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Training and supporting older people to be home- or community-based carers



Ninety per cent of care for people living with HIV is carried out in the home, by family or members of the community. Many of these carers are older people, predominantly older women.

In sub-Saharan Africa, an estimated 22.5 million people are living with HIV, making it the worst affected region of the world. For women, prevalence is highest in the 30–34 year age group and for men, the 35–44 age group.¹ This means that many older people have taken on the responsibility of caring for their grandchildren who may have been orphaned as a result of AIDS, as well as their adult children living with HIV. Caring for family members has had a huge impact on older people's physical and emotional wellbeing, as well as their financial situation.

The increased availability of antiretroviral therapy (ART) has had a significant impact on AIDS-related morbidity and mortality. In 2010, 49 per cent of people in sub-Saharan Africa in need of antiretroviral therapy were receiving it, leading to a 20 per cent decline in AIDS-related deaths. While access to ART has increased significantly, it is important to note that a large percentage of those in need still do not have access.

“What I have always feared most is almost happening – that I have to go out and beg to survive and take care of my grandchildren.”

Older woman, Ethiopia

While this increased access to ART has led to fewer people being bedridden and in need of physical and nursing care, the need for broader care and support has not diminished. In situations where people are taking ART, carers are playing a crucial role in supporting adherence. A main part of this support being provided by older carers is the provision of adequate nutritious food for those in their care taking ART.

Challenges faced by older carers

Older carers face many challenges associated with providing care:

Poor health: advanced age and declining health can affect older people’s ability to provide quality care. Older people are also susceptible to illnesses being suffered by those they are caring for.

Financial hardships: many older carers lack a secure income and struggle to meet the needs of the people they are caring for. Many are forced to sell hard-earned assets to cover the costs of providing care. In addition, the time spent caring and older people’s decreased physical capacity, can limit their ability to work.

Psychosocial impacts: older carers often experience stress, isolation and depression related to their caring responsibilities, often arising from the inability to provide adequate care and support. Many are concerned about what will happen, particularly to their grandchildren, after their death.

Time poverty: increasing care responsibilities mean that older carers have less time for themselves. This is particularly true for older women, as caring has implications on their ability to maintain social interactions.

Stigma: although HIV-related stigma has reduced in some contexts and for some people, many older carers still feel stigmatised and face discrimination. Many older carers do not disclose their family members’ HIV status because of fear of how people will respond. This can lead to isolation and stress, as older carers miss out on potential sources of help and support, including services specifically designed to help them.

Training and supporting older carers

Many older people are making an enormous contribution to the response to HIV (see case study below) in their role as caregivers. It is important to ensure that older carers can provide effective care and support and can do so without significant detrimental effects on their own livelihoods and wellbeing. In order to do this, it is vital that older carers receive appropriate training and support to help them fulfil their role.

Contributions of older carers: Aisha Saidi, 62

Since the deaths of my younger sister in 1993, her husband and another of my nieces – all of AIDS-related illnesses – I decided to become a home-based carer. When my younger sister was sick I didn’t know what was wrong with her or how I should care for her, so when I heard about the training, I knew I had to be part of it so I could help others in the community. It was a very difficult time when my sister died.

I learned many things during my training. I learned how to look after and care for people with HIV. I learned how to give counselling, how to advise people on when to take their ART, about nutrition and the importance of a good diet when taking ART. I know how to safely wash patients by wearing gloves. I also advise people about getting tested for HIV and promote safe sex practices in the community through condom use. Before the training I didn’t know any of these things, and if I had, I would have been able to help my family more.

A few days ago, a community member came to see me as she had been sick for some time. I advised her to go to the hospital for an HIV test. I accompanied her there and unfortunately she was positive. I will now support her with the taking of drugs, and will visit her and counsel her whenever she needs my help.

Encouraging older men to become carers

The majority of older carers are women. Men should be encouraged to take an active role in caring for people with HIV to redress this gender imbalance.

“This training has been very helpful and I am able to educate many people in the village when they come to me for advice. Many young members of the community come to talk to me now they know I’m a home-based carer and I am able to advise them.”

Older man, Tanzania

Training older carers

Training programmes to help older people become home- or community-based carers should follow these guidelines:

Selection of trainees

Selecting participants: identifying older people who are suitable to be trained as carers should be a process that is undertaken through discussions with community members, including older people, and local leaders. Those selected should be committed to the programme and providing care. They should be respected by their communities, and should understand the importance of maintaining confidentiality. Older people who are already providing care should be included where possible.

Promoting a gender balance: efforts should be made to encourage older men to participate in the training and become carers. Most carers are women, and training programmes should try to overcome the gender stereotypes that lead to this unequal division of caring responsibilities.

The range of trainers

Training government trainers: a training of trainers programme should be initiated with government-certified trainers, where possible, training community resource people to provide onward training to older carers.

Training of community resource people: a cascaded training approach is recommended to build a pool of community resource people who are tasked with providing ongoing training and support to older carers. Where possible, the community resource people should be older people themselves, and should have a basic level of literacy.

Training older people: older people should be trained to provide effective care and support as home and community-based carers.

Content of the training

Training curriculum: basic training should follow the guidelines/curriculum approved by the government in the particular country to ensure that carers are equipped with the skills and knowledge to respond to the specific contexts in which they are providing care. Additional material may need to be added to address older carers’ particular needs, and any challenges they face.

Older people’s health: while the training should include some information specific to HIV, care needs and the way in which care should be provided will be similar irrespective of the illness being suffered. The training should provide information on broader health issues, including conditions commonly experienced by older people. This will help older carers provide appropriate care and advice for those in their care, and will help them look after their own health too.

Addressing stigma: training should include modules on stigma and discrimination, as well as older people’s human rights and the rights of those in their care. Information should be given on entitlements and how to access support.

Treatment adherence: with increased access to antiretroviral therapy and the role of carers in supporting adherence, training should include information on treatment literacy and nutrition. Training in counselling and psychosocial support is also crucial.

Training methodology and approach

Adult learning: a tailored adult learning and participatory approach should be adopted in line with the skills and capacities of the older people being trained. The training methodology should include: lectures, group work discussions, presentations, time for individual reflection, demonstrations, and role plays.

Practical approach: there should be an emphasis on practical learning, with less time spent in the classroom. Practical sessions are critical to enable older carers to see how to apply their training in real-life situations and to ensure that the training provides the skills necessary for these situations.

Duration: the duration of training needs to be long enough to ensure an adequate level of skill, but the exact duration and how the days are structured can be agreed with the participants. This allows for their needs and any challenges they face to be taken into account.

Providing materials

Provision of care kits: at the end of the training, older carers should be provided with home-based care kits containing the items they need (e.g. gloves, basic first aid materials), to deliver safe and effective care and support. Coordination with government and other stakeholders is critical in ensuring a continuous supply of care kits for older people who are home or community-based carers.

Supporting older carers

In addition to training, older carers also need support with the economic, health and emotional challenges they might face. Further information is given in practical guidelines on psychosocial support for older carers and income-generating activities for older people affected by HIV and AIDS.

Key points

- **Caring for people with HIV brings many challenges for older people** – it affects their health and emotional wellbeing, and economic security.
- **Older carers need training and support to provide safe and effective care** – training should be adapted, both in terms of content and delivery, to take into account older people's skills and needs, and any challenges they may face.
- **Following training, older carers need ongoing support** – to ensure that their own emotional, physical and financial wellbeing is not negatively affected by their caring role.

Notes

1 UNAIDS, 2010 Report on the Global AIDS Epidemic, www.unaids.org/globalreport/global_report.htm

2 World Health Organization, HIV/AIDS, Antiretroviral therapy, www.who.int/hiv/topics/treatment/data/en/index2.html

Practical guidelines on HIV and AIDS are available at:
www.helpage.org/resources/practical-guidelines

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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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