

The cost of love

Older people in the fight against AIDS in Tanzania



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HelpAge International is a global network of not-for-profit organizations with a mission to work with and for disadvantaged older people worldwide to achieve a lasting improvement in the quality of their lives. We work with over 500 partner organizations in 88 countries to empower older people, promote their rights and end age-based discrimination.

HelpAge International Tanzania works to achieve a wider understanding of ageing issues, particularly poverty in old age, within civil society and the government in Tanzania. The Tanzania programme began in 1987 and through its country-wide network of over 50 national NGOs it supports a broad spectrum of work.

HelpAge International Tanzania works at policy level by raising awareness of ageing issues with public policy makers, civil society and older people themselves, and strengthening older people's organizations by providing training in lobbying and advocacy skills. We actively collaborated with the Department of Social Welfare on the National Ageing Policy, and with the Office of the Vice President to mainstream ageing into the National Strategy for Growth and Reduction of Poverty, 2004.

We also work at a practical level through projects focusing on health, income, and community and home care for older people. This includes supporting eye care work in Zanzibar in collaboration with the Ministry of Health and Mnazi Moja Hospital.

HelpAge International's partner organizations and key collaborators have their own alliances with around 200 other organizations and community based groups, who work actively to promote the ageing agenda in Tanzania.

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Contents

Executive summary	2
1. Introduction	4
HIV/AIDS and older people in Tanzania	
Older people are a diverse group	
HelpAge International's work on HIV/AIDS	
Participatory research on the impact of HIV/AIDS on older people in Tanzania	
The policy context	
Structure and purpose of the report	
2. Risk factors for older people affected by HIV/AIDS	8
HIV/AIDS information bypasses older people	
Risks to older people of HIV and AIDS-related illnesses	
Stigma and discrimination	
3. Older people who care for people living with AIDS, orphans and vulnerable children	11
The cost of care	
The needs of orphans and vulnerable children	
The importance of social networks and communal support	
Coping with stress, illness and grief	
4. Support for older people and their families affected by AIDS	16
The need for disaggregated data	
Direct income support to meet basic needs	
Review and implementation of existing policies	
Information for older people	
Promote and support older people's right to participation	
5. Recommendations for action	20
Key resources	22
List of boxes	
Box 1 International commitments on AIDS, Ageing and Poverty	6
Box 2 Sources of information on HIV/AIDS for older people	8
Box 3 The daily cost of care for a person living with AIDS	11
Box 4 Daily routine of older women	12
Box 5 Unmet needs of orphaned children Tanga municipality, Tanga region	13
Box 6 Coping mechanisms for older people at Gumba village, Kibaha district	14
Box 7 Information needs identified by older people	18

Executive Summary

Over the last decade the HIV/AIDS¹ epidemic has had devastating and under reported economic, social, health and psychological impacts on older women and men, especially in sub-Saharan Africa. Older people are carers of those who are ill with HIV/AIDS and their orphaned children, and are themselves at risk of infection. Yet little information exists on the exact extent of the needs and contributions of older people in the fight against AIDS in Africa in general, and Tanzania in particular.

AIDS in Tanzania

Tanzania now has an HIV prevalence rate of ten per cent and a rising number of orphaned children. As the epidemic takes hold, it impacts on the lives of Tanzania's older people who care for their sick sons and daughters. When their children die, the older people not only lose their main source of economic and social support, but also become the main guardians and carers for their orphaned grandchildren. The risks and difficulties that they face are still scantily acknowledged in HIV/AIDS policies, programmes and research.

There are nearly two million people over the age of 60 in Tanzania, forming 5.7 per cent of the total population. Many older people live in remote rural areas where they face extreme poverty and lack of services, a situation made worse as they assume new care-giving roles.

Over recent years, as the impact of HIV/AIDS has been felt ever more keenly, HelpAge International (Tanzania) and its partner organisations have begun to equip themselves with information and skills to support older people affected by HIV/AIDS.

This report presents the findings of an initial participatory study undertaken among older women and men, their communities and key stakeholders in five regions of Tanzania. The study's aim was to explore the multiple impacts on, and roles of older people in the fight against HIV/AIDS epidemic.

Main research findings

Older people at all the research sites lacked access to adequate information about HIV/AIDS, its causes, methods of transmission and treatment. The main sources of information for older people were found to be oral communication from health visitors, community meetings and the radio, rather than written materials or posters. Low levels of literacy, especially among rural women, language constraints and limited access to written materials were all found to contribute to lack of information. This has implications for design and implementation of HIV/AIDS education and prevention campaigns, which will need to work harder to target older people with appropriate messages, non-written forms of information and include them in prevention activities.

Risk of infection

Older people face risks of infection with AIDS-related illnesses due to their own sexual behaviour, because they lack knowledge of how to protect themselves. The risk is increased by customs such as polygamy and wife inheritance, as well as by their role as caregivers to people living with AIDS (PLWA). Furthermore, older women reported that they, like younger women, are sometimes forced into transactional sex as a result of poverty.

Stigma

Stigma and discrimination means prejudice against all those affected by AIDS, including older people who may be HIV-positive themselves or caring for their dying children and orphaned grandchildren. The ensuing shame, fear and anxiety reduces their access to services such as home visits and prevents them from employing protective measures such² as wearing gloves when attending patients under their care.

¹ Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome

² Report of the Global AIDS Epidemic, UNAIDS, July 2004

Economic impact

The most obvious impact of HIV/AIDS on older women and men in the study sample was the economic strain of their care-giving role. Costs of necessities such as food, water, medicines and health care for the affected adult children, in addition to clothes and schooling for their grandchildren, were found to outstrip four or five-fold the meagre income they earn.

Often this sets off a downward spiral of distress - from sales of property to indebtedness - that jeopardises the sustainability of their long - term livelihood. Older women in particular have to adjust their daily lives to accommodate their caregiving responsibilities and therefore end up with less time available to engage in productive activities. This is particularly the case when caring for someone in the final stages of AIDS or when the orphaned children under their care are still very young.

Lack of household resources was found not only to reduce school attendance, but also delay it and to reduce incentives to continue into secondary education.

Changing roles

Family roles are changing considerably under the pressure of AIDS. The capacity of social networks is undermined as they cannot absorb the ever-increasing demand for resources or disintegrate as a result of stigma and discrimination. Older people cited lack of funds to contribute to communal activities, the shame related to having an AIDS-affected person in the home, and the multiple demands on their time as factors hindering their participation in or support for community activities.

Stress

When all of these factors combine, they place a tremendous amount of stress on older people, people living with AIDS and orphaned children. There is rarely time or space to deal with the feelings of grief, loss, stress and anxiety which accompany AIDS as it enters families and communities.

Despite these setbacks, older people, their families and communities are surviving by employing a range of coping mechanisms. A concerted effort is needed by the Government of Tanzania, non-governmental organisations, AIDS service organisations and associations of people living with AIDS to acknowledge and support older people in dealing with the stress of AIDS in their lives. The research highlights a number of areas in which action is needed to channel support towards older people who play an important role in the fight against AIDS in Tanzania.

Recommendations for action

1. Disaggregate all data and information on HIV/AIDS and poverty by age.
2. Provide direct income support, including social protection measures, to older people and AIDS affected families.
3. Review existing national policies on health, HIV/AIDS and poverty reduction to include older people.
4. Provide older people with information on HIV/AIDS and home care support.
5. Empower and support older women and men to enable their active participation in local and national policy and programme processes on HIV/AIDS, poverty reduction and local planning.

1. Introduction

Over the last decade the HIV/AIDS epidemic has had devastating and under reported economic, social, health and psychological impacts on older women and men,³ especially in sub-Saharan Africa. Older people are carers of those who are ill with HIV/AIDS and their orphaned children, and are themselves at risk of infection. Yet little information exists on the exact extent of the needs and contributions of older people in the fight against AIDS in Africa in general, and Tanzania in particular.

The AIDS epidemic has been recognised as the major challenge to development today by many governments throughout Africa and the international community as a whole. In 2003 the United Nations Joint Programme on AIDS (UNAIDS) estimated that some 38 million people around the world were HIV positive, 25 million of them in Africa alone.⁴ International data on infection rates does not include the over-50 age group. Older people are therefore largely invisible in international data on HIV/AIDS. Yet not only are older people themselves infected with the HIV virus in growing numbers, but also they play a key role in giving care to people living with AIDS and to the ever-increasing numbers of orphaned children.⁵

A 2002 study in Zimbabwe showed that nearly 40 per cent of people living with AIDS were cared for by their older parents, and that nearly 30 per cent were cared for by their grandparents.⁶ In 2003 there were 43 million orphans in sub-Saharan Africa, 12.3 per cent of all children. Twelve million of these are orphaned due to AIDS.⁷

Recent quantitative analysis of data from 27 sub-Saharan African countries showed that one third of all households are headed by older people.⁸ Over 60 per cent of orphaned children live in grandparent-headed households in Namibia, South Africa and Zimbabwe, and over 50 per cent in Botswana, Malawi and Tanzania.⁹

HIV/AIDS and older people in Tanzania

The situation in Tanzania is very similar. According to the 2004 National AIDS Control Programme report, two million Tanzanians are estimated to be HIV positive. This is an overall prevalence rate of roughly 10 per cent. Tanzania is home to some 2.5 million orphans (14 per cent of all children in Tanzania). Of these nearly one million are estimated to be orphaned by AIDS.¹⁰ 64 percent of children who have lost both parents are living in a household headed by a person over the age of 55. Furthermore, as the epidemic advances, the number of children living with grandparents increases in relation to those living with other relatives.¹¹ Between 1992 and 2000 the proportion of orphaned children¹² living in a grandparent-headed household increased from 45 to 53 per cent, compared to a reduction of those living with other relatives from 40 to 31 per cent.

There are nearly 2 million people over the age of 60 in Tanzania, 5.7 per cent of the total population of 35 million. The lives of many older people in Tanzania are characterised by poverty, ill health, inadequate agricultural inputs leading to reduced quantity and quality of food, lack of power over decision-making, unemployment and discrimination. Furthermore, older people in Tanzania are taking on unrecognised additional roles as a result of the HIV/AIDS pandemic. There is the increased responsibility of caring for sick adult children, and subsequently bringing up orphaned grandchildren, who may also be HIV positive.

Older people are a diverse group

It is important to stress, however, that older people are not a homogenous group. Their wellbeing and quality of life depend on a number of factors including age, gender, occupation, social status, class, type of marriage and marital status as well as type of household and location.

This research highlights the economic, social, psychosocial and health impacts of HIV/AIDS

³ The United Nations and the Government of Tanzania define older people as those over the age of 60. Definitions however vary according to life expectancy, culture, and people's own perceptions of age. Data related to HIV deals mainly with the 15-49 year olds. In this case HelpAge International classes all those over 50 as older persons.

⁴ *Report of the Global AIDS Epidemic*, UNAIDS, July 2004

⁵ *2004 Report on the Global AIDS Epidemic*, UNAIDS, 2004

⁶ *Impact of AIDS on Older People in Africa: Zimbabwe Case Study*, World Health Organisation, Ageing and Life Course Unit 2002

⁷ *Children on the Brink 2004*, UNAIDS/UNICEF/USAID 2004

⁸ The data sets (DHS & MICS) categorised older people as those over 55.

⁹ Double orphans and single orphans not living with surviving parents. 'Grandparents' growing role as carers' by Monasch, R and Clark F in *Ageing and Development* 16, HelpAge International 2004; Africa's Orphaned Generations, UNICEF, 2003

¹⁰ *Children on the Brink 2004*, UNAIDS/UNICEF/USAID 2004

¹¹ Roeland Monasch, *The role of older people as carers of orphans in Sub-Saharan Africa – a quantitative analysis*, unpublished March 2004

¹² Double orphans and single orphans not living with surviving parent.

on older people. The extent of these impacts on the lives of older people will, however, vary according to individual, household and or community circumstances. For example, the impact of HIV/AIDS on an older woman, who is widowed, living alone, and is taking care of her adult HIV positive son or daughter with his or her children in a remote rural village is quite different from a married woman, living in an urban area with her husband and other adult family members to help her. Likewise the burden of caring for orphaned children placed on a poor, single older man or woman with no adult children is quite different from that of another man or woman who is married and whose healthy adult children are working and providing support.

HelpAge International's work on HIV/AIDS

HelpAge International, with its network of organisations in over 70 countries, has been working with older people in poor communities for some twenty years, and has over ten years' experience of supporting older people affected by HIV/AIDS. As the epidemic has progressed HelpAge International and its partner organisations have launched a response through programmes that combine prevention, care and support.

Interventions are community-based and take an intergenerational approach. They promote inclusive programming through participation and consultation, in which the rights of all people, including older women and men, children, and those who are sick, poor and vulnerable are recognised. The programmes have mutually reinforcing components linking poverty-reduction measures to people's rights to food, housing, health care, and education. They address the specific needs of AIDS-affected households such as information, home care, and counselling.

HelpAge International has been active in Tanzania since the late 1980s and has supported work that includes awareness raising on ageing issues with public policy makers, civil society, and older people themselves. It has also prepared age care organisations with advocacy and lobbying skills, and helped to build their organisational capacities. In addition, practical projects focusing on priority needs of older people, such as health, income generation, community and home care have also been supported.

This work has been carried out through collaborative links with over 200 non-governmental and community-based organisations that are making exceptional efforts to ensure that older people and their needs and rights become visible and stimulate specific responses. Over recent years, as the impact of HIV/AIDS is felt ever more keenly in communities in Tanzania, HelpAge International and its partner organisations have begun to equip themselves with information and skills to support older people affected by HIV/AIDS. This study has been part of that process.

Participatory research on the impact of HIV/AIDS on older people in Tanzania

The study's overall objective is to increase knowledge, understanding and awareness of the impact of HIV/AIDS on older people in Tanzania among public policy makers, civil society, and age care organisations. The study explores the impacts of HIV/AIDS on older people in seven districts in five regions of Tanzania.¹³

The data and information presented here were obtained mainly from primary sources, using participatory methods such as seasonal calendars, institutional mapping, focused group discussions, key informant interviews and observations, as well as district and national feedback workshops. Additional secondary data was obtained from a desk review of existing data and literature. In total, 1,983 respondents participated in the research. Interviews and feedback meetings were held in the seven districts with District officials, councillors, council chairpersons, religious leaders, teachers, civil society representatives working on HIV/AIDS, regional and district AIDS Control Co-ordinators, and older people, people living with AIDS and orphaned children.

¹³ Muheza and Tanga municipality in Tanga, Iringa Municipality in Iringa, Kibaha and Bagamoyo in Coastal Region, Kinondoni Municipality in Dar es salaam and Arumeru district in Arusha Region

Researchers encountered some limitations in the process of collecting data on the impact of HIV/AIDS on older people in Tanzania. First, the research timescale and design facilitated a 'snap shot' of the situation of older people; it neither allowed for field visits to the most remote areas of Tanzania, nor for examining change over time. This arguably meant that the study did not reach the poorest and most vulnerable older people. Nor was it possible to compare and contrast the situation of older people within 'before and after' or indeed 'with or without HIV/AIDS' scenarios.

A map of Tanzania showing research sites



Second, as has already been mentioned, the diverse situations in which older people in Tanzania live are important in understanding the impact of HIV/AIDS on their lives and those of their family members. This diversity has not been fully explored and the study therefore only presents a general picture. A much deeper and more detailed analysis is needed to establish which older people are most vulnerable to the impact of HIV/AIDS, and how this vulnerability differs from that of other age groups or other people affected by the epidemic.¹⁴

The policy context

The international community has made a number of commitments to tackle HIV/AIDS and to reduce poverty as well as to mainstream ageing (see box 1). However, so far little has been done by national governments or the international community to put in place policies, programmes and resources to act upon these commitments.

Box 1 International commitments on AIDS, Ageing and Poverty

- The UN Declaration of Commitment on HIV/AIDS (2001) commits member states to 'ensure the development and implementation of multi-sectoral national strategies that address...gender and age-based dimensions of the epidemic' and 'strengthen family and community-based care'. It further commits governments 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 caregivers.'
- The Madrid International Plan of Action on Ageing (2002) commits all UN member states to the improvement in the assessment of the impact of HIV/AIDS on the health of older persons infected and for those caring for infected or surviving family members', to the 'provision of adequate information, training, treatment, medical care and support to older persons living with HIV/AIDS and their caregivers', and to 'introduce policies to provide support, health care and loans to older caregivers to assist them in meeting the needs of children and grandchildren in accordance with the Millennium Declaration.'
- The Africa Union (AU) Policy Framework and Plan of Action on Ageing (2002) commits AU member states to 'protect the rights and needs of older people affected by HIV/AIDS and other epidemics, including the recognition that older people are sexually active and at risk group and that they are the major providers of care for those who are sick and for orphaned grandchildren.'
- The Millennium Development Goals (2000) commit UN member states to halving, by 2015, the number of people living in extreme poverty and halting and reversing the spread of HIV/AIDS.

¹⁴ National Multi-Sectoral Strategic Framework on HIV/AIDS (2003-2007) Prime Minister's Office, United Republic of Tanzania, February 2003, pp 47 & 49

The Government of Tanzania is a signatory to all these international commitments. However, it is also bound by national policies such as the Poverty Reduction Strategy, the National Policy on HIV/AIDS and the National Ageing Policy.

At the time of going to press, Tanzania's National Strategy for Growth and Reduction of Poverty (NSGRP, 2005/06-2009/10) was in the final stages of preparation. This strategy mainstreams vulnerable groups including older people, children, women and people living with AIDS and proposes a range of initiatives to deal with HIV prevention, including the care and support of those affected. It also aims at mitigating the effects of HIV/AIDS through the development of social protection measures such as pensions for older people, and social safety nets for children and other vulnerable groups.

The national policy and multi-sectoral framework on HIV/AIDS do not specifically acknowledge the needs of older people, but stress the link between poverty and HIV/AIDS and outline a range of policy interventions in the areas of the rights of people living with AIDS and orphaned children, prevention, testing and care. The Tanzanian Government is specifically committed to 'develop financial safety nets (health insurance schemes, social security packages) to prevent the financial ruin of families and individuals due to treatment costs' and to ensure 'the basic livelihood of persons, families and communities who are the hardest hit by the impact of the epidemic'.

Furthermore, in October 2003 the Tanzanian Government launched the National Ageing Policy, which recognises older people as a resource in development, and their rights within the framework of Tanzania's constitution. The policy commits the Tanzanian Government to, amongst other things, review costs and access to quality health care for older people, raise awareness of their needs, counsel and train older people in the care of people living with AIDS, and ensure that they participate in the planning and implementation of development plans. Furthermore it seeks to establish a credit fund for older people and encourage district councils and civil society to build the capacity of older people to engage in income generation activities.

This policy context provides a conducive and enabling environment in which to respond to the needs of older people and support their contributions to society and to the fight against AIDS. As ever, the challenge lies in the implementation of policies and international commitments. The development of key strategies at national and local level, financing mechanisms and the allocation of responsibilities are critical to ensure that policy initiatives are turned into action at the local level where it can really make a difference to the lives of poor and vulnerable people, old and young.

Purpose and structure of the report

This policy report aims to present the overall findings of the research, highlight the key policy messages and outline core areas of support for older people and to identify areas for further investigation.¹⁵ It is intended for policy makers in government, civil society, age care organisations and donor organisations, to help them better understand the links between old age, poverty and HIV/AIDS in Tanzania. It aims to elicit appropriate responses to support the diverse needs and roles of older people in tackling the HIV/AIDS epidemic in Tanzania and beyond.

The following three sections outline the main findings of the study in relation to the risk of infection among older people in Tanzania, their role in caring for people living with AIDS and orphaned children, the support they need and the challenges they face in providing this support. This is followed by a set of recommendations to help develop a response to older people within HIV/AIDS and wider development policies and programmes, outline areas for further research.

¹⁵ A full research report can be obtained from HelpAge International Tanzania. Contact details are included at the end of the report.

2. Risk factors for older people affected by HIV/AIDS

HIV/AIDS is mistakenly perceived as a young persons' disease, which does not affect older people. The focus is almost exclusively on the 15-49 age group and, more recently, on the increasing numbers of orphaned children. Little attention has been paid to older people's sexuality and the multiple risks which they may face as a result of HIV and AIDS. Limited data is available on infection rates among older people in Tanzania or globally. The few statistics that do exist, however, suggest infection does exist in this age group. For example, in December 2002, it was estimated that in Tanzania 1.3 per cent of those aged 60-65 and 0.8 per cent of those aged 65 and above were HIV positive.¹⁶ Checks on blood donors in Tanzania revealed that 6.3 per cent of male and 5.2 per cent of female blood donors over the age of 55 tested HIV positive.¹⁷

HIV/AIDS information bypasses older people

Older people seldom have access to information on HIV/AIDS and when they do, it is incomplete or often incorrect. Prevention campaigns are almost exclusively targeted at young people and 'high risk groups' such as commercial sex workers, drug users, and pregnant mothers,¹⁸ and ignoring the information needs of older people. Some older persons who participated in the study confessed that they were not sure about the cause of HIV or how it is spread. Such persons may not be aware of the risks they face of contracting or transmitting the virus.

The main sources of information on HIV/AIDS identified by older people in the areas studied included the radio, newspapers, posters, workshops, village health educators and monthly public meetings, home care volunteers, and local NGOs. Gender differences exist in access to information, to the disadvantage of older women. Older women identified the main sources of information as: peer educators, home care visitors, the radio and posters (ranked in this order). Older men ranked the radio first, followed by peer educators, government leaders during official visits, and then home care visitors.

A daily activity analysis in the rural communities showed that older women work on the *shambas* (farms) in the morning, returning home to undertake domestic chores in the afternoon and evening. The peer-educators and home visitors are therefore important sources of information and support for older women as they make home visits. Men, on the other hand, would farm their plots or undertake casual labour in the mornings and in the afternoons mix with other village men, attend public meetings or socialise in the community, where they would be exposed to and have more access to discussions about HIV/AIDS. In urban areas older people are much better informed than their rural counterparts.

Box 2 Sources of information on HIV/AIDS for older people

Source of Information	Accessibility	Coverage	Effectiveness of message	Remarks
1. Radio	xxx	xxx	xxx	Cheaper, covers range topics, more people have access to it
2. TV	x	xx	xxx	Expensive, few people have one shocks due to images shown
3. Newspapers	0	x	0	Need Money to buy it, few older people care read due to illiteracy and sight problems (small print)
4. NGOs/Community workshops/seminars	0	x	0	Older people aren't their target group don't address problems faced by older people, older people unable to read messages, unreachable

Source: 7 older men, 10 older women, Tandale ward, Kinondoni Municipality, Dar es Salaam
Key xxx - most preferable, xx - less preferable x - poor, 0 - none

¹⁶ AIDS among elderly people in the rural community, Lake Zone, Tanzania, Msobi N., Fimbo B., Msumi Z. 2004, Poster Presentation to XVI International AIDS Conference National Aids Control Programme, Tanzania

¹⁷ HIV/AIDS/STI Surveillance Report No. 17, URT, National Aids Control Program, Tanzania 2003

¹⁸ National Policy on HIV/AIDS, Prime Minister's Office, United Republic of Tanzania, 2001

It is worth noting that written forms of information feature little among older people because of their low levels of literacy and limited access to written information. Illiteracy is high among older people in rural areas, especially among women. An analysis of the Household Budget Survey (2002) shows that very few adults in rural areas have any education above primary level; and that rural women have the lowest education.¹⁹ Over one third of adult rural women had no education. Adult literacy has received attention in the new Tanzania's National Strategy for Growth and Reduction of Poverty (NSGRP, 2005/06-2009/10) but this also has implications for targeting older people with educational campaigns on HIV/AIDS, which will need to work harder to target older people with appropriate messages, non-written forms of information and include them in prevention activities.

Risks to older people of HIV and AIDS-related illnesses

Discussions with older people identified a number of potential risks of contracting HIV or AIDS-related opportunistic infections. These included their own sexual activity without adequate knowledge or awareness of risks and preventative measures. Excessive drinking, especially among older men, was cited in a number of communities as exacerbating this problem. In focus group discussions in Arusha and Iringa older men said they drank in local pubs, often frequented by much younger women with whom they would engage in unprotected sex. Spouses are put at risk through these extra marital relationships.

Some older women explained with some candour how their poverty had forced them into transactional sex, especially when they had taken on additional care-giving responsibilities. Older women talked of cases where they, like younger women, were forced to sell sex in return for basic goods when they were unable to find casual work or were 'tired of begging from neighbours or relatives'. Eight out of eighteen older women in one focus group discussion at Mabawa ward in Tanga municipality said they had to resort to this method to pay for fish.

'Some elderly women go to the sea shore to buy fish directly from the fishermen. On the days when they have no money one has to offer sex to the fishermen in order to get fish to feed the grandchildren.' Older woman, Mabawa ward, Tanga municipality

Older women from Kibaha District in the Coast Region also spoke of engaging in transactional sex with young men selling water. Water shortages are common in many parts of Tanzania, especially in rural areas. Urban areas such as Tandale ward in Kinondoni municipality also suffer from chronic water shortages, where older people cannot afford the 150 Shillings (US\$ 0.10) to pay even for one bucket of water. Women respondents in this ward reported similar cases of offering sex in exchange for water.

Cultural practices such as polygamous marriages and wife inheritance are posing a serious problem in the face of increasing HIV and AIDS. Polygamous marriages between older men and younger women put both partners and the other wives at risk. The custom of wife inheritance, while intended to protect the widow and her children and to keep property and assets within the clan, can increase the risk of contracting and spreading HIV when the deceased husband was HIV positive. In both cases it is not the custom itself, which is causing the spread of HIV, but the unprotected sex between the relevant parties.

A further perceived risk of infection for older people comes from the increased exposure to HIV and AIDS-related illnesses. Older women in particular might face this risk while caring for their HIV-positive sons and daughters, especially in the later stages of AIDS, although this has not been substantiated by medical evidence.

"I cared for my two sons and close relatives who were constantly sick with all my heart. I did not know that what they were suffering from was AIDS. In the end they all died. They left me with three children as orphans. At the moment I am fine. However, I am worried what will happen if I test and find that I am also infected with HIV, because I did not protect myself in any way when I was looking after the sick." One of the older women, Kinondoni District, Dar es Salaam.

'Our men, they do not let a bat pass by. Every girl who passes in front of their eyes they want to sleep with her.'

Older woman, Tanga Municipality

¹⁹ Household Budget Survey 2000/01, National Bureau of Statistics, Dar es Salaam, July 2002

After the death of my daughter, who was looking after me, I tried to make money in different ways, but selling sex was most profitable.'

*Older widow with five grandchildren,
Arumeru district, Arusha region*

Few older people access voluntary counselling and testing services (VCTs) themselves. For example, in Tanga it was reported that in the first six months of 2004 not a single older person had visited a VCT.²⁰ People often discover they are HIV positive while living in the urban areas and return home to be cared for by their parents in rural areas when they are already quite sick. There is no obligation on the persons living with AIDS to disclose their status to their parents, carers or even partners, since confidentiality is key to HIV prevention and care.²¹ While this leaves family members uninformed about the illness of those they care for, greater public awareness and targeted education would reduce stigma for those affected and enable caregivers to provide appropriate care and to protect themselves.

The increased exposure to opportunistic infections and AIDS related illnesses such as Tuberculosis, to which older people are particularly prone, must also be taken seriously. Older people's health suffers considerably as a result of their care-giving role.

Stigma and discrimination

Stigma and discrimination are two serious negative consequences that those affected with HIV/AIDS suffer. For many, therefore, to disclose their HIV status is to jeopardise family, job and social status. The stigma and discrimination often extend to the children, parents and other family members and friends of persons living with AIDS. As a result, older people caring for people living with AIDS are often reluctant to admit that their children are HIV positive or have died of AIDS.

One older woman refrained from wearing gloves while caring for her dying sister, as this would confirm to neighbours and relatives that the sister was HIV positive.

'I knew that my sister was HIV positive but I did not want to use the gloves when washing her clothes nor bathing her. She brought me some gloves, but I kept them fearing that people might suspect she was HIV positive. When she died I threw them in the pit latrine.'
Older woman at Pera village, Bagamoyo District, Coastal region

Many people, including older persons, prefer to say that their children are ill because of witchcraft or tuberculosis than face the social isolation resulting from the stigma surrounding an AIDS death in the family. Social ties and traditional support mechanisms can be weakened when ignorance and stigma marginalise a family affected by HIV/AIDS, at a time when older people and their families most need support.

Home care visitors reported in four of the research sites²² that older people even declined to be visited on a frequent basis to avoid raising suspicion in the community. This means that older people not only miss out on important information and advice on the disease, but also fail to get support for the people living with AIDS and other people under their care.

While taking care of those living with AIDS, older people therefore face a number of risks: including lack of information on HIV/AIDS; lack of prevention programmes focused on their situation and needs; risky working conditions; and stigma and discrimination.

²⁰ Tanga regional AIDS coordinator, HelpAge International Policy workshop on the impacts of older people and HIV/AIDS, Dar es Salaam, September 2004

²¹ *Opening up the HIV/AIDS epidemic: Guidance on encouraging beneficial disclosure, ethical partner counseling and appropriate use of HIV case-reporting*, UNAIDS/WHO 2000

²² Kibaha, Bagamoyo, Arumeru and Tanga Municipality

3. Older people who care for people living with AIDS, orphans and vulnerable children

The primary impact of HIV/AIDS on older people in most AIDS-affected countries is in their role as caregivers to people living with AIDS (PLWA), who in most cases would be their adult sons and daughters, and to children orphaned and/or made vulnerable by AIDS. Tanzania is no exception.

In Iringa municipality, one of the study sites, 350 (28 per cent) out of 1,240 children of school-going age were orphaned, of whom half lived with their grandparents. While the average family size in Tanzania is eight people, one family headed by an older woman in Iringa included 16 orphans.

The study revealed that this role created difficulties in the economic, social, psychosocial and health aspects of older people's lives. Older people are not a homogenous group, as highlighted in the introduction to this report. The extent of the impact therefore depends on factors including age, gender, occupation, income levels, location, family circumstances, and household type and resources.

The cost of care

Older people's role in caring for their adult sons and daughters and other relatives as well as orphaned grandchildren was found to have a variety of economic costs and effects on their livelihood. First, many are forced to redirect their resources from their own needs to those of the people under their care, especially to pay for health care and food. People living with HIV and fighting AIDS have much higher nutritional needs than other adults and require certain types of food to keep healthy. Furthermore, their demand for water is higher, especially if they need regular washing and dressing of wounds. Obtaining water is expensive in Tanzania and can also be time consuming if it has to be fetched from afar. The average daily cost of providing basic care for a person with AIDS was estimated by respondents to be over five times what an older person could, on average, expect to earn in a day's work (see box 3).

Box 3 The daily cost of care for a person living with AIDS

Item	Tanga Municipality	Iringa Municipality
Food	Tshs 2000	Tsh 2000
Drugs	Tshs 1500	Tsh 1500
Firewood Charcoal	Tshs 250	Tsh 400
Soap	Tshs 250	Tsh 250
Other	Tshs 1000	Tsh 1000
Total	Tshs 5000*	Tshs 5000*
<i>Self reported average daily income for an average person</i>	<i>Tsh 400 -1000</i>	<i>Tsh 200 -1000</i>

Source Field Notes: Pongwe village, Tanga Municipality, and Mtwivila ward, Iringa Municipality 2004

*USD 1 = ca Tsh 1000

This table does not include costs for water, transport or emergency health care. Transport alone in the form of bicycles, if hired, would cost TSh 4,000 to get from a rural village to the nearest hospital. Given that the period of care provided to PLWA by older parents in their home until their death can be anything from a few months to a couple of years, this places a tremendous strain on the economic resources of the household and on the strength and ability of the older caretaker to plan or save for the long term, especially for the future of the orphaned children.

²³ HIV/AIDS and Ageing: A briefing paper, HelpAge International 2003, *Forgotten Families: Older people as carers of orphans and vulnerable children*; HelpAge International and the International HIV/AIDS Alliance 2003; *2004 Global Report on the AIDS Epidemic*, UNAIDS 2004; *Impact of HIV/AIDS on older populations*, Fact Sheet, UNAIDS 2002

‘Going to bed with an empty stomach is quite common and happens many times.’

Orphaned child at Pera village in Bagamoyo district, Coastal region

Older people in the study reported a range of activities to raise income. These included petty trading (in e.g. fruits, buns, and charcoal), brewing and selling alcohol, harvesting and selling forest products such as firewood, wild fruits and vegetables, occasional transactional sex as outlined above, and selling family property. Older women’s lack of rights to own or control property makes the latter difficult for them. Often the time older people have to engage in these activities is limited due to the care they provide for the people living with AIDS.

Older women, in particular have had to adjust their daily lives to accommodate their care giving responsibilities and therefore have less time available to engage in productive activities. Some of them have had to abandon their enterprises altogether. In the words of an older woman from Dar es Salaam: ‘This is a full time job that keeps one busy day and night’. This is especially the case when among those in their care are orphaned children, in particular when these are very young. In a focussed group discussion with 17 older people in Pera village, 7 of those who were left with infants or toddlers said they spend 80 per cent of their time looking after these infants, especially if they are also ill.

Box 4 Daily routine of older women

05.00AM	Wake up, pray, fetch water.
06.00AM	
07.00AM	Wash and clean, prepare breakfast, prepare grandchildren
08.00AM	Farm work
09.00AM	
10.00AM	Collect firewood, fetch vegetables/ food
11.00AM	
12.00AM	prepare food, wash family clothes
01.00PM	
02.00PM	Lunch, sell farm crops on market
03.00PM	
04.00PM	
05.00PM	Prepare food to be cooked by grandchildren
06.00PM	Selling fruit and snacks at evening market
07.00PM	
08.00PM	Return home, dinner, bath children
09.00PM	
10.00PM	Bed

Source: 17 older women Masunguru Ward, Muheza District

Many older people reported having to sell assets (including land and property) or using savings in order to cover the costs of the people under their care. Often this sets off a downward spiral of dispossession leading to poverty. Selling of assets jeopardises the sustainability of their livelihood in the long term.

‘I had saved about TSh 4,000. I had to spend some of it to send my sick son to hospital. Then I had to buy him medicine and food. It was not enough. My husband had no money and I had to borrow another TSh 4,000 from a neighbour, which was not enough. After that I had to sell three pairs of "Kangas" (wrap around cloth) and obtained Tsh 9,000.’ Older woman, Mabawa ward, Tanga

‘My son was a long distance truck driver who was plying from Dar es Salaam to Mombasa. He was renting a two-roomed house in Muheza town. He was brought home very sick and I had to take him to Muheza hospital where he was hospitalised frequently for about three months. In caring for him, we sold all his property, radio, furniture, cooking utensils, tables etc. in order to raise money for his medical bills and food. He died during the fourth month. Four months later, his wife became very sick and died after two months. This time, there was nothing to sell. I really don’t know how we managed. They left behind three orphans, one of whom also died shortly after. The two are now aged eight and 16 years respectively. The older one was selected to continue with secondary education but due to poverty, I have to sell some of my land to pay part of her school fees. It is quite tough for me.’ Older woman, Muheza District, Tanga region

This cumulative impoverishment increases older people’s vulnerability and they become dependent on support from neighbours, relatives or community and NGOs. Lack of government support for older people or for households affected by AIDS exacerbates this situation, threatening many of the poorest older people and the children in their care.

The needs of orphans and vulnerable children

Older people’s poor economic status has a knock-on effect on the well being of the orphaned and vulnerable children in their care. Orphaned children identified their needs as food, shelter, clothes, bedding, and emotional support, in particular love. Information gathered from orphaned children in two primary schools in Tanga municipality, showed that they lacked many of the basic necessities to protect their health and well being.

Box 5 Unmet needs of orphaned children Tanga municipality, Tanga

Type of need	Number	% of Orphans
Inadequate bedding (e.g mattress)	16	26
No mosquito nets	41	67
No bed sheets	51	84
No regular meals	31	51
Poor shelter /housing	17	28

Source: Survey data N=61 (52 were living with grandparents)

Older people in Tanga indicated that they require on average TSh 25,000 per month to meet the needs of one orphaned child, including food, clothes and school costs. Food is a particular worry, as one orphaned child in Bagamoyo district, Coastal region remarked: ‘Going to bed with an empty stomach is quite common and happens many times.’ Children said they resorted to begging from neighbours, something from which their grandparents tried to dissuade them.

Although primary school tuition in Tanzania is free, children are required to provide pens and pencils, textbooks, exercise books, school uniforms as well as to bring food and pay for travel expenses. These are often beyond the means of families, especially those headed by older people.

‘I have not enrolled them (his four orphaned grandchildren) in school because I don’t have the money to pay for their school expenses.Older man Kinondoni, Dar es Salaam.

‘Quite often, in a class you will find six or seven orphans with no pencils, pens or textbooks.’ Assistant Headteacher, Mtwivila Primary School Iringa

This problem becomes worse once the children reach secondary school, where fees are charged. At public schools annual fees are TSh 120,000 (US\$120), in addition to transport, food and uniforms. As a result enrolment and attendance are often erratic, performance poor and schools suffer from a high drop out rate. Orphans are less likely to be in school and more likely to fall behind or drop out, compromising their abilities and prospects. In Tanzania the school attendance rate for single orphans is 71 per cent and only 52 per cent for double orphans.²⁴ Some older people are known to ask their grandchildren to repeat their final year at primary school in the hope that they will have saved enough to send them to secondary school the following year. Repeating a year and prohibitive expenses can demotivate children from pursuing school.

Yet despite these economic difficulties older people and their families do manage to survive through a precarious reliance on community members, through begging or by other survival strategies. This study shows that older people adopt a wide range of options that are combined depending on the environment, existing opportunities, the skills they have, access to natural resources, and other human capital available at household level. The mixture of options adopted often varies from place to place and from one household to another depending on the assets they have and opportunities available.

‘Whether I pass my examination or not, my grandmother cannot afford to pay for my secondary school fees’

Young girl, at Masuguru ward, Muheza district.

²⁴ Africa’s Orphaned Generations, UNICEF 2003

‘There is nothing we can do. We can’t push this burden away, even if we would like to.’

Older man, Kibaha District,
Coastal region

Box 6 Coping mechanisms for older people at Gumba village, Kibaha district

Ranked option	Preference	Effectiveness
1. Casual labour	xxx	x
2. Selling charcoal	xx	x
3. Selling firewood	x	x
4. Building poles	x	x
5. Petty business	xxx	xx
6. Involve children	xx	xx

Source: Survey Data 14 Older People cared for people Living with AIDS and Orphans

Close relatives and their own children are a source of regular support, providing older people with materials or cash assistance to support themselves. However, this support base is often intermittent, insufficient and gradually eroded by AIDS deaths.

In many cases orphaned children, particularly when they are over 10 years of age, provide a good source of support for older people and fill a gap in support from other close relatives. At a discussion with 33 orphaned children from Mtwivila primary school, all explained that after school they assisted their grandparents with household cleaning, cooking, and farming, as well as income generation for the family (selling maize, fruits, firewood and charcoal; collecting and selling sand, casual labour). This income helps provide for food and other essential household needs and also assists them to buy some of their school materials.

The importance of social networks and communal support

Older people in the study noted that the first social impact is the change of roles in the family. Whereas previously they expected to be cared for by their adult children in their old age, the older people themselves are now the ones having to care for their adult sons and daughters when they are sick, see them die and then raise the grandchildren.

As one older woman from Kinondoni in Dar es Salaam said: ‘It is very difficult to shift this responsibility to other family members. Even our grandchildren are jobless, they cannot support us.’ Very often, if the grandparent is already old and frail and the children are old enough, a relationship of mutual support develops whereby old and young support each other in whatever way they can. Being the main blood relative, custom and tradition demands that the ultimate responsibility for the children lies with the grandparents, a role which they accept as given.

Informal and formal social networks are a typical feature of most African societies, including Tanzania. People cooperate and assist each other in building houses, farming, or caring for the sick, depending on the tribe, class, and location. Today, the sheer magnitude of the impact of AIDS in some communities has stretched these social networks and mechanisms to the limit, reducing their capacity to fulfill their traditional role. However, stereotypes and stigma related to AIDS have also led to people living with AIDS, their children and caregivers being excluded from these social networks.

‘All the 16 children, we have raised them ourselves – just me and my husband, we have not been assisted by anybody.’ Older woman, Iringa Municipality

Older people also noted a decrease in their participation in community level decision-making. They experienced exclusion from community activities and organisations because of the increased time and money they had to spend on caring responsibilities, or because they were too ashamed to attend public meetings due to their poverty or having AIDS patients in their family.

Loss of social status and social networks has a marked impact on the needs of older people caring for people living with aids and orphaned children. The loss in social status relates to

the stigma attached to AIDS and the shame of admitting that a family member or oneself has engaged in what is seen to be promiscuous and irresponsible behaviour. Women in particular are chastised for being bad mothers and not raising their children properly, or for not being a good wife, with the result that the husband has extra-marital affairs.

In Dar es Salaam region older people spoke of diminishing trust and ability of families to cooperate. This lack of social support, coupled with the economic hardships make some families and older people, in particular, very concerned for their future and that of the children under their care.

'The most important asset that an older person might need is an extended and well placed social network that is effective and readily available.' Older woman, Dar es Salaam

Coping with stress, illness and grief

Alongside the social exclusion that can accompany an AIDS-affected family, older people, people living with AIDS and children orphaned or made vulnerable by AIDS suffer anxiety, grief, loss, and often confusion over the effects of a still poorly understood and highly stigmatised disease. Older people in the study listed depression, sadness, stigmatisation, loss of loved ones, loss of main source of support, and despair at not being able to care adequately for orphaned children as the main psychosocial impacts.

'When your child gets AIDS you are also infected psychologically, because the support you used to get ends, and he or she is brought to you for care, only to die soon.' Older woman Kibaha district, Coastal region

The strain of caring for people living with AIDS in the final stages of the illness can also be very harrowing and tiring and takes its toll on older people's own health. Self-assessments by older people of their health status show that they felt they were suffering from increased incidence of tuberculosis, stomach ulcers, and hypertension. AIDS-related dementia, common in the final stages of the illness, can also be difficult for older people to deal with.

'You gave birth to them yourself, but caring for them when they are sick with AIDS requires a lot of patience, courage and tolerance. Most AIDS patients develop mental problems. If you are not tolerant you can lose your temper and the interest to care. They do not appreciate what you do for them and they use rude language that upsets you.' Older woman, Kinondoni, Dar es Salaam

Being responsible for all the needs of numerous children is a big responsibility, which grandparents take very seriously. They often get distressed about not being able to provide enough food and clothes for the children, or meet their educational needs.

'I have lost two of my children, each left behind two children. That makes four orphans, all of school-going age. In the morning the children want to go to school, they ask for a pen or exercise book but I have none to give. The child starts crying and I also find myself crying.' Older man, Bagamoyo District, Coastal region

Older people also worry about what will happen to the grandchildren once they themselves die or are no longer able to care for them. An old man from Iringa noted: 'All the time I have to think, who is going to look after the orphans when I am not there?'

This myriad of needs, stresses and roles in AIDS-affected families, and in particular the impacts on older women and men, is rarely acknowledged by AIDS service organisations, government policies and programmes or international NGOs and development agencies. Yet older people are often at the forefront of fighting the impacts of AIDS on their communities, families and themselves and therefore deserve adequate support, resources and recognition.

The child starts
crying and I also
find myself
crying.'

*Older man, looking after four orphaned
children.*

4. Support for older people and their families affected by AIDS

As the previous sections have shown, HIV/AIDS in Tanzania is having a wide range of impacts on older people and those under their care. Few policies or programme interventions currently target older people as beneficiaries or actors. Older people identified some support from NGOs at local level, including material needs, mobilisation of community support and basic requirements for the schooling of orphaned children. However, these programmes are heavily reliant on external donor funding, putting their long-term sustainability into question.

Furthermore, the scope of these programmes countrywide is limited, leaving many communities and individuals without any support. For example, where NGOs are supporting orphaned children with basic school items their coverage is still relatively low. The study shows that out of 61 orphaned children surveyed in Kibaha district, Coastal Region, only seven had been visited by the local NGO. In Tanga district 22 per cent of orphaned children (30 out of 136) were receiving support from a local NGO. 19 out of the 30 children receiving support are cared for by their grandparents, but older people interviewed in this district said they were not aware of the intervention programmes or other organisations providing assistance.

Yet unless the needs of older people are actively supported within the fight against AIDS, older people will continue to suffer, families and communities will fall into poverty and the impact of HIV/AIDS will not be abated. This section aims to outline some of the needs that the study identified, as well as the challenges of reaching and involving older people.

The need for disaggregated data

The lack of data on older people, their households and the people under their care, means that little is known about the real situation of older women and men in Tanzania. Data on older people is largely unavailable at village, district and national levels, and when it is, it does not disaggregate according to gender, location, tribe, socio-economic status or other factors.

A case in point is the national HIV surveillance data, which, as is the case around the world, collates information only for 15-49 year-olds, without providing information on the over-50s, or breaking this category into further age groups (50-59, 60-69 and so on). Voluntary testing and counselling services do not collate reports of infection data based on all age groups. Infection rates among older people are, therefore, largely unknown and older people are not encouraged to seek testing.

Lack of information on older people and of disaggregated data have led to poor policy and programme design, and thus poor response to the needs of older people. Furthermore, an in-depth research is required to explore the areas highlighted in this study.

Direct income support to meet basic needs

The core basic needs identified by older people in the study included shelter, food, clothes, water, health care, medication for people living with AIDS and schooling for children. Often the only sources of support available for older people are their own children and other close relatives. However such support may be limited either by geographical distance between the older people and their children or relatives, (many live in urban areas and send only periodic and inadequate remittances), or due to other factors such as their children's own financial difficulties, health status and willingness to provide support. Sometimes older people's support base is significantly eroded by the death of the very children upon whom they relied, especially if a number of orphaned children are left under the grandparents' care.

Economic support for older people and their families is, therefore, key to securing their own wellbeing and that of any children in their care. Some countries in Africa are implementing or

developing social protection mechanisms for older people, orphaned children and other vulnerable groups. In South Africa, Namibia and Botswana, for example, a social pension is provided for older people. This goes a long way to offset the additional financial burden experienced by older people as carers of orphans and vulnerable children. The government of Zambia has launched a cash transfer scheme targeting households affected by AIDS, especially older people headed households with orphans. Each household receives ZMK 30,000 a month (US\$ 6.20), most of which is spent on food, clothes, soap and farming inputs. 60 per cent of members of beneficiary households are children under the age of 19, and school attendance and nutrition among the children have improved since the introduction of the cash transfer.²⁵

Tanzania's National Strategy for Growth and Reduction of Poverty (NSGRP, 2005/06-2009/10) includes a number of strategies aimed at developing social protection measures (including pensions for older people). Such mechanisms that provide reliable and regular income support may be the most effective way to tackle the impoverishing effects of AIDS on those affected.

Whilst Tanzania's Universal Primary Education Programme reduces the burden on families in terms of school fees, many other barriers exist that stop children from enrolling, staying on and performing well in school. Many of the orphaned children encountered in this study had no prospect of progressing to secondary school, and thus little opportunity to escape long-term poverty. Prolonged economic and in-kind support to poor families with vulnerable children is essential if national education targets are to be met.

Older people raised concerns about the lack of credit and loans from government institutions to enable them to establish economic projects. They noted that although the government supports both the Youth Development Fund (YDF) and the Women's Development Fund to encourage these groups to engage in income-earning activities, no such facility exists for older people.

As an old man from Mtwivila ward in Iringa municipality stated: 'We are denied loans and credits on the pretext that we might die anytime and hence will not be able to return the loan. In other words, we are not creditworthy.' Clearly, age limits and age discrimination in credit and loan schemes must be removed, and small-scale investment programmes must be developed to enhance the livelihood opportunities of older men and women. Furthermore, this is a commitment of the Tanzanian government in the National Ageing Policy.

Review and implementation of existing policies

Pervasive poverty at the local, regional and national level is perceived to hamper all attempts to control the AIDS epidemic and to mitigate its impacts. Despite well-intentioned national level policies, lack of decentralised funds, accountability and poor local capacity for implementation lead to poor quality services being delivered at the local level. In this study inadequate infrastructure, such as poor rural roads and feeder roads in urban areas, was cited as particularly hampering the lives of the poor. This leads to high transportation costs, which add to the difficulties older people face in accessing services. This in turn may prevent people living with AIDS from receiving the care they need and orphans from attending schools. Poor implementation of national policies underlies many of the problems facing older people and their families in Tanzania.

Older people in Tanzania are exempted from paying health costs, according to a directive circulated by the Ministry of Health in 2000, reiterated in the National Ageing Policy. However, there has been no follow up in terms of the nature of the exemption, resources for treatment and drugs, or enforcement of the directive. The directive is interpreted to mean different things in different areas. Many health workers and doctors participating in this study, especially at local level, and even older people themselves are unaware of the existence of this directive. Furthermore, older people cited negative attitudes among health personnel and poor understanding of geriatric medicine as barriers to accessing services they are entitled to.

'We keep on hearing that there are policies and programmes that target older people, but we have never seen or benefited from them.'

Older man, Muheza District, Tanga

²⁵ Test Phase Results of the Pilot Social Cash Transfer Scheme, Kalomo District, Zambia (4th Report), by Dr. Bernd Schubert, Progress Report on the PWAS Administered Pilot Scheme for AIDS Affected and other Destitute and Incapacitated Households, Kalomo District, Zambia, May 2004.

'We would rather go to a traditional healer than go to hospitals where there are no drugs, and doctors are not committed to their work. When an older person enters their office, before asking you what the problem is, they write a prescription and hand it to you.' Older man, Kibaha district, Coastal region

Older people themselves need to know their entitlements in order to be able to demand services. Even when village leaders step in to give support, lack of enforcement means older people still come away empty-handed.

'One day two old women came to my house asking for the letter ²⁶ to allow them to access free medical services. I heard from the radio that medication was free to older people. I wrote them a letter as chairperson of the village to go to Muheza District hospital. To my surprise they came back in the evening, very depressed, and told me that the nurses had chased them away. In fact they were told that my letter was bogus and that I am not one to make decisions on this matter.' Village Chairperson in Muheza district, Tanga region

Similarly the health impacts of HIV/AIDS on older people, including their own risk to infection, must be acknowledged. The national policies on health and on HIV/AIDS need to be reviewed and amended to include older people in the group of those at risk of infection since they are carers of people living with AIDS and orphans. Home-based care programmes for people living with AIDS must include training and provide counselling for older women who bear the economic, social and emotional impacts of their children's illness and premature deaths.

The draft national policy on orphans and vulnerable children outlines the most vulnerable children as those orphaned or made vulnerable by AIDS irrespective of whose care they are under. More information is needed on what social protection measures are available or feasible for vulnerable children and their caregivers and these must be implemented and delivered.

Information for older people

Older people indicated that in order to undertake effectively the new roles ascribed to them they need information about national policies and local bylaws on HIV/AIDS and sources of support for them.

Box 7 Information needs identified by older people

- National policies, regional, district and village level bylaws and strategies
- Incidence of HIV/AIDS at national, regional, district and village level
- Causes and symptoms of HIV/AIDS and how HIV is spread
- Preventative and curative measures, especially AIDS-related illnesses
- Sources of support for older people, especially those caring for people living with AIDS and orphaned children.

Source: Compilation - all research sites: Arusha, Iringa, Coastal region, Tanga and Dar es Salaam

Policies specifically designed for older people, people living with AIDS and orphaned children or impacting on them must be disseminated in ways that are accessible, transparent and user friendly for the target groups. Older people must be aware of their rights and entitlements in order to hold service providers and local government departments to account.

As stated in Section 2, older people lack sufficient information on HIV/AIDS, meaning they may not acknowledge the risk of infection to themselves, or change their behaviour accordingly. They rely largely on oral forms of communication and written HIV/AIDS information does not provide an effective way of reaching them, especially older women. Older people have a right to, and need for information on HIV/AIDS to protect themselves

²⁶ The directive states that the only proof of eligibility required to access free treatment is a letter from the chairperson of village government or district chairperson verifying the older person's age and entitlement to the free health care.

and those under their care. They also play crucial roles in the education of others. Older people expressed an interest in being involved as peer health educators, especially to raise awareness among other older people on issues of HIV/AIDS. They must also be encouraged to access voluntary testing and counselling services in order to inform themselves about their own HIV status and be included in counselling on the people living with AIDS under their care.

'Older people's role in prevention is also important, as infected themselves and as carers of people living with AIDS and orphans and vulnerable children.. Older people can be good conduits of correct information, good conduits for counselling. Prevention is a thematic area of the Multi-sectoral Framework on HIV/AIDS and older people are a resource we should exploit for this purpose.' Halima Shariff, TACAIDS Commissioner, HelpAge International Policy workshop on the impacts of HIV/AIDS on older people, Dar es Salaam, September 2004.

An issue of considerable concern, especially to older women, is to know the HIV status of adult sons and daughters under their care. However, doctors are not permitted to disclose this information to parents, partners or family members. But in view of older people's concerns for their own risks, as well as the need for adequate information to care safely for people living with AIDS, they felt it was important that they be informed of the HIV status of the people under their care.

This raises the question of confidentiality clauses in national policies and guidelines for HIV testing and international human rights agreements²⁷ on the rights of people living with AIDS. However, effective counselling of the HIV patient and the inclusion of older people as primary caregivers in pre- and, especially, post-test counselling services and training for home-based care could alleviate these concerns. It could create an open and enabling relationship between the patient and caregiver or other family members, without having to contravene confidentiality agreements. This will become increasingly important with the roll-out of anti-retroviral therapies for the treatment of people living with AIDS in Tanzania.

Promote and support older people's right to participation

Older people noted that their participation in decision-making at community and household level had declined as they got older, but also as a result of HIV/AIDS. Many are increasingly ashamed of mixing with other community members due to the stigma attached to AIDS. At other times their desperate economic situation erodes the potential resources or material support they might have contributed to community activities. Lack of participation not only limits older people's social networks but also means they miss out on information about key issues such as HIV/AIDS and access to services and assistance which is disseminated at these meetings. Decision-making structures which older people identified as important included village councils, committees of the village government (e.g. health, education), and the HIV/AIDS committee.

Older people must be supported to fulfill their right to participate. This means providing them with economic support, dealing with stigma and discrimination and supporting social networks. Some progress has been made in supporting older people's participation in local structures through programmes implemented by HelpAge International Tanzania and partners, such as the older Citizen's monitoring project, advocacy and capacity building.

At the national level, the involvement of HelpAge International Tanzania and partners in the review and design of Tanzania's National Strategy for Growth and Reduction of Poverty (NSGRP, 2005/06-2009/10) has also ensured that issues of ageing, older people affected by HIV/AIDS and caring for orphaned children and older people's participation are mainstreamed throughout the national strategy. It is important that these issues are retained in the final strategy, have specific actions and resources attached, implemented and monitored within the framework of the NSGRP.

²⁷ Greater Involvement of People Living with or Affected by HIV/AIDS, Paris Declaration, Paris AIDS Summit, December 1994, <http://www.ecpp.co.uk/parisdeclaration.htm>

²⁸ For more information see <http://www.helpage.org/advocacy/OCMBackground/OCMBackground.html> or contact HelpAge International Tanzania.

5. Recommendations for action

HelpAge International supports the efforts of the Government of Tanzania to respond to the rights and needs of its poorest citizens in its National Strategy for Growth and Reduction of Poverty (NSGRP, 2005/06-2009/10), which also includes actions to target those affected by HIV/AIDS, including older persons. We would welcome dialogue with the government, its donors and supporting development agencies and non-governmental and faith-based organisations to the additional issues raised in this study. The recommendations presented here emphasise the need for a coordinated response to HIV/AIDS that acknowledges, includes and supports the roles and contributions of older people in the fight against HIV/AIDS and poverty in Tanzania and supports orphans and vulnerable children in particular. For this reason we urge that the recommendations of this study be incorporated into all HIV/AIDS and poverty-related interventions, including those detailed in the operational targets of the NSGRP

1. Disaggregate all data and information on HIV/AIDS and poverty by age

- The Government of Tanzania should work with development partners, district authorities, and non-governmental organisations to collect information on older people, disaggregated by age, gender, location and poverty status. Routine data from voluntary testing and counselling services should be analysed and collated to reflect the age and gender of clients and proportion testing HIV positive.
- Organisations of older people, research institutions and non-governmental organisations working on HIV/AIDS should be encouraged and supported to work together to carry out specific data collection and analysis into the situation of older people and their dependents.
- Data on how HIV/AIDS affects older women and men should be made public in national poverty and HIV/AIDS-specific surveys.

2. Provide direct income support, including social protection measures, to older people and AIDS affected families

- The Tanzania's National Strategy for Growth and Reduction of Poverty (NSGRP, 2005/06-2009/10) goal of the Government of Tanzania to deliver social protection measures, such as cash transfers, to increased numbers of older people and vulnerable households, orphans and vulnerable children should receive full support and adequate financing. International agencies should support the development, implementation and monitoring of the social protection goals of the NSGRP, including cash transfer schemes, and increased support to poor households and vulnerable groups targeting older people, orphans, other vulnerable children and people living with AIDS. (NSGRP, 2005/06-2009/10, goal 4 cluster 11)
- Taking into account the existence of Tanzania's National Ageing Policy, and the commitment of the NSGRP to operationalise the policy, national credit funds, loan schemes and local development-funded schemes should broaden their access to include older people wherever possible.

3. Review existing national policies on health, HIV/AIDS and poverty reduction to include older people

- Policies such as the Health Directive (2000), which provides exemptions from healthcare costs for older people, should be made known throughout Tanzania, financed and implemented in accordance with NSGRP. The commitment to provide older people with identity cards to access free medical treatment (NSGRP, 2005/06-2009/10) goal 5.4) must be accompanied by administrative safeguards to ensure the sustainable

supply of appropriate drugs. Health staff should be appropriately trained to support the health of older people.

- The National Policy on HIV/AIDS and the draft policy on Orphans and Vulnerable Children should be reviewed to include older people as a group at risk of infection. This will complement the commitment of the National Strategy for Growth and Reduction of Poverty (NSGRP, 2005/06-2009/10), that older people will be targeted for information and prevention programmes, and for support as carers of people living with AIDS and orphans and vulnerable children.
- As part of its commitment to respond to older persons in the context of the NSGRP the Government of Tanzania must put in place a resourced and time-bound action plan for the implementation of the National Ageing Policy, ensuring its coherence with NSGRP goals.

4. Provide older people with information on HIV/AIDS and home care support

- Older people should be included in all national and local public awareness-raising initiatives on HIV/AIDS by the Government of Tanzania, TACAIDS and programmes and events by civil society agencies. Appropriate mechanisms to enable older people to access HIV/AIDS information must be developed and supported, such as the use of public meetings, village health workers, the radio, peer educators and home care visitors.
- Government and non-government agencies engaged in HIV/AIDS work should consult with older people on a regular basis about their information needs and how information could be delivered to them. These include: information on national policies and local development plans; the causes and symptoms of HIV/AIDS and how HIV is spread; preventative and curative measures; care for people living with AIDS; and sources of support.
- Older people must receive information and support in their care-giving role for people living with AIDS and orphans and vulnerable children including the administration of anti-retroviral drugs and the treatment of opportunistic infections, as well as child care skills and the protection of children's rights.

5. Empower and support older women and men to enable their active participation in local and national policy and programme processes on HIV/AIDS, poverty reduction and local planning.

- The participation and representation of older people, and older women in particular, in HIV/AIDS programme planning at local, district and national levels must be improved. This will require support to older people and their organisations to participate in development processes and planning, as well as sensitising local district and national officials to the right older people have to participate and the roles they play in households and communities.
- The participatory mechanisms of local social networks and community-based structures must be strengthened so that they can respond to the rights and needs of all vulnerable community members, including older people, people living with AIDS and orphaned children. The stigma and discrimination against all those infected and affected by HIV/AIDS, especially that of older headed households, must be tackled.

Key resources

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HelpAge International www.helpage.org

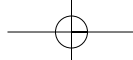
Government of Tanzania www.tanzania.go.tz

United Nations Joint Programme on AIDS www.unaids.org

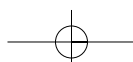
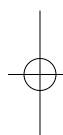
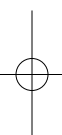
World Health Organisation WHO www.who.int

United Nations Children's Fund UNICEF www.unicef.org

International HIV/AIDS Alliance www.aidsalliance.org



NOTES



NOTES

Tanga Elderly Women Resource Centre (TEWOREC)

TEWOREC was established in 1998, and has built a strong track record, knowledge and experience on HIV/AIDS of ageing issues and older people, women and orphans. It has focus centres in two districts of Muheza and Tanga, and also operates in the rural and urban areas, where its work has earned them the respect of these communities. It is also a member of an NGO cluster of organizations in the Tanga Region addressing HIV/AIDS and STIS, and is engaged in campaigns for information sharing and dissemination on these issues. Its members are experienced trainers on peer education, HIV/AIDS and STIS, child survival and development, family planning, awareness training to older people on home-based care and support to orphans, advocacy, on ageing and development and counselling.

Good Samaritan Social Services Trust (GSSST)

GSSST was established in 1998 with the aim of responding to social 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 the ageing issues. Its core competencies include participatory research, health and social work, and of providing counselling, and health services in the communities, especially to the older people, and has participated in a number of studies such as *Baseline Survey On Health Delivering Services*, 1994, and *Needs Assessment for Older People in Mbezi Luis, Dar es Salaam*, 2000. GSSST has attracted funding from various donors, including the European Development Fund for Health Care Services in 1995.

Southern Highlands Senility Organisation (SHISO)

Established in 1995, the focus of its work is on HIV/AIDS and civic education. It is also actively engaged in promoting intergenerational linkages by working with local schools and educational authorities. It supports vulnerable older people to access free medicine by linking them with government health centres, and provides support and guidance to older people on legal issues. The organization also has built strong experience on HIV/AIDS, working with trained volunteers at the grassroots level, and providing home-based care to people living with HIV/AIDS and older people affected by the disease.

Arusha Retired People's Association (CHAWAMA)

CHAWAMA was initiated in 1998 as a community based welfare group, largely made up of people with skills and experience in different professional disciplines, who have come together as volunteers to provide mutual support in their old age and to campaign for the rights of older people. Its work includes HIV/AIDS, civic education, promoting intergenerational links by working with local schools and educational authorities, and supporting vulnerable older people to access free medical care. One of its particular strengths is working with, and addressing the needs of, older people at grassroots level.

Lead Researcher: Mr. Loserian Sangale

Loserian Sangale, an independent researcher and an experienced sociologist, compiled the research findings. His specific strengths include rural and urban development and poverty reduction programmes, and HIV/AIDS. He is an experienced trainer, and has facilitated capacity building trainings with community members, extension staff, civil society organizations working in HIV/AIDS, as well as training in psycho-social support for orphaned children, micro finance credit management, theatre for development, social mobilization and in management and organizational development. He has also consulted for many other NGOs and international agencies, including DFID, HelpAge International, and Oxfam (Ireland).



Not enough is known about the impact of HIV/AIDS on older people.

This report by Help Age International, Tanzania is based on a participatory study carried out in 2004 in selected areas located in five regions: Tanga, Arusha, Dar es salaam Municipality, Iringa, and the Coastal Region. This report presents the key issues facing older women and men affected by HIV/AIDS in Tanzania, including their role in providing care and support to their sons and daughters living with HIV/AIDS and to their grandchildren, often left orphaned by the death of their parents. It draws on participatory methods, interviews and key dissemination seminars with respondents that included older women and men, organizational and community leaders, district government officials, older carers and young people, many of them orphans. The report includes recommendations to help policy makers, programme planners and communities in Tanzania respond to and support the needs and contributions of older women and men in the fight against HIV and AIDS.

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HelpAge International Tanzania
P. O. Box 9846
Dar es Salaam

Email: haitz@helpagetz.org
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