

“OUR HEARTS ARE WILLING, BUT...” CHALLENGES OF ELDERLY CAREGIVERS IN RURAL KENYA

Older adults are increasingly playing the principal role in caring for younger adults sick with HIV/AIDS and for orphaned grandchildren. Recent research conducted in Thailand, Zimbabwe, and Uganda found that over two-thirds of elderly respondents were the main caregivers of ill adults or orphans whose parents had died of AIDS (Knodel et al. 2001; WHO 2001; Ntozi and Nakayiwa 1999). Often older people have no alternative but to provide nursing care to their ailing adult children and to become active parents again, in addition to providing for themselves. Such tasks can be particularly challenging in resource-poor settings. Despite their important role in caregiving, there has been little research to better understand their unique caregiving needs, given their age and economic circumstances, and ways in which their needs can be addressed by HIV/AIDS programs.



RUINET

In response to this gap, the Horizons Program and Plan International Kenya conducted an exploratory study in six villages in Bondo District, Nyanza Province, Kenya. Bondo District has an estimated adult HIV prevalence of 22.5 percent and is home to many children who have been orphaned by AIDS. The aim of the study was to identify the specific roles played by older people in caring for people living with HIV/AIDS and AIDS-affected children, determine the challenges they face as caregivers and their coping mechanisms, and identify the types of interventions needed to support elderly caregivers.

Methods

Data were collected in August and September 2003 using multiple qualitative methods. First, researchers conducted key informant interviews with 12 community leaders, including chiefs, retirees, teachers, and members of community-based organizations. Second, eight focus group discussions (FGDs) were conducted with 61 caregivers aged 50 and older, and one FGD was held with eight community leaders. Third, in-depth interviews with 11 older caregivers were carried out to provide detailed information about caring for the sick and for children affected by HIV/AIDS.

In addition, the researchers conducted participatory group activities using such tools as social mapping, problem ranking, and problem analysis with a wide range of community members. The purpose of these activities was to determine the key problems facing elderly caregivers, the causes of and potential solutions to their problems, and the perceptions of orphans regarding their relationships with elderly caregivers. A total of 144 married adults of reproductive age, older people aged 50 to 80 years, and youths, including orphans, participated in the group activities and discussions.

Key Findings

Older caregivers provide a wide range of services to ill adults and children affected by AIDS.

Results show that the elderly play a major role in caregiving and that specific roles often differ according to the sex of the caregiver. Older women mainly provide palliative care to the sick including providing food and feeding the sick, washing and changing their bedding, and administering medicine.

In the morning when you wake up, you remove the sick from bed and take them outside. Because he urinates on himself and passes stool in bed, I go to the lake and wash the beddings. When I come back home, I prepare porridge for the patient.

In-depth interview, female caregiver, 69 years old

Older men largely provide financial and other types of material support, run errands and make decisions about how the patient should be cared for, including when to take them to a health facility for treatment.

An important role for male and female elderly caregivers is to provide love, compassion, counseling, and spiritual support to both adults and children.

You have to get closer to them and console them [children] so that they do not think of their parents. You console them by talking to them and finding out what their needs are.

In-depth interview, female caregiver, 75 years old

One thing we try to do is to console the sick especially if you know that the person has AIDS. We tell the patient that the sickness is like any other and that h/she should hope to get well. We do this so that the patient does not become worried that h/she is dying soon.

Male focus group participant, 69 years old

Older caregivers are also responsible for providing clothing, shelter, school fees, uniforms, books, and other school requirements for children in their care. They also ensure discipline and provide moral instruction.

We are teaching them how to lead better lives, a life full of respect and humbleness. We are also teaching them the word of God.

Female focus group participant, 63 years old

Poverty and ill health are major problems among the elderly and greatly impede their role as caregivers.

Study respondents noted that most households headed by older caregivers are poor. This includes some households that were well off prior to being affected by AIDS, but then depleted their resources to meet the health care expenses of household members infected with HIV.

Inadequate food was ranked by study respondents as the most pressing problem among older caregivers. Inadequate food for themselves and those that they care for was attributed to lack of income to purchase food, lack of knowledge and skills in modern farming techniques, and cultivation of small portions of land that cannot yield enough food.

I would say inadequate food is really frustrating me since I cannot feed my grandchildren well. I don't have the ways and means of getting this food. As a caregiver I must also eat well and if my grandchildren get enough food then I'm happy.

In-depth interview, female caregiver, 73 years old

Inability to meet the educational needs of children because of poverty was another major problem cited by study respondents. Although primary school education is free in Kenya, older caregivers often cannot afford other requirements such as uniforms and books. Moreover, secondary school is not free, so many children affected by poverty are forced to drop out of school at the primary level.

Inadequate shelter was found to be a problem among the very poorest older caregivers, who live in dilapidated houses that leak during the rainy season.

In addition to poverty, old age and ill health limit the elderly's capacity to perform their caregiving activities. They often complained of debilitating ailments, such as poor vision, joint aches, and high blood pressure.

What is affecting me most is that I am also sickly even though I am caring for my patient. When my patient wants what I don't have, I get disturbed. Following all this, I have developed high blood pressure.

In-depth interview, female caregiver, 73 years old

My health is not good. My feet are swollen and my toenails have become black. The skin on my legs is peeling off. At the moment I'm in a lot of pain. I cannot do much. I guess this must be old age. I cannot blame it [my sickness] on caring for these orphans.

In-depth interview, female caregiver, 81 years old

The study communities have poor access to quality and affordable health care.

Respondents report that their communities are poorly served by health facilities. The few existing health facilities in the area are far away, have few health providers, and charge for services.

Our hearts are willing but we are incapacitated due to a lack of resources. Even when one takes a child for treatment at a health facility, money is required without which you do not receive treatment.

Female focus group participant, 61 years old

There were also reports of negative attitudes of health workers towards patients.

I don't know how these health providers are trained. I hate going to a health facility around here. The nurses' attitude towards the sick is uncaring...sometimes I think they work under a lot of pressure because they are few. They don't care and are unwilling to help.

Female key informant, 57 years old

Accessing drugs is also a key problem, as health facilities have limited availability. While patients are often given prescriptions, poor caregivers are unable to afford the medicines prescribed. There are a few community health workers in the area but community members have to purchase the drugs they stock. As a result, elderly caregivers often resort to buying cheap drugs, mainly painkillers, from shops, or use traditional herbs for managing their patients' conditions.

Older adults derive satisfaction from their caregiving roles, yet many lack adequate knowledge, skills, and resources for patient care.

Respondents report that many elderly caregivers nurse the sick with limited knowledge about HIV/AIDS, which may compromise their own health and that of their patients.

They [older caregivers] are not knowledgeable about some of the diseases affecting their patients. They also don't know modern ways of taking care of the sick and are exposing themselves to the risk of certain diseases unknowingly.

Male key informant, 59 years old

In-depth interviews with older caregivers showed that many lack basic supplies such as gloves, antiseptic, soap, and painkillers that are needed for patient care. Some also report lack of knowledge regarding what food to cook for patients and children, how to prepare certain foods when they are available, and what constitutes a balanced diet in general.

Despite their burdens, elderly caregivers overall are positive about their caregiving roles, experience a sense of satisfaction caring for ill adults and children, and believe they are doing the best they can. In addition, they are determined to care for the offspring of their ill and dead children, and in this way, continue their lineage.

Disciplining children is a major challenge faced by the elderly.

The study revealed that many caregivers lack skills for disciplining children. Some overindulge the children because they fear that they may run away or become depressed.

We don't quarrel with them because this would make them sad and loose hope. We just pamper them to be good.

Female focus group participant, 69 years old

Other caregivers punish children excessively or simply ignore them when they make mistakes, hoping the children will change.

There were also reports of children who are very sensitive, demanding, jealous, or hard to satisfy. The elderly find it challenging to care for such children, especially adolescents.

At the adolescent stage, it becomes difficult for some older caregivers to instill discipline in these children. The children become rebellious and communication breakdown sets in. Sometimes the caregivers come to us complaining that the orphans just keep crying when told to perform certain tasks or simply do not talk to their guardian.

Male key informant, 55 years old

Orphans often face significant hardships when raised by elderly caregivers.

Children cared for by the elderly are frequently forced to leave school and engage in productive activities due to lack of food in the household and money for school fees. Male children are often employed to herd cattle while others work for fishermen along the beach for meager remuneration. Female children are mainly employed as housemaids. Such children are often overworked and underpaid or not paid at all. Other children go to live with relatives or friends when their elderly caregivers cannot provide for them. Young male orphans may be forced to marry so that their wives can support the elderly by performing household chores.

Older caregivers often give children inappropriate roles. In discussions with orphans, many complained of being given adult roles and heavy workloads by their elderly guardians, an issue that was also raised in interviews with key informants.

I don't like the heavy tasks my grandmother gives me. She sends me to fetch firewood, posho mill with a heavy load of maize or millet....

Male child, 6 years old

Girls with infant siblings are frequently responsible for babysitting, preparing food, and feeding and bathing the baby. These roles often force them to drop out of school and become "mothers" at a very early age.

I was told to stop going to school to baby sit my sister. I take care of her the whole day, bathe and feed her....

Female child, 9 years old

Caregiving compromises older caregivers' emotional wellbeing and involvement in gainful activities.

Respondents reported a variety of sources of stress for elderly caregivers, including patients who are hostile, patients who fail to get better, and their own inability to provide for the basic needs of those in their care. They also worry about what will happen to the children when they die.

I have no problem taking care of them [orphaned grandchildren].... My only worry is what might happen to them should I die. They will be in trouble!

In-depth interview, female caregiver, 82 years old

Elderly caregivers spend a lot of time providing care hence they have limited time to socialize or attend community events, leading to social isolation.

It [nursing the sick] is hindering me from visiting friends and attending educational functions where one can get good teachings.

In-depth interview, female caregiver, 71 years old

Provision of care also negatively impacts the elderly's economic activities. Some participants reported that they are unable to regularly tend to their farms, go to their jobs, or carry out income-generating activities as they used to do in the past.

There are difficulties one has when caring for a sick person. For instance, I am employed but I cannot go to work regularly because of attending to the sick ... Sometimes I do go [to work] late because he [patient] cannot do anything for himself like going to the toilet, bathing or eating.

Female focus group participant, 54 years old.

Farming.... I still do though not as much as before. Sometimes a day can come that I totally miss to tend to my farm because of being held here caring for the patient.

In-depth interview, female caregiver, 68 years old

Elderly caregivers rely on a wide range of financial coping strategies.

Most elderly caregivers are involved in small-scale farming and businesses, such as selling vegetables and fish by the roadside. Others engage in manual labor, selling property, leasing land, or begging.

My husband planted these orange trees that you see here. They only take a short time to ripen. When they ripen, I wait until I can fill a sack, then I sell [them] and use the proceeds to buy stocks for family upkeep. I started doing this from the moment I had these orphans.

Female focus group participant, 58 years old

During the month of April we weed for people or just do any work to earn some money.

Female focus group participant, 60 years old

A lucky few still get income from employment or from a pension while others get some support from surviving adult children, relatives, or deceased children's estates but this is rare.

...It is only my son who provides for me. During my days I worked tirelessly to feed my family but now they have all died except one. When he gets something he shares with me but when he doesn't, we stay hungry.

In-depth interview, female caregiver, 74 years old

Some caregivers, mainly women, rely on revolving loan funds as a source of income. Individuals form small groups in which they contribute a small amount of money at a time, which is then given to one group member. Sometimes the pool of money is invested by the group member in livestock, the value of which can multiply over time. Unfortunately this activity is only limited to caregivers who have money and given that it is a female dominated activity, men rarely participate.

Older caregivers occasionally receive relief food from the government and from non-governmental organizations operating within the communities. But the food rations are often inadequate, thus caregivers need to look for alternative sources of food.

Religion is an important source of emotional and spiritual strength for elderly caregivers.

All of the caregivers interviewed are members of a church in their community and they frequently acknowledged their belief and trust in God to improve their situation. They also encourage the children in their care to pray.

We praise God and have put all our needs before Him. God will not forsake you and will give you something no matter how small.

Female focus group participant, 68 years old

Sometimes you don't even have an idea what you will eat and then suddenly someone just calls you and gives you some flour.... This definitely is help from God.

Female focus group participant, 64 years old

Conclusion and Recommendations

The study indicates that older people are playing major caregiving roles amidst a multitude of challenges that include limited resources, knowledge, skills, and social support related to patient care and child rearing.

Respondents were asked to suggest solutions to the identified problems of older caregivers. The following suggestions to improve the situation of elderly caregivers have implications for government, specifically the health, social welfare, and agriculture sectors, and for non-governmental organizations, churches, and community groups:

- Help communities to identify their resources and how to use them.
- Provide training to elderly caregivers in modern farming techniques, food security, and income generating activity startup and management.
- Increase the knowledge and skills of elderly caregivers in child rearing and home-based HIV/AIDS care, and increase their access to caregiving supplies.
- Develop mechanisms for providing support to households headed by the elderly for orphans to remain in school.
- Strengthen the capacity of existing health facilities by increasing staff, ensuring on-time service provision, training providers to have positive attitudes toward their patients and their work in general, and ensuring a regular supply of essential drugs.
- Train community health workers to assist elderly caregivers in managing patients at home.
- Build houses for destitute caregivers.
- Provide psychosocial support for older caregivers, people living with HIV/AIDS, and orphans and vulnerable children.
- Link communities with organizations involved in HIV/AIDS care and support services.

