

Building bridges

A home-based care model for supporting older carers of people living with HIV



Older women provide the backbone of AIDS care in Africa. Isn't it time they were supported?

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age helps

HIV is causing a shift in household structure and responsibilities. At a time in their lives when many older people might have expected to be supported and cared for by their adult children, a growing number are taking on caring roles for family members living with HIV, and for orphaned and vulnerable children.

Older women provide the backbone of AIDS care in Africa, but their contribution is rarely recognised and they receive little or no formal support. HelpAge International has developed a model for supporting older home-based carers in the crucial role they play in the response to HIV and AIDS.

This summary guideline describes a model for supporting older home-based carers developed by HelpAge International in Tanzania, which is now being implemented in several districts in Tanzania.

Ninety per cent of care for people living with HIV is done in the home by family and community carers.¹ Recognising this, in 2005 the Tanzania Ministry of Health and Social Welfare published national guidelines on how to meet the social, psychological, legal and economic needs of people living with HIV and their families.

However, the guidelines do not address the specific needs of older carers. In Tanzania, up to 45 per cent of care of people living with HIV and AIDS is carried out by older people, mainly older women.² The Government guidelines assume that all carers are mobile, literate, energetic and economically productive, and that families affected by HIV and AIDS can afford to pay for medication, food and shelter.

The reality is that large numbers of older carers face huge challenges, and providing care has a major impact on their lives. They have no regular income to pay for the costs of caring and they live in dilapidated and insecure houses. Looking after their family members often has economic, health and emotional impacts on their lives.

The guidelines also fail to consider the importance of peer education for older carers, which is culturally more acceptable than discussing and learning about HIV and AIDS from younger generations. Nor do the guidelines encourage voluntary counselling and testing clinics to ensure their services are sensitive to the needs of older people.

Based on their experience, HelpAge International's programme and partners in Tanzania have developed a model for supporting older carers of people living with HIV. The model has four main components:

- **collecting baseline data**
- **training older carers in home-based care and counselling**
- **setting up support groups**
- **linking older carers to services.**



***When older people
care for others***

***they need support
themselves***

Baseline data

Governments and other organisations involved in the provision of care and support must have statistical evidence on the nature and scale of the epidemic and response so that they can develop appropriate interventions. Data is rarely collected on who is providing care or the support these carers need and receive. HIV and AIDS data collection also rarely includes older people. All data needs to be disaggregated by age and sex.

Key stakeholders need to know the number of older carers in the community, and the number caring for orphans and vulnerable children. They need to know what institutions could support older carers, and what type of support they may provide. As time goes on, they will need to know the number of older carers reached through their interventions, the number of older people trained as home-based carers, and the number of older carers who are in contact with health and social services.

They also need more general information on the communities they are working in. This includes the total population of each community, the number of older people and their main economic activities, and details of local institutions involved in the HIV and AIDS response (government organisations, non-governmental organisations, community-based organisations, schools, health clinics).

Other essential information includes the total number of households, and how many are headed by older people; the total number of orphaned and vulnerable children, and how many are cared for by older people; the number of people living with HIV or other chronic illnesses, and how many older people are caring for these people; the number of traditional healers; and the prevalence of HIV in the community.

This information can be collected by trained older carers in collaboration with staff of district AIDS control offices, NGOs and community groups. It should be shared with communities, and all relevant stakeholders, both government and non-government.

Training of carers

A crucial aspect of supporting older home-based carers is to select older carers to train as community home-based carers. The HelpAge International home-based care model recommends training two older volunteers from each community, where possible keeping a gender balance in order to encourage male participation and reduce the burden on older women. In some cases, older people may nominate younger people for training.

The trained older carers can then train other older carers in their community to provide nursing care, psycho-social support, counselling and pain control. They can also provide information on HIV and AIDS and available services, advise on the nutritional needs of people living with HIV, explain how to administer drugs, and facilitate referrals.

Those selected for training should have at least a basic level of literacy. They should be willing and able to volunteer, be accepted in their community, be able to communicate well, respect confidentiality, and be reasonably fit. They should also have previous experience of caring for a sick person.

The training should be conducted by staff of local government or non-governmental organisations, such as health centres. The district AIDS control programme should organise the training of trainers.

Topics to cover should be identified in consultation with the older carers to best meet their needs. They may include basic facts about HIV and AIDS, the concept of home-based care, stigma and discrimination, opportunistic infections, hygiene, communication skills, nutritional needs of people living with HIV, psychosocial support, counselling, how to administer drugs, and how to make referrals.

The training will take at least seven days and should use participatory, adult-learning methods. At the end of the training, older carers should be given home-based care kits containing items including bleach, disposable syringes, needles, gloves, dressings, routine medicines, disposable bags, mouth wash, plus instructions on how to use these, and information leaflets on diet, lifestyle and precautions.

Support groups

Because of the stigma surrounding HIV and AIDS, and the demands of caring, people living with HIV and their carers can become very isolated. Support groups can make a big difference.

Different types of groups can provide different support and services. Groups of older carers provide emotional and practical support to each other. Self-advocacy groups can influence policy and services in favour of people affected by HIV and AIDS, and help them claim any social protection entitlements they may be eligible for. Groups of people living with HIV and AIDS provide a chance for members to share experiences, challenge stigma, become more confident, and obtain information.

Older carers' groups generally consist of 8-10 people who meet monthly, or at least every two months. The group may be coordinated by the local AIDS committee, with technical support from the health centre and district AIDS coordinator.

Self-advocacy groups might consist of 5-6 older people who meet at least every two months. Members should receive three days' training in the needs of older carers; rights and entitlements of people living with HIV and AIDS and older carers; and how to carry out advocacy. The training can be coordinated by the district AIDS control programme and conducted by staff of local government social welfare departments, NGOs or faith-based organisations.

A support group of people living with HIV and AIDS may have 20-30 members who meet at least every two months. Experience shows that it takes time for these groups to become effective, as members gradually build up trust in each other.

Trained home-based carers can support the setting up and guiding of the support groups.

Links to services

Older home-based carers need access to a range of services. They need to be introduced to organisations that can help them, such as NGOs working on HIV and AIDS, faith-based organisations, peer educators, district AIDS control programmes, hospitals, health centres, dispensaries, voluntary counselling and testing services, and social service departments.

These organisations may be able to replenish home-based care kits, inform older carers about health and social services and how to access them, provide practical advice and psychosocial support, and collaborate with older carers on data collection and analysis.

Older home-based carers play a key role in helping people living with HIV and AIDS to receive appropriate medical care. They need to know when to refer those in their care to health facilities. Health service staff also depend on home-based carers to monitor the progress of patients after they have gone home.

Links with traditional healers are also important, since traditional healers are often the first port of call for older carers seeking healthcare for themselves or those in their care. Trained older home-based carers need to establish a good working relationship with traditional healers, to help increase the number of referrals from traditional healers to formal health services.

1. UNAIDS 2004 AIDS Epidemic Update, 2004

2. HelpAge International, baseline data from HIV and AIDS project in four areas, 2006

Read more:

View the full *Building Bridges: Home-based care model for supporting older carers of people living with HIV in Tanzania* at www.helpage.org/Researchandpolicy/HIVAIDS/Resources



The model of home-based care to support older carers was developed by HelpAge International's Tanzania office in collaboration with partner organisations:

- Good Samaritan Social Services Tanzania (GSSST)
- Tanga Elderly Women Resource Centre (TEWOREC)
- Southern Highlands Senility Organization (SHISO)
- Walio Katika Mapambano na AIDS Tanzania (WAMATA)
- Arusha Retired People's Association (CHAWAMA)

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HelpAge International helps older people claim their rights, challenge discrimination and overcome poverty, so that they can lead dignified, secure, active and healthy lives.

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