalities; Arusha and Tanga urban - by HelpAge International Tanzania (HAI) and its partner organizations namely; CHAWAMA, SHISO, TEWOREC, WAMATA and GSSST. The project was designed to identify practical solutions to specific problems that older carers face. These were first presented in the research report *The Cost of Love* published by HelpAge International in 2004.

The key findings from the project which influenced the design of the HBC Model are:

- The existing national home-based carers guidelines do not focus on the specific needs and the role of older people or younger carers
- Home-based carers have not been trained on issues related to ART and there is an overall lack of human resources to support the delivery of ART services
- Home-based carer training tends to be medically oriented hence focusing on medical personnel such as clinicians, pharmacists, laboratory personnel, nurses, counsellors and home-based care providers with medical backgrounds
- Providing comprehensive care and linking services in a continuum of care from relevant health facilities to care at community level is lacking
- The underlying assumptions of the national guideline for Home-based carer providers are that all carers are mobile adults, literate, energetic and productive, and that the family has the necessary economic means to pay for medication, adequate food and shelter
- It is easier for older people to reach their peer groups with HIV and AIDS messages due to the cultural role they play in society as advisors
- The focus of voluntary counselling and testing (VCT) services has been on youth and there is no sensitization and mobilization for older people to utilize the services

The HBC Model, described below, is aimed at national policy makers, relevant district level authorities, local health service providers, local government, and older people and other civil society organizations.

2.1 The Home-based Care Model Components

The HBC Model is a community based approach to support older care givers and is based on four main components:

- Collection of baseline information
- Training of older carers in home-based care and counselling
- Initiating support groups for trained home-based carers, peer educators and for self advocacy
- Linking older carers to support services.

"There is little or no data on the numbers of older people affected by the pandemic."

2.1.1 Collecting baseline information

Local, district and national bodies responding to HIV/AIDS have little or no data on the numbers of older people affected by the pandemic. Therefore, a first step in implementing the HBC Model is to review and analyze existing data on HIV/AIDS. If this does not exist, then to collect baseline information either on the missing information or on the following key indicators:

- Number of older people caring for PLWHA, and orphans and vulnerable children (OVC)
- Number of formal and informal institutions providing support to older carers and type of support being provided
- Number of older people reached through HIV/AIDS interventions
- Number of people reached by trained older people trained as home-based carers
- Number of people who are linked to available health and social services.

This information should be collected at the initial stage of implementing the HBC Model and can serve as indicators to be assessed over time.

In addition to this information it is also important to collect background information on the communities or catchments areas where the home base care services will be provided. Background information would include:

- Total population size in each ward/village
- Number of older people and their main economic activities
- Details of local institutions working in the area (Government, non government organization , community based organization, schools, health clinics)
- Total number of households and number of households headed by older people
- Total number of OVC and number of OVC under the care of older people
- Number of PLWHA/chronically ill
- Number of older people caring for PLWHA/chronically ill[2]
- Number of traditional healers
- Prevalence of HIV in the community from existing data.

The background information can be collected using a combination of approaches. Data on population, number of older people, OVC, traditional healers, number of households and those headed by older people is available from local statistics offices including census data from village and street registers. Data on numbers of PLWHA/chronically ill and those under the care of older people can be obtained from council multi-sectoral AIDS committees, health clinics, regional hospitals, district AIDS control coordinator offices and older people themselves.

The background information can be collected by older people trained as community home-based carers, peer educators or support group members in collaboration with village and ward government offices, district AIDS control coordinator offices and/or non government organizations (NGOs) and community based organizations (CBOs), which are also involved in home-based care programmes. The background information should be shared with the communities, older people themselves, multisectoral AIDS committees, National AIDS Control Programme, TACAIDS, National Bureau of Statistic's regional offices, Ministry of Heath and Social Welfare, and relevant NGOs/CBOs.

2.1.2 Training of older carers in home-based care and counselling

The identification and selection of older volunteers to be trained as community home-based carers and counsellors is a crucial component of the home-based care model. The following criteria can be used in identifying older carers to be trained as home-based carers:

[2] Chronically ill is a term used to describe a person who is continuously ill or sick for more than 3 months

- Basic level of literacy
- Willingness and capacity to volunteer
- Community acceptance of the selected candidate
- Previous experiences in caring for the sick
- Good interpersonal skills/ability to provide feedback and reports.
- Able to maintain discretion and confidentiality
- Level of physical strength
- In some cases older carers choose young people who meet the criteria[3]

The training should be conducted by government, NGO or faith-based organizations (FBOs) health or social service staff that are operating at community level, such as health centre and or dispensary health staff. The coordination of the training can be undertaken by the District AIDS Control Coordinator's Office (DACC) which should also organize the training of trainers in collaboration with NGOs/CBOs.

The number of older home-based carers to be trained would depend on the catchment area with the target of two trained home-based carers per village and with a gender balance.

Older people and older home-based carers should be consulted in identifying which topics to be covered in the training programme. The training methods should be those used for adult learning and be very interactive and participatory including group sessions, visual aids, practical training sessions, and role plays. At the end of the training the group should be provided with home-based care kits. Training Topics might include those identified in the draft National AIDS Control Programme's *Curriculum for Training Community Home-based Care Services Providers as Antiretroviral and Direct Observed Tuberculosis Therapy Supporters, (December 2006)* prepared by the Ministry of Health and Social Welfare, as follows:

- Introduction to community based care
- Basic facts about HIV/AIDS
- Preparing patients, families and community on ART (Treatment preparedness)
- Communication skills and counselling
- Treatment adherence
- Nutrition for PLWHA
- Principles and practice of palliative care
- Management of HIV/AIDS related symptoms in HIV/AIDS
- Care of the care givers (We have suggested that this topic should take into consideration the special needs of older carers which were described on pages 1 and 2 above).
- Dealing with stigma and discrimination in HIV/AIDS
- Community involvement and participation
- Reporting and recording
- Field work practice

Family care – skills building for older carers at household level

The identification and imparting skills in home-based care and counselling to older carers at household level is a crucial component of the home-based care model. The identification of older carers should be through local leaders, peer educators and neighbours and from medical staffs and CSOs working on HIV/AIDS.

"Older people and older home-based carers should be consulted in identifying which topics are covered in the training programme."

[3] The criteria were developed in consultation with older people themselves after reviewing guidance provided by the Ministry of Health and Social Welfare in the *Guidelines for Home-based Care Services.*

"The training methods should be those used for adult learning and should be interactive and participatory."

The imparting of skills to older carers should be done by trained volunteers who have been trained as community home-based cares who are operating at community level through home visits under the support from health centre and or dispensary health staff. The coordination of this training should be undertaken by the District AIDS Control Coordinator's Office (DACC) in collaboration with multisectoral AIDS Committee and NGOs/CBOs. The skills building exercise should target all older carers in the catchment area, including all household members, both male and female. And it should be done during home visits by volunteer trainers. Older carers should be consulted in identifying which skills to be imparted, and could include:

- General awareness about HIV/AIDS(prevention, control and transmission)
- Parenting skills
- Basic nursing skills
- General hygiene and sanitation
- Communication and negotiation skills
- Psychosocial support skills including bereavement
- Reducing pain
- Nutritional needs of PLWHA
- Counselling skills
- Adherence – including how to administer drugs
- Making referrals.
- Information on available services
- Income generating activities skills

The training period should be 21 days. The skills building exercise should take into consideration the special needs of older carers. It should also include relevant topics and information in the National AIDS Programme's *Curriculum for Training Community Home-based Care Services Providers as Antiretroviral and Direct Observed Tuberculosis Therapy Supporters, (December 2006)* (draft prepared by Ministry of Health and Social Welfare)

The skills building exercise should be a continued process. The training methods should be those used for adult learning and should be interactive and participatory, including group sessions, visual aids, role plays, and learning by doing.

At the same time older carers should be provided or replenished with support gears such as gloves from the volunteer HBC trainers.

2.1.3 Facilitating support groups

Establishing support groups is another key component of the home-based care model. These can be:

- Older home-based carer groups
- Older people's self-advocacy groups (SAGs)
- PLWHA support groups.

a. Older home-based carer groups

The size of the older home-based care group should be eight to ten older home-based carers. Other older carers at the family level should also be encouraged to form their own support groups. The size of the group will depend on how manageable and efficient the group might be. The main aim of the group is to provide mutual support and to share experiences and information. The group can reinforce lessons learned and ensure sustainability of the home-based care model. The group should meet monthly or at least every two months within their locality.

It is the role of the group members to decide where they should meet. But it has been observed that many groups meet at local government offices at the village or street level or at school. The village or street multisectoral AIDS committee should coordinate this group. Medical practitioners at the dispensary and health centre level and district AIDS control coordinator should provide technical support and guidance to the group.

"Establishing support groups is another key component of the home-based care model."

b. Self-advocacy groups

The size of the self-advocacy group (SAG) should be five to six older people. The main aim of the SAG is to influence for more inclusive policies and integrated practices to improve support for their needs.

The SAG should receiving training for three days covering the following topics:

- Increased understanding about the needs of older carers
- Rights and entitlements of older people related to relevant policies such as Health, National Ageing Policy and National Strategy for Growth and Reduction of Poverty (MKUKUTA)
- Meaning of advocacy
- Components of advocacy and developing advocacy initiatives:
    - Setting objectives
    - Evidence gathering
    - Networking and forming coalitions
    - Identifying target audiences
    - Developing and delivering key messages and issues
    - Monitoring impact.

The training of the SAG can be coordinated by the DACC's office and conducted by local government social welfare staff, NGOs or FBOs. It can be conducted at their localities either at school or village/street government offices.

Following the training the SAG will be empowered to undertake advocacy initiatives and interact with and influence key stakeholders at local government and district level, including the media. Priority issues can include:

- More inclusion of older people in policies which impact on their lives, e.g., national and local AIDS policies, social protection, poverty reduction, etc.
- Implementation of policies, programmes, rights and entitlements aimed at benefiting older people
- Improved audio visual material
- Integrated practical training for the illiterate so as to improve support mechanisms for older carers.

The SAG should meet at least every two months. SAG can be coordinated by the social welfare staff at the district and lead by older people themselves. District AIDS control coordinator's office and district social welfare staff, NGOs or FBOs should provide technical support and guidance to the group.

The trained home-based carer is the one responsible for organizing the formation of the PLWHA support group and providing guidance and support to the members. The group should meet at least every two months, but participation will depend on the wellbeing of the member.

c. PLWHA support group

The volunteer HBC trainers should encourage or link PLWHA to existing support networks relevant to them. In the place where such networks do not exist, PLWHA should be encouraged to form their own group. The size of the PLWHA support group should be between 20-30 PLWHA. The main aim of the PLWHA support group is to provide the PLWHA with counselling and psychosocial support, sharing experiences, challenging the sti ma associated with the disease through mutual support amongst the group, opportunity to gain confidence through coming together to speak openly amongst themselves

"Home based carers cannot operate in a vacuum without support."

and receive updates or information related to the disease. Experience has shown that the groups need patience; time and trust among the members and the trained home-based carer to be effective.

2.1.4 Linking older carers to support services

Home-based carers cannot operate in a vacuum without support. For instance they need medical and health care technical support in effectively carrying out their role as a care giver. Therefore, a crucial HBC Model component is the linkage between older home-based carers and the various support groups with different stakeholders working in HIV/AIDS in the districts such as NGOs, FBOs, CSOs, peer educators, DACC's office, hospitals, health centres, dispensaries, and social service staff.

The stakeholders can provide vital training, technical, material and moral support to older HBCs and the support groups which is a key to the success of the HBC Model. For instance, local health facilities are a potential resource for replenishing home-based care kits and stakeholders can increase the awareness of older home-based carers, peer educators and older people on the available local, provincial and national services available to them.

Mechanisms of providing technical support by stakeholders can include:

- Providing initial and refresher training for older home-based carers and peer educators
- Regular monthly meetings between local health facility and social services staff and older home-based carers and peer educators to share experiences, lessons learned, address priority issues which arise, enhance collaboration regarding referrals and working with traditional healers
- Providing technical advice on an on-going basis on issues related to care-giving and psychological support
- Collaborating with home-based carers and peer educators in data collection and analysis and monitoring interventions.

This interaction will raise the awareness of service providers to the vital role being carried out by older home-based carers and peer educators to the fight against HIV/AIDS.

Older home-based carers in turn provide on-going training in basic skills of caring and support to older carers of PLWHA including children, whereas older peer educators can share information amongst older carers and refer them to trained older home-based carers and other community support services.

Home-based carers also play a key role in the referral system identifying and referring patients to health facilities. Coordination and communication is very important between home-based carers in relation to support needs and the referral system. Health staff in turn depends on home-based carers to monitor patients referred to and treated by them once they return to communities and households.

The links with traditional healers is also an important one for older home-based carers, as traditional healers can be the first port of call for older carers in seeking health care for themselves and those under their care. Older trained home-based carers need to establish a good working relationship with traditional healers to ensure exchange of information on treatment and care issues and to enhance the referral system between traditional healers and the formal health system in collaboration with older home-based carers.

Tanga Elderly Women Resource Centre - (TEWOREC)

TEWOREC was established in 1998. The focus of their work is mainly on HIV/AIDS, targeting older people particularly older women and orphans, mainly in two Wards of Muheza and Maramba in Tanga, but also now operates in the wider rural and urban areas, where its work (including HIV/AIDS, child survival and support to orphans, training to older people on home based care and counselling), has earned them the respect of these communities. It is a member of an NGO cluster of organisations in the Tanga Region, which is campaigning for information sharing and dissemination on HIV/AIDS and STI related issues. In 2003/4, it participated in RFE supported research project.

Good Samaritan Social Services Trust - (GSSST)

GSSST was set up in 1998 to respond to social and economic problems experienced by older people in Dar es Salaam. It is part of a network of age care organizations in the Coastal Zone, where it actively lobbies and advocates for change on behalf of its elderly constituency. Its core competencies include participatory research, health and social work, counselling, and health services in the communities, especially targeting older people. In 2003/4, it participated in RFE supported research project.

Southern Highlands Senility Organisation - (SHISO)

SHISO was established in 1995. The focus of its work is on HIV/AIDS and civic education, and is also actively engaged in promoting intergenerational linkages by working with local schools and educational authorities. It supports vulnerable older people to access free health care by linking them with government health centres, and provides support and guidance to older men and women on rights and legal issues. Its strong experience in HIV/AIDS has enabled them to train volunteers who work at the grassroots level providing home based care to people living with HIV/AIDS (PLWHA) and support to older people affected by the disease. In 2003/4, it participated in RFE supported research project.

Chama cha Wazee na Wastaafu Arusha - (CHAWAMA).

Largely made up of volunteers with skills and experiences in different professional disciplines, it was set up in 1998, initially as a community based welfare group to provide mutual support to its members in old age. It has now broadened its mission to promote stronger inter-generational understanding and works with local schools and education authorities. It also supports vulnerable older people to access free health care, and to address the needs of older men and women at grassroots level. In 2003/4, it participated in RFE supported research project.

Walio Katika Mapambano na AIDS Tanzania (WAMATA)

WAMATA is one of the leading national NGOs dealing with HIV/AIDS in Tanzania. It was founded in 1989 by a group of professional individuals and families who were in different ways, affected by and concerned with the spread and impact of the HIV/AIDS pandemic. Its work focuses on HIV/AIDS policy and strategy, advocacy and lobbying for policy and legal reforms at national level, and more direct support to PLWHA. WAMATA also supports orphans in a practical way by providing school fees, uniforms, materials, nutrition and care. It has strong experience in volunteer counselling and of conducting training in peer education and care.

The development of this home-based care (HBC) model by HAI in Tanzania for supporting older carers of PLWHA was the result of a pilot project during 2005/2007 in 57 communities in Arumeru, Arusha, Bagamoyo, Iringa, Kibaha, Kinondoni, Muheza, and Tanga. The project was implemented by CHAWAMA, GSSST, SHISO, TEWOREC, and WAMATA. The material presented here would be a resource for HBC service providers. This model would be particularly useful in community HBC settings where majority of older carers may not have had any training in HIV/AIDS caring role. The model includes key components to be considered when developing a community HBC programme to support older carers, and lends itself to be integrated into the national HIV/AIDS policies, guidelines, curriculum and programmes.

Published by

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