

Ageways

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71

Practical issues in ageing and development

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HIV and AIDS

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25
years as
a global
network
2008

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Comment

AIDS affects all ages

Welcome to *Ageways* 71. In large areas of the world, HIV and AIDS continue to have devastating consequences for people of all ages. But where are older people in the statistics, and why are they missing from official responses?

This issue highlights older people's role in the epidemic, primarily as carers of millions of adults and children affected by HIV and AIDS, and also as a group at risk of infection through sexual activity.

It sets out the case for including older people in data, policies and programmes on HIV and AIDS, and it gives practical examples of how to make this happen.

Celia Till
Editor

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Future issues

Ageways is published twice a year. Issue 72, due in October 2008, will mark **HelpAge International's 25th anniversary** by focusing on older people's associations and networks.

Letters

Build on existing support

I am happy that at last the issue of social pensions is coming onto the social agenda, and that organisations such as HelpAge International are helping to keep it there (*Ageways* 70).

In Ghana, the extended family remains the primary institution that provides social security nets for vulnerable groups like older people. However, rapid urbanisation and migration are fast-changing the family structure and rendering it less effective in this role. For this reason the government has initiated a review of existing social protection mechanisms, including the state pension scheme.

At a presentation of the initial findings of the review, examples of several pension schemes, within and outside Ghana, were presented. However, nothing was said regarding the family social protection system. It was as if this no longer existed.

My comment was that any proposal should first study these positive existing practices, no matter if they are fading, and explore ways of building on them. If not, there is the danger of relieving the family of its responsibilities and, as often happens, when a time comes in which the state is not able to shoulder the responsibility, there will be nothing for older people to fall back on.

Currently the Ghanaian government gives tax relief to those caring for a number of children and dependent parents. This, however, applies only when someone files his or her income tax returns. The majority of people don't do this.

It should be possible to devise a scheme where remittances are acknowledged and tax relief granted.

Such a scheme would allow the family to continue to be part of any state social protection framework for older people.

Tony Dogbe, Director, Participatory Development Associates, PO Box UP 876, KNUST, Kumasi, Ghana.
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HIV and cultural practices

I have started working with a group of 32 older people in Lilongwe East, where the issue of HIV and AIDS is common because of cultural practices such as wife exchange, polygamy and initiation ceremonies. For this reason, I requested *Ageways* so that I can assist other social workers and trainers to gain more knowledge in the field of older people, youth, and HIV and AIDS.

Moses G Chisale, Managing Director, Cutting Edge Development Agency (CEDA), Private Bag B334, Capital City, Lilongwe 3, Malawi.

Editor's note: You may be interested in the article on page 12, which looks at the role of traditional healers in relation to cultural practices and HIV and AIDS.

Elders' club is popular

I am the founder of the Elders Club of Beau Bassin/Rose Hill, which is ten years old. I devote most of my time to the welfare of older people, especially those residents of charitable homes and those living independently in very poor situations.

The club, which groups some fifty persons, is very active in many ways, and more people are joining. There are requests to organise other such clubs around the island and we are giving serious thought to this. We base ourselves on Christian principles, but the club is open not only to Christians, but to everyone, both male and female.

Jean-Maurice Rangasamy, 15c Abbe Mazuy St, Beau Bassin, Mauritius.

News



Older activists take to the streets in South Africa for Age Demands Action 2007.

25
years as
a global
network
2008

2008 is HelpAge International's 25th anniversary. This is a great opportunity to celebrate the network's experience and achievements, and help raise

the profile of the network and its work over the next 25 years.

Plans for marking the occasion include the use of an anniversary logo and statement (used in full or part) in talks, publications, articles, presentations and other materials:

Ageing is a triumph of our times, yet over 100 million older people live on less than a dollar a day. HelpAge International has been working since 1983 to improve the lives of disadvantaged older people, through a global network that today spans more 70 affiliate organisations in 50 countries.

HelpAge International has a vision of a world in which all older people fulfil

their potential to lead dignified, healthy and secure lives. Older people may be marginalised today, but they offer an enormous potential for development tomorrow.

A special issue of **Ageways** will be published to mark the anniversary. Issue 72 (October 2008) will highlight the role of older people's associations and networks.

The 25th anniversary will also be featured in this year's Age Demands Action campaign, in which delegations of older people across the world will present their issues to government representatives on and around 1 October, International Day of Older Persons.

The aims of Age Demands Action 2008 are to build an informed constituency of older activists; secure commitments from governments towards improving the lives of older people; and to focus attention on older people and ageing as a key issue for the 21st century.

More information: www.helpage.org

Directory helps older people in Dominica

The first directory of services specifically for older people and their carers has been published in Dominica.

The *Directory of services for older people in Dominica* provides details of more than a hundred services, including emergency services, healthcare, social care, income support, livelihood services, welfare, commercial services (including age-friendly retailers and banks), legal assistance and utilities.

The directory is the result of collaboration between HelpAge International, the Dominica Council on Ageing, the United Nations Development Programme and the Government of Dominica. It forms part of a programme of support to social protection reform in Dominica.

Studies of social protection provision and the social impact of natural disasters, carried out as part of the programme, highlighted older people's problems in relation to housing, access to medical and social services, and 'making ends meet' in the face of the rising cost of living.

The directory can be downloaded from: <http://www.bb.undp.org/uploads/file/pdfs/poverty/Directory%20of%20services%20-%20Dominica.pdf>

We welcome letters from readers. Please write to: The Editor, Ageways, HelpAge International, PO Box 32832, London N1 9ZN, UK. Fax: +44 20 7713 7993 Email: ctill@helpage.org Please include your name, organisation (if any) and postal address. Letters may be edited.

The impact of AIDS on older people

HIV and AIDS are having a devastating impact on large numbers of older people, particularly in their role as carers.



Kate Holt/HelpAge International

In worst-affected countries, most orphaned children live with their grandparents.

More than 33 million people worldwide are estimated to be living with HIV. In 2007, approximately 2.5 million people became infected with HIV, and 2.1 million people died as a result of AIDS. Sub-Saharan Africa remains the most seriously affected region.

HIV and AIDS affect all sections of society. Increasing numbers of older people are affected, primarily in their role as carers. Older people are also infected by HIV.

Up to two-thirds of people living with AIDS are cared for by parents in their 60s and 70s. In 2007, there were an estimated 11.4 million children orphaned by AIDS in sub-Saharan Africa alone. In highly-affected countries, more than 60 per cent of orphaned children live in households headed by their grandparents.

HelpAge International estimates that in severely-affected communities in Africa and Asia, half of all older people care for adult children living with HIV, or children affected by AIDS, or both.

Caring role

Caring affects older people in many ways. At a time in their lives when they might expect to receive support from their families, they not only lack this support, but they also have to meet many additional costs, including medicines, healthcare and, later, funerals of those in their care. They may also have to pay for children's food and school expenses. Their own earning capacity is diminished and they may be unaware of social protection entitlements such as foster-care grants or school fee exemptions. Many poor households have to sell their assets to cover their expenses.

Older carers face many emotional stresses from nursing sons and daughters who are terminally ill, seeing them die, and worrying about their own future and that of their grandchildren. Becoming a parent again in later life can itself be very stressful. Because of the stigma surrounding HIV and AIDS, and the demands of caring, older carers and their families often become socially isolated.

Older carers often have serious health problems of their own but little time to care for themselves. In addition, caring puts them at risk of infection from HIV-related illnesses such as TB.

Older people are generally excluded from HIV education programmes, but they need to know how HIV is transmitted so that they can protect themselves from infection, both through caring (although the risks are very low) and in other aspects of their lives. They also need to be able to educate those in their care about the epidemic.

Older women and men are affected by HIV and AIDS in different ways. Women usually carry out most of the physical care, while men may be expected to provide financially. Men tend not to have as strong social networks as women, which can make them more vulnerable.

'The hospital expenses were getting higher and higher until we ran out of money. We finally had to sell the land that we had bought for our child.'

Vanida, older carer, northern Thailand

What are HIV and AIDS?

The human immunodeficiency virus (HIV) attacks the body's immune system, making it hard to fight off infections. The virus destroys immune system blood cells known as CD4 cells.

When the number of CD4 cells in a person with HIV has fallen below a certain level, and the person has developed a serious illness such as pneumonia, cancer or TB, the person is diagnosed with acquired immune deficiency syndrome (AIDS).

The most common ways for HIV to be transmitted are: through unprotected vaginal or anal sex (without a condom); from mother to child during pregnancy, birth or breastfeeding; through contaminated syringes and needles shared by drug users; and through use of contaminated equipment or blood during medical procedures.

Without treatment, HIV infection progresses to AIDS in an average of ten years. This average is for a person who is eating a reasonable diet. In someone who is malnourished, HIV may progress to AIDS and death more quickly.

There is no vaccine or cure for HIV. However, antiretroviral therapy (ART) can extend the time between HIV infection and the onset of AIDS.

The cost of ART has reduced substantially in recent years. In many countries, ART is provided free of charge. As a result, 3 million people in low and middle income countries had access to ART in 2007, an increase of 42 per cent since 2006. However, there is still a long way to go if international commitments to universal access to treatment are to be met by 2010.

ART is complicated to administer. It consists of a combination of drugs that must be taken at the same time each day, in conjunction with a well-balanced diet. This is often a challenge for people in developing countries, who also have to meet the costs of medical tests, transport to health facilities and treatment for opportunistic infections.

One group of older people whose needs are often overlooked are those who have lost a child to an HIV-related illness, but have no surviving grandchildren, and no other children from whom they can receive support. They may be regarded as not affected by AIDS, yet their need for support is as compelling as that of older people who are still providing care.

Sexual activity

Many older people are sexually active and at risk of HIV infection through sexual activity. Figures from UNAIDS reveal that in Botswana, 21 per cent of people in their early 50s are HIV-positive, compared with 25 per cent of 15-49 year-olds.

In Uganda, 7 per cent of men aged 50-59 are living with HIV (the same as the national adult rate). The rate for women in their fifties is 5 per cent.

New policies

The impact of HIV and AIDS on older people is often neglected in international and national policy, leading to a lack of focus on older people in HIV and AIDS programming. However, following advocacy by HelpAge International and partners, older people's issues are gradually becoming recognised.

The UN Political Declaration on HIV/AIDS, adopted in 2006, commits governments to providing support and rehabilitation to older people, particularly in their role as carers. UNICEF's 2007 *State of the World's Children* for the first time acknowledged the role of grand-parents who care for children orphaned by AIDS.

The Africa Health Strategy adopted by African Union health ministers in 2007 recommends developing

programmes to combat childhood illnesses, with particular emphasis on orphans and vulnerable children and their older women carers.

In 2007, UNAIDS began to publish HIV and AIDS data on those over the age of 15, instead of only those aged 15-49. However, this change does not include prevalence data, so pressure needs to be maintained on UNAIDS to include this.

Recommendations

Including older people in policy is a good start, but more concrete support is needed. For example, some southern African countries have introduced social (non-contributory) pensions in recognition of the difficulties that HIV is creating for grandparent-headed households.

Governments and civil society organisations need to:

- ensure that issues affecting older people are included in national and international policies on HIV and AIDS
- ensure that issues affecting older people are included in programming
- involve older people in programme design, implementation and monitoring
- break down HIV and AIDS data by age and sex, and collect data on carers, broken down by age and sex
- raise awareness of how older people are affected by HIV and AIDS, internationally, nationally and locally
- increase older people's access to HIV and AIDS education, to help older people to protect themselves and educate those in their care
- support home-based care programmes that meet older people's specific needs
- provide older people with health and psychosocial support
- include older people in income-generating activities
- promote universal social pensions as a way of ensuring a minimum income for families affected by HIV and AIDS
- support older people to claim social protection entitlements.

Creating a clearer picture

Rachel Albone explains why more data is needed on how HIV and AIDS affect older people.



Kate Holt/HelpAge International

Older people are affected by AIDS, mainly as carers, but are missing from data.

Like any other population group, older people are both infected with and affected by HIV. Yet they are generally neglected in the response to the epidemic. One of the reasons for this neglect is lack of data.

There are three main problems: HIV and AIDS data is either not collected on older people at all, or not analysed by age; older people's issues are excluded from key indicators; and data is not collected often enough.

Global reporting on HIV and AIDS excludes older people. UNAIDS has long focused attention on the 15-49 year age group. In 2007, UNAIDS expanded some of its monitoring to include people over 50, but it continues to provide HIV prevalence figures for the 15-49 age group only.

UNAIDS also measures progress towards the 2001 UN Declaration of Commitment on HIV and AIDS, using 25 core indicators. None of these

indicators includes people over the age of 50, or considers who is providing HIV and AIDS care.

At the national level, HIV and AIDS data is collected from a variety of sources. A recent workshop in Tanzania, led by HelpAge International, identified 10 different sources of data on HIV and AIDS. Most are surveys coordinated by government statistics offices and national AIDS control programmes.

Despite the number of surveys, very little is known about who provides HIV and AIDS care. Surveys rarely ask about the responsibilities that carers take on, the problems that AIDS-affected families encounter, or whether these families are receiving assistance.

Another problem is that data is not collected often enough to capture the dynamic nature of the epidemic. More frequent data collection would enable policy makers to follow trends,

anticipate needs and develop more appropriate responses.

Responsibility for national data collection lies mainly with governments. However, other organisations also have a role to play. UNAIDS needs to amend the indicators used to monitor the epidemic, as these often guide monitoring at the national level.

Partnerships should also be formed between governments, international agencies, bilateral donors, NGOs, academics, activists and others to provide financial and technical support to governments. In addition, service providers, including NGOs, have a responsibility to undertake data collection at the local level.

HelpAge International is actively engaged in discussions on data collection. In 2007 its Tanzania programme successfully advocated for the inclusion of two questions on carers in the national HIV indicator survey. The National Bureau of Statistics also expressed interest in including a section on older people in its 2009 survey.

HelpAge International's partners in a number of African countries are analysing data from voluntary counselling and testing (VCT) centres, and advocating with governments to follow their lead (see *Ageways* 68). In Thailand, the National Statistical Office included indicators on the caring burden of older people in the 2007 older people's survey.

International organisations have begun to recognise the need for better data on older people, particularly as carers. They have made a number of commitments, which can be used to support advocacy:

The UN Declaration of Commitment on HIV/AIDS (2001) commits member states to 'review the social and economic impact of HIV/AIDS at all levels of society, especially on women and the elderly, and particularly in their role as caregiver'.

UNICEF's *Children and AIDS: second stocktaking report* (2008) states that 'more accurate data disaggregated by age and sex are key to determining how much of budgetary resources is allocated to the needs of young children, adolescent boys and girls and those who care for them.'

The African Union Health Strategy 2007-2015 recommends that 'data should be disaggregated by gender and age to enable more focused action'.

Call for action

HelpAge International is calling for improved data collection to provide a more accurate picture of the epidemic, allow governments to prioritise budgets and target the most vulnerable people, and enable older people to be included in policy and programming:

- Existing data should be further analysed to show household composition by age, sex and socio-economic status.
- Future surveys should record qualitative data, including caring roles and support received by households; income and expenditure; and use of, access to and satisfaction with HIV services.
- Longer-term surveys should be undertaken to understand how the arrangements of AIDS-affected families change over time, and what impact caring has on older people, people living with HIV and vulnerable children.
- International and national indicators for monitoring the epidemic should be expanded to include all people. Data should be broken down by age and sex to give a clear indication of the impact of the epidemic on different population groups.

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Reducing the risk of infection

Douglas Lackey explains why older people need to be included in prevention programmes.

Many people think that only younger people are at risk of HIV infection, because of a wrongly-held assumption that older people are not sexually active. The fact that international data on HIV has only been published for the 15-49 age range reinforces these assumptions.

Yet many men and women continue to have sex as they age. In a study in Thailand, more than half of married men in their later fifties and married women in their earlier fifties reported having sexual intercourse in the previous month.

Risk factors

UNAIDS reports that 'a substantial proportion of people living with HIV are 50 years or older'. The main cause of HIV infection in older people is the same as in younger age groups – heterosexual sex. Older people engage in the same higher-risk behaviours as younger people.

There are some factors that place older people at higher risk of HIV infection than younger people. Older people are generally excluded from AIDS education programmes, so they do not learn how to protect themselves. In older women, a decrease in vaginal lubrication and thinning of the vaginal walls increase the risk of infection during unprotected sex. Health workers may not consider testing older people for HIV, because they, and older people themselves, do not think that older people are at risk.

The following measures would reduce the risk of HIV infection in older people:

- Publish data on HIV infection, broken down by age and sex. This would show how many older people are infected, which would help with planning prevention programmes.
- Make HIV and AIDS services sensitive to older women and men. For example, set specific times for older people to seek advice from trained health workers; train older people as peer educators and counsellors; and make sure that older people can obtain male and female condoms and lubricants.
- Research the links between age and HIV infection, including a possible risk of infection by older carers of people living with HIV and AIDS, about which very little is currently known.
- Include HIV and AIDS issues in the training of professional and voluntary carers of older people.
- Develop HIV prevention messages for older people, including older carers. This means involving older people in developing these.
- Enact legislation to eliminate elder abuse.
- Ensure that HIV and AIDS prevention strategies include older people as a vulnerable group, especially those caring for people living with HIV and AIDS or for children affected by HIV and AIDS.

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How to support older carers

Older women provide the backbone of AIDS care in Africa, but receive little or no formal support. HelpAge International has developed a model for supporting older home-based carers.



Emma Judge/HelpAge International

Older carers of people living with HIV need training and access to services.

Most care of people living with HIV and AIDS is carried out at home. 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 cater specifically for 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. The 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 can barely make ends meet. They have no regular income to pay for the costs of caring, and they live in dilapidated and insecure houses.

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 and AIDS. The model has four main components: collecting baseline data; training older carers; setting up support groups; and linking older carers to services.

Baseline data

Organisations that seek to support older carers of people living with HIV and AIDS need basic facts and figures,

so that they can develop appropriate interventions. Data should be broken down by age and sex.

They 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 (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 orphans and vulnerable children, and how many are cared for by older people; the number of people living with HIV and AIDS 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.

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 guidelines recommend training two older volunteers from each community, keeping a gender balance.

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, psychosocial support, counselling and pain control. They can also provide information on HIV and AIDS and available services, advise on the nutrition needs of people living with HIV and AIDS, 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 training of trainers.

Topics to cover should be identified in consultation with the older carers. 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 and AIDS, psycho-social 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, 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 leaflets on diet, lifestyle and precautions.

Support groups

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

Groups of older carers enable members to 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, although the actual number of people at each meeting will depend on their health. 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 should be responsible for setting up and guiding the groups.

Links to services

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 clinics, and social services departments.

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

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 (see page 12).

This article is based on 'Building bridges: home-based care model for supporting older carers of people living with HIV/AIDS in Tanzania' (details on page 14).

HelpAge International's partners were Good Samaritan Social Services Tanzania (GSSST), Tanga Elderly Women Resource Centre (TEWOREC), Southern Highlands Senility Organization (SHISO), Walio Katika Mapambano na AIDS Tanzania (WAMATA), and Arusha Retired People's Association (CHAWAMA). The project was funded by the Rapid Funding Envelope.

More information: Mussa Mgata, Programme Manager, HelpAge International, Tanzania (address on page 15). Email: mmgata@helpagetz.org

Overcoming barriers to testing

How can older people be encouraged to use voluntary counselling and testing services? A workshop organised by HelpAge Kenya provides some ideas.

In 2007, HelpAge Kenya organised a three-day workshop for 22 voluntary counselling and testing (VCT) counsellors to discuss ways of improving access of older people to VCT services.

VCT is a process that enables a person to make an informed choice about whether to learn about their HIV status, and to be tested in confidentiality if they decide to have a test. VCT includes confidential pre-test, post-test and follow-up counselling.

The counsellors provided feedback from older people on the barriers to using VCT services. Age was felt to be a barrier, as the general perception is that older people are not sexually active, and therefore do not need to know their HIV status. VCT services are associated with youth. The term 'youth-friendly VCT' appears on some signposts for VCT clinics.

Long distances to VCT clinics, discouragement by religious leaders from using services, and insufficient information on VCT were also cited as barriers. The fact that the majority of VCT staff were young people was an obstacle, as older people said they felt uncomfortable about talking about their sexuality with younger people. Some older people feared that the

results would be faulty, or that counsellors would expose their status.

The counsellors reported that older people felt that they had a wealth of knowledge and therefore wondered what they would be informed about by VCT counsellors. They also said that some older people thought that they would be undressed by young people at VCT clinics.

The current government requirement that the client has to read their own results is a challenge for older people who are not literate or have poor vision. Some older people have hearing difficulties and the counsellor has to shout, which breaches confidentiality as people in adjacent rooms hear the conversation.

Counsellors also referred to limited provision of antiretroviral therapy and lack of support groups for older people.

They suggested ways to address these barriers:

- organise peer education, involving older people as peer mobilisers
- provide door-to-door counselling and testing
- organise cultural festivals popular with older people, with traditional musical instruments and board

- games, and then introduce the subject of HIV and AIDS and VCT
- collaborate with other VCT sites to attend to those fearing stigma and discrimination from their relatives or neighbours
- enhance the skills of VCT counsellors in providing services for older people
- provide mobile VCT services
- use theatre, sports and tournaments to promote VCT services
- strengthen referrals through local existing structures such as faith leaders, community health workers and local administrators.

Involvement of older people in special days like World AIDS Day is critical, as it reminds everybody that older people are also vulnerable to HIV and AIDS. Integrating healthcare for other illnesses such as backache, malaria and typhoid within a VCT centre, and conducting periodic free medical camps together with VCT services, is also important.

Changing the name from VCT to 'comprehensive care check-up' could help to reduce stigma. Involving people living with HIV and AIDS in mobilisation and sensitisation campaigns for all age groups is another effective strategy.

The counsellors noted that behaviour change is a process that requires patience, not quick fixing. They observed that with sustained advocacy, backed by supportive policies and programmes, more older people would come forward for testing.

This article is a shortened version of an article by Martin Mubisi in Older People and HIV/AIDS in Africa' issue 2 (details on page 14). Martin Mubisi is Projects Officer, HelpAge Kenya, PO Box 34339, 00100, Nairobi, Kenya. Email: helpageken@mitsuminet.com

'I went to the hospital some time ago with a dislocated knee, but they never tested me, so I don't know if I am HIV-positive or not.'

Older Kenyan woman whose husband died of AIDS

Never too old to learn

Older people in Cambodia are glad to learn about HIV and AIDS.



Nile Sprague/HelpAge International

Sessions demonstrating condom use prove to be popular.

Today about 65,000 Cambodians are living with HIV and AIDS, most of them cared for at home by older relatives.

Older carers often pay the economic price of HIV and AIDS – footing medical and funeral bills – and take in orphaned grandchildren. They face prejudice and isolation. However, when village education sessions on HIV and AIDS are organised, many Cambodian elders report being turned away because they are ‘too old’.

With funding from the Mercury Phoenix Trust, HelpAge International worked with older people’s associations to raise awareness and improve community support for older people affected by HIV and AIDS in 10 villages in Banteay Meanchey province in north-west Cambodia.

In 2006, 10 volunteers from each village were given training on HIV and AIDS transmission, prevention, treatment services and home-based

care. They were taken on an exchange visit to a project where older people’s associations provide financial support for families affected by HIV and AIDS. For the first time, they met people who were openly HIV-positive, and had frank discussions about fear and discrimination. The volunteers were then asked to share their learning with friends and family.

The project villages organised five community education sessions led by HelpAge International. Topics included: transmission, prevention, hygiene and nutrition, treatment services and the impact of HIV and AIDS on individuals and families. Sessions demonstrating condom use were popular. Few women had ever seen a condom before or knew how to use one.

While many AIDS programmes in south-east Asia aim to reduce discrimination, there is little published research on their effectiveness. HelpAge International evaluated the project’s impact by doing a baseline

survey of beliefs before the project, then another survey at the end of the year-long project in 2007. More than 70 people took part in focus group discussions or individual interviews.

The study found that the project had significantly increased people’s understanding of HIV and AIDS. Most participants had discussed HIV prevention with friends and family. Women, particularly, felt better equipped to talk about the disease.

‘HIV/AIDS education is very important for us so we can give education to our children and grandchildren,’ a woman in Tabao village said.

Discrimination against people with HIV and AIDS, mainly based on fear, decreased significantly. The number of people saying they would not visit families affected by HIV and AIDS halved. ‘We should encourage our children to play with children whose parents have HIV,’ a participant said. ‘They cannot catch HIV from playing together.’

The role of community support was highlighted. ‘If there is someone in the village with HIV, it is important that we go and visit them to encourage them,’ an older woman in Smach village said. ‘If we can, we should also give them some rice because they might be too sick to work.’

Many older people expressed their thanks at being included in the project when they had previously felt excluded. They described the learning – a mix of presentations, demonstrations and games – as fun.

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Working with traditional healers

HelpAge International's partners in southern Africa are supporting traditional healers to respond to HIV and AIDS.



MUSA

Traditional healers in South Africa learn about HIV-related illnesses.

Most older people in sub-Saharan Africa go to traditional healers, rather than visit formal health services. They find it easier to communicate with traditional healers because they speak the local language, and their services are readily available and affordable – paid for either in cash or in kind.

However, people seeking treatment for HIV-related illnesses are not always well served by traditional healers. Traditional healers are often not well informed about HIV and AIDS. They may not know how to treat someone or when to refer them to hospital. They generally work in isolation, both from each other and from formal health services.

Traditional healers are often reluctant to refer clients to formal health services. Many are not literate, making it difficult for them to write referral letters. Many think that it is not

important to keep records about their clients.

HelpAge International's partners in Zimbabwe and South Africa have been working with traditional healers to increase their knowledge of HIV and AIDS and strengthen links with formal health services, with funding from Comic Relief.

HelpAge Zimbabwe held awareness-raising sessions with representatives of ZINATHA, the coordinating body for traditional healers in Zimbabwe. The ZINATHA representatives then mobilised traditional healers to attend training sessions facilitated by health ministry staff in conjunction with ZINATHA.

At first, the response was not encouraging. Many traditional healers suspected that HelpAge Zimbabwe was working in collaboration with the regulating authorities to clamp down on those who were not registered.

After the first training session, however, participants mobilised their peers, and the number of traditional healers requesting to participate almost doubled.

Following the training, traditional healers are reported to be using sterilised equipment and avoiding contact with body fluids – some using plastic bags in place of gloves when these are not available. Most now encourage clients to bring their own gloves.

In South Africa, the Muthande Society for the Aged (MUSA) has run similar activities with traditional healers. Both HelpAge Zimbabwe and MUSA have helped to build relationships between traditional healers and government health services. Traditional healers are referring more clients to clinics and hospitals. Some have requested further supplies of equipment from the Ministry of Health and other NGOs.

ZINATHA has developed an HIV and AIDS policy, which has been approved by the Ministry of Health. In South Africa, some traditional healers want to develop a code of conduct. MUSA plans to help them with this.

Data from local clinics and hospitals shows that, along with pregnant women, families headed by older people form the majority of traditional healers' clients. Therefore any referral systems developed between traditional healers and health ministries must ensure that the particular needs of older people, and those they care for, are met.

It is possible that referring more clients to hospital could substantially reduce traditional healers' source of livelihood. One option may be to provide start-up capital for income-generating activities, or to pay a commission for each referral.

With thanks to Douglas Lackey, HIV/AIDS Team Leader, HelpAge International Africa Regional Development Centre, Edna Mbesa, HIV/AIDS Coordinator, MUSA and Adonis Faifi, Programmes Manager, HelpAge Zimbabwe.

Clubs that ease the stress of caring

In Vietnam, 'empathy clubs' are helping to ease the stress felt by older carers of people living with HIV and AIDS.

Hong lives in Vietnam with her husband and their 28-year-old son, who is HIV positive. When Hong first found out about her son's status, she was so upset that she could not eat for five days. Then, she says: 'I realised I couldn't change what had happened, and it was my responsibility as a mother to care for him.'

This meant staying in hospital with her son, making sure he received anti-retroviral treatment, and feeding him a good diet after he returned home. This cost a great deal, and Hong depleted her savings, borrowed from her sister and spent her pension to cover the costs.

Hong's situation is becoming increasingly common in Vietnam. Although HIV prevalence is much lower than in neighbouring countries, it is rising steeply, mainly among intravenous drug users and sex

workers. The number of people living with HIV more than doubled between 2002 and 2006. More than half of those needing care are looked after by their mothers.

Despite the enormous financial, physical and emotional stresses placed on them, older carers are not specifically recognised by national policies, and few civil society organisations support them.

The most substantial initiative for older carers are self-help groups, or 'empathy clubs', supported by the Vietnam Women's Union. Since 2005, the Vietnam Women's Union has been working with HelpAge International and local organisations to extend the clubs. There are now 67 clubs in four provinces – Hanoi, Nam Dinh, Quang Ninh, and Thai Nguyen.

The empathy clubs enable older carers to share experiences and develop practical responses to their needs.

Each club has a member-elected management board and about 50-60 members. At least 70 per cent of members are older people, most of them women. Monthly meetings usually include a guest speaker, an experience-sharing session, and updates about club activities.

Through the clubs, members learn how to care for people living with HIV, how to reduce the risk of HIV transmission, and how to obtain anti-retroviral treatment, condoms, clean needles and other medication. The clubs arrange regular health check-ups for members and advise them on self-care. Members also visit people living with HIV and other older carers.

The clubs raise awareness in the local community about HIV and AIDS and the vital role of older carers. They provide counselling for people living with HIV and AIDS and those at higher risk, and they put them in touch with local services.

The clubs also provide loans and training for livelihood activities, and assist with the costs of educating orphans and vulnerable children.

Hong has benefited greatly from joining an empathy club. She has shared her story with others, participated in school education sessions, and taken out a loan to help her son start a small business. She is now the chairwoman of her local club, and keen to help families facing the same challenges.

The Vietnam Women's Union recognises that the empathy clubs have limited resources and cannot meet all the financial, psychosocial and health needs of older carers. So another key role of the clubs is to lobby government authorities, mass organisations, communities and individuals for more resources and services.

This article is taken from 'Committed to caring: older women and HIV & AIDS in Cambodia, Thailand and Vietnam' (details on page 14).



Increasing numbers of older Vietnamese women care for people living with AIDS.

Resources

Publications

Older People and HIV/AIDS in Africa

Bi-annual newsletter published by HelpAge International Africa Regional Development Centre.

Ageways

A question of authority (caring for grandchildren in Tanzania) – issue 69.
Stories and memories (psychosocial support in Mozambique) – issue 69.
Opening eyes to AIDS care in Africa (community data) – issue 68.
Care of the person who is dying – issue 63.
HIV/AIDS and older people – theme of issue 61.

Committed to caring

Reports how older people, primarily women, provide HIV and AIDS care in Cambodia, Thailand and Vietnam.

HelpAge International, 2007

Stronger together

Outlines HelpAge International's call for a major shift in the response to HIV and AIDS.

HelpAge International, 2007

Raising awareness of HIV and AIDS in southern Sudan

Outlines the role of older people as counsellors and carers.

HelpAge International, 2007

A better deal for older carers in South Africa

Describes how the Muthande Society for the Aged (MUSA) helps older people in South Africa to claim entitlements.

HelpAge International, 2007

Living together

Explains how older carers in Mozambique have set up support groups to help meet their economic needs.

HelpAge International, 2007

Counting carers

Guide to improving data collection and analysis on households affected by AIDS.

HelpAge International, 2007

Building bridges

Describes a model for supporting older carers, developed by HelpAge International and partners in Tanzania.

HelpAge International, 2007

Making cash count

Review of cash transfer schemes in east and southern Africa for supporting the most vulnerable children and households.

Save the Children UK, HelpAge International and Institute of Development Studies, 2005

Coping with love

Highlights the contributions that older people in Thailand are making to their households, and the lack of support available to them.

HelpAge International, 2005

The cost of love

Presents the key issues facing older women and men affected by HIV and AIDS in Tanzania.

HelpAge International, 2004

Building blocks: Africa-wide briefing notes – supporting older carers

Explains why programmes designed to support orphans and vulnerable children need to pay more attention to the needs of the older people who care for them.

*International HIV/AIDS Alliance, 2004
English, French and Portuguese.*

Forgotten families

Discusses the role of older carers in supporting orphans and vulnerable children, and the economic and social importance of this relationship.

HelpAge International and International HIV/AIDS Alliance, 2003

The impact of HIV/AIDS on older people in Cambodia

Studies the roles of older people in households affected by HIV and AIDS.

HelpAge International, 2004

Code of good practice for NGOs responding to HIV/AIDS

Code of practice to which HelpAge International is a signatory.

www.hivcode.org

UNESCO guidelines on language and content in HIV- and AIDS-related materials

UNESCO, 2006

unesdoc.unesco.org/images/0014/001447/144725e.pdf

Website

www.helpage.org/Researchandpolicy/HIVAIDS

Provides facts and figures, research updates, case studies, agenda for action and links to resources.

International agreements

Africa Health Strategy 2007-2015 (2007)

Recommends developing programmes to combat childhood illnesses, with particular emphasis on orphans and vulnerable children and their older women carers, and disaggregating data by gender and age.

www.africa-union.org/root/UA/Conferences/2007/avril/SA/9-13%20avr/doc/en/SA/AFRICA_HEALTH_STRATEGY_FINAL.doc

UN Political Declaration on HIV/AIDS (2006)

Commits governments to providing support and rehabilitation to older people, particularly as carers.

http://data.unaids.org/pub/Report/2006/20060615_HLM_PoliticalDeclaration_ARES60262_en.pdf

UN Declaration of Commitment on HIV/AIDS (2001)

Commits UN member states to 'review the social and economic impact of HIV/AIDS at all levels of society, especially on women and the elderly, particularly in their role as caregivers and in families affected by HIV/AIDS, and address their special needs.'

http://data.unaids.org/publications/irc-pub03/aidsdeclaration_en.pdf

HelpAge International publications can be downloaded or ordered free of charge from:
www.helpage.org/Resources

If you do not have web access, you can order them from the London office (address on page 16).

HelpAge International Affiliates

Caribbean

Action Ageing Jamaica
ECHO, Grenada
HelpAge Barbados/Barbados
National Council on Aging
Haitian Society for the Blind
HelpAge Belize
National Council of and for Older Persons/HelpAge St Lucia
Old People's Welfare Association (OPWA), Montserrat
REACH Dominica
Society of St Vincent de Paul (SVP), Antigua

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Age-in-Action, South Africa
APOSEMO, Mozambique
CEM Outreach, Sierra Leone
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HelpAge Ghana (HAG)
HelpAge Kenya
HelpAge Zimbabwe
Kenya Society for People with AIDS

(KESPA)
Maseru Women Senior Citizen Association, Lesotho
Mauritius Family Planning Association
Muthande Society for the Aged (MUSA), South Africa
Regional Centre for Welfare of Ageing Persons in Cameroon (RECEWAPEC)
Senior Citizens' Council, Mauritius
Sierra Leone Society for the Welfare of the Aged
Sudanese Society in Care of Older People (SSCOP)
Uganda Reach the Aged Association

Asia/Pacific

Bangladesh Women's Health Coalition (BWHC)
China National Committee on Aging (CNCA)
Coalition of Services of the Elderly (COSE), Philippines
COTA National Seniors Partnership, Australia
Foundation for Older Persons' Development (FOPDEV), Thailand
HelpAge India
HelpAge Korea
HelpAge Sri Lanka

Helping Hand Hong Kong
Instituto de Acção Social de Macau
Mongolian Association of Elderly People
NACSCOM, Malaysia
Office of Seniors Interests, Australia
Pakistan Medico International
Resource Integration Centre (RIC), Bangladesh
Senior Citizens Association of Thailand
Senior Citizens Council of Thailand
Singapore Action Group of Elders
Tsao Foundation, Singapore
USIAMAS, Malaysia

Europe

Age Action Ireland
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Centre for Policy on Ageing, UK
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Elderly Woman's Activities Centre, Lithuania
HelpAge Deutschland
Help the Aged, UK
Mission Armenia
NGO Lastavica, Serbia
Second Breath (Gerontological

Association of Moldova)
Slovene Philanthropy
UMUT (Resource Centre for Elderly People), Kyrgyzstan
WorldGranny
Zivot 90, Czech Republic

Latin America

Asociación Gerontológica Costarricense (AGECO), Costa Rica
Caritas Chile
CooperAcción, Peru
CESTRA, Colombia
ISALUD, Argentina
Mesa de Trabajo de ONGs sobre Personas Mayores (Lima Co-ordinating Group), Peru
Red de Programas Para al Adulto Mayor, Chile
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Learning from each other

Older people in South Africa are learning to educate their peers about how to care for family members who are living with HIV and AIDS.



Leila Amanpour/HelpAge International

Peer education is helping women like Nokwazi, who cares for her son.

The Muthande Society for the Aged (MUSA) is a community-based organisation providing services to older people in Durban, South Africa. Many of these older people, though in need of support themselves, care for family members living with HIV and AIDS, or for children affected by AIDS. MUSA realised that by training older people as peer educators, it would be easier to reach these older carers.

The peer educators programme started in October 2007 with funding from Comic Relief. MUSA selected five older people for training. The training concentrated on HIV prevention, the signs and symptoms of HIV and AIDS, the importance of accessing voluntary

counselling and testing services and not trying to hide one's HIV status, and the importance of antiretroviral therapy and adherence.

The training also examined myths about labelling older people as being bewitched. It covered a range of health issues including tuberculosis, gastric problems and dementia associated with old age. Other topics included nutritional supplements, rights to pensions and other benefits, and how to recognise and report cases of abuse.

Wider reach

MUSA produced and distributed pamphlets in the local languages, which boosted the peer educators' confidence. On graduation, each peer educator was provided with a small incentive – a certificate of participation, a bag and a T-shirt.

MUSA had under-estimated the impact the peer educators would make. At a media briefing workshop, a journalist from one of the national radio stations said: 'The peer educators have opened our eyes and shown us the importance of educating older people about HIV and AIDS. We are going to include them at least once a month in our programmes to reach the nation.'

This is a shortened version of an article by Edna Mbese in 'Older People and HIV/AIDS in Africa' issue 2 (details on page 14). Edna Mbese is HIV/AIDS Coordinator, MUSA, PO Box 10070, Marine Parade, Durban 4056, South Africa. Email: msfta@saol.com

HelpAge International has a vision of a world in which all older people can lead dignified, active, healthy and secure lives. We are a global network striving to ensure that people everywhere understand how much older people contribute to society and that they must enjoy their rights to healthcare and social services and the economic and physical security they need.

Ageways exchanges practical information on ageing and development, particularly good practice developed in the HelpAge International network. It is published twice a year by HelpAge International, with funding from Help the Aged (UK).

Ageways is also available on the web at: <http://www.helpage.org>

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Front cover: A grandmother with her orphaned granddaughter in northern Mozambique.
Photo: Emma Judge/HelpAge International

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