Chapter 4

A grandmother in Zimbabwe with some of her 15 dependents, all orphaned by AIDS.

CAREGIVING

Recommendation: Recognize and support home-based caregivers of AIDS patients and orphans

When AIDS enters the household, women and girls provide the care. Globally, up to 90 per cent of the care due to illness is provided in the home by women and girls.[1] This is in addition to the many tasks they already perform, such as taking care of children and the elderly, cooking, cleaning and, in subsistence areas, fetching water and fire wood. Women are also deeply involved in work at the community level, often as volunteers. The value of the time, energy and resources required to perform this unpaid work is rarely recognized by governments and communities, despite its critical contribution to the overall national economy and society in general. The devastating effect of HIV/AIDS on women's work is even less recognized. Poverty reduction strategies and national AIDS plans seldom take women's caregiving into account; it remains unpaid and therefore undervalued in economic terms.

Yet the work is overwhelming. In developing nations, poverty and the privatization of public services have combined with AIDS to turn the care burden for women into a crisis with far-reaching social, health and economic consequences. In many of the hardest-hit nations—and increasingly in all countries affected by HIV/AIDS—women and girls take on the major share of care work by nursing the sick and taking in AIDS orphans, while trying to earn an income that is often their family's only means of support. In addition, women may be cultivating crops to feed their families.

The devastation is most evident in Africa. A study in 15 villages in Uganda found that many households had a 'missing' generation of family members: men and women who had succumbed to AIDS and would normally have been prime income earners.[2] The loss of the members of this generation robbed communities of more than financial support; farming techniques, culture and wisdom that were traditionally passed from one generation to the next were also lost.

There are areas in sub-Saharan Africa where the risk of famine has increased due to the death of farmers and the inability of others in the community to provide sufficient support to bridge the gap.[3] Ethiopia, which has lost hundreds of thousands to famine in recent decades, is facing another major crisis as AIDS robs villages of young farmers, both male and female. In urban areas, women may not be able to hold a job in either

the formal or informal sectors because they spend so much time caring for others.

Throughout Africa, as more people die from the effects of AIDS, women become heads of households and sink deeper into the poverty that disproportionately affects female-headed households. Those who are already poor fall even further down the economic ladder. A recent study in South Africa found that households that had experienced illness or death in the recent past were more than twice as likely to be poor than non-affected households and were more likely to experience long-term poverty.[4] The Secretary-General's report on Southern Africa revealed that two thirds of caregivers in the households surveyed were female, with almost a quarter of them over the age of 60.[5]

Much of the increased poverty in these households is directly related to their caregiving responsibilities. Many AIDS widows, for example, are young and have dependent children, which limits their ability to contribute to farm work and earn an income. Female-headed households also tend to have more children, including AIDS orphans, than male-headed households. In Zambia, a study revealed that there were twice as many female as male-headed households caring for children who had lost both parents. In addition, female heads of household had taken on the responsibility for more orphans than male heads of household.[6]

Caring for an AIDS patient can increase the workload of a family caretaker by one third. This is a burden in any family but particularly onerous for the poor, who already spend much of their day earning a subsistence living. A rural woman interviewed in Southern Africa estimated that it took 24 buckets of water a day, fetched by hand, to care for a family member who was dying of AIDS—water to wash the clothes, the sheets and the patient after regular bouts of diarrhoea.

As the crisis deepens in Africa, girls are being taken out of school to provide home-based care. In Swaziland, school enrolment is estimated to have fallen by 36 per cent due to AIDS, with girls the most affected.[7] At the same time, older women are pushed into the labour force to support their grandchildren and adult children with AIDS.[8] Grandmothers, aunts and cousins may be caring for orphaned children from several families. In Kenya, a health-care trainer described a woman who was raising 10 children of her late brother and sister along with six of her own. She worked as a home health-care provider, in charge of 13 patients, four of whom depended on her for their daily provisions.[9] The burden is enormous on women like this, who have nowhere to turn when the workload becomes overwhelming.

Conditions are most difficult for women in rural areas. Many people who migrated to cities in search of work return home to their villages when they develop AIDS—to be taken care of and to die. But since in the

FOOD FOR HEALTH

For several years, the United Nations World Food Programme (WFP) has been distributing food to families affected by HIV/AIDS. In May 2003, WFP began distributing food for the first time in Myanmar, where infection rates are among the highest in South-East Asia. The food is distributed as part of a package of home-based community care that is being administered by the Myanmar Nurses Association. "This one-year pilot programme is a first step in our efforts to ease the suffering of people in Myanmar living with the disease and help to slow its spread," said WFP Country Director Bhim Udas. The food gives poor families a better chance for survival, and serves to prevent the practices that trigger infection, like migrant or sex work.

Source: "UN begins food aid in AIDS-stricken Myanmar," *Reuters NewMedia*, 19 March 2004

developing world most health-care facilities are located in or near urban centres, the women in rural villages caring for AIDS patients have little moral or material support. Hardly any have received training or even minimal supplies to care for patients.

Women's role in the care economy intensifies their poverty and insecurity since a large proportion of an already meagre income is used to support their caregiving and purchasing of items such as water, gloves and medicines or paying for funerals. The increased workload, loss of family income and deepening poverty make women more dependent on others and exacerbate gender inequalities.

Ironically, even when community support programmes are developed to serve people living with HIV, they tend to rely on women as unpaid volunteers who—despite the fact that they are often as poor or poorer than the people they are assisting—receive neither stipends nor incentives. The Report of the Secretary-General's Task Force on Women, Girls and HIV/AIDS in Southern Africa points out that there is little recognition or compensation for volunteers, who may be subject to exploitation and severe stress. The most successful community-based mobilization efforts provide counselling and support for volunteers, try to provide incentives such as food or job training when possible and encourage men and boys to share the burden of care.

Commitments to Caregiving

The Millennium Declaration adopted by all UN Member States in 2000 declared that all people have the right to live free from fear and want. The eight Millennium Development Goals set up by the international community include eliminating poverty and hunger, reducing the spread of HIV/AIDS and achieving gender equality and empowering women. These goals will be impossible to achieve if women's caregiving work is not shared and given appropriate support.

Supporting Women's and Girls' Caregiving

There are many community-based programmes already operating that show how much can be done with relatively few resources. In Haiti, the HIV Equity Initiative (HEI) model, using paid *accompagnateurs* to provide in-home health services, has been successful at comparatively low cost (see Box, p. 24). The model is being expanded to other nations, according to Paul Farmer, a co-founder of Partners in Health, which helps run the HEI. The money saved by using *accompagnateurs* can be channelled into social services that are just as important as treatment for HIV. "Within every community beset by poverty and HIV are scores of willing individuals who wish to be trained as community health workers," he said. "Working with these *accompagnateurs*, we can develop lower-cost means of assessing impact so that resources may be channelled into food, water and improved housing for HIV-affected families….Such resources can be spent on improving TB diagnosis and treatment, and on linking HIV services to prenatal care."[10]

THE UNGASS COMMITMENT

The Declaration of Commitment approved at the UN General Assembly Special Session (UNGASS) on HIV/AIDS in 2001 calls on nations to "review the social and economic impact of HIV/AIDS at all levels of society, especially on women and the elderly, particularly in their role as caregivers, and in families affected by HIV/AIDS and address their special needs."

Source: UNGASS Declaration of Commitment 2001, www.un.org/ga/aids/coverage

In the Zambian Copperbelt, a region with high HIV prevalence rates, NGOs and churches are providing a service similar to the HEI's. Created with the help of Brigette Syamalevwa, a renowned AIDS activist who died in 2003, the Copperbelt programme sends trained volunteers to patients' homes with medication for opportunistic diseases and TB. Volunteers take some of the burden off women who are caring for patients. They provide emotional support and counselling and help clean, dress and feed patients. They will clean the house, wash clothes and fetch and boil water if they see that family members cannot handle these chores.[11] Over 90 per cent of the volunteers are women and, as in Haiti, some are HIV-positive, although not all the volunteers are open about their status and many have not been tested. "I like my voluntary health work because I am able to reassure some of the patients who find it difficult to accept their HIV-positive status," said one woman who has been a volunteer for several years. "I share my personal experience that denying your status doesn't help to prepare your mind, body or your soul to live with the virus."[12]

Even when *accompagnateurs* or volunteers are available, family members remain the primary caretakers and need their own support services so as not to be overwhelmed by the responsibility. Training programmes are being set up in places like Kenya, for example, to provide basics such as nursing kits with rubber gloves and masks and to teach caregivers how to use them. These programmes also try to address HIV's emotional and financial drain. When training involves entire communities, this approach can help relieve some of the stigma directed at AIDS patients and their families. Ghana has been experimenting with distance learning courses through the University of Ghana to train women and men in local communities as 'change agents' in the fight against HIV.

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MEN AS CAREGIVERS

Zimbabwean men have become increasingly involved in caring for AIDS patients, challenging the stereotype that caring for the terminally ill is women's work. For 48-year-old Luckson Murungweni, it would once have been inconceivable that he would care for the chronically ill, let alone those dying from AIDS.

"As men, we never viewed ourselves as crucial in providing care to those being claimed by the AIDS pandemic. But things changed last year when councillors approached us and urged us to become involved," Murungweni said. Now he is the focal point of a home-based care project in rural Goromonzi, some 35 kilometres east of the capital, Harare.

With the support of the Hospice Association of Zimbabwe (HOSPAZ), district councillors helped men form a group that would complement the efforts of the women providing home-based care. Although the men were initially reluctant to participate for fear of stigma, the relatively novel idea eventually took off and now has spread to other parts of the country. The Zimbabwe Red Cross Society currently has its own home-based project in which 105 out of 900 facilitators countrywide are men.

"To me it is encouraging to see men becoming less idle and less chauvinistic. Their decision to participate in community-based caregiving is a great shift in the way they have perceived the AIDS issue—they are coming to realize that AIDS is just one of the diseases that needs to be fought by society as a whole," said Murungweni.

Source: "Men Break with Tradition to Become AIDS Caregivers," *IRIN Plus News*, 17 May 2004

Nationwide, 366 participants have taken part so far and are working in their communities to identify caregivers who need support and to provide information on HIV.[13] The programmes in Ghana and Kenya have shown that communities are most receptive to new information about HIV when they learn from colleagues and neighbours whom they already know and trust.

One training programme that has been very effective is known as Stepping Stones. It involves a series of meetings where various peer groups such as young women or older men meet separately at first and then come together for larger discussions about issues that are important to them. It

In subsistence economies, women spend much of their day performing tasks that maintain their households, like gathering water. Caring for an AIDS patient can increase their workload by a third.

"Our grandma is really caring for and supporting us. She is doing her best to provide what we need, but I am in third grade, my brother in the first, and my youngest brother in pre-school. I am not sure my grandmother will be able to pay our school fees when we go to higher class."

Jackeline, aged 14
Juba, Sudan

has been used in many parts of Africa to help communities decide for themselves how to respond to HIV and determine where the need is greatest. By also focusing on behaviour change, it allows community members to see how certain attitudes and actions may have contributed to the rise of HIV.[14]

Alice Welbourn, one of the creators of the Stepping Stones method, described a session in Uganda where some of the older women in a village drew a diagram about life in the community, the good and the bad, during one of their sessions. Then an elderly woman presented it to a larger group of villagers. This woman, who could neither read nor write, stood in front of a flip chart diagram and described what had only become apparent as the women began talking with each other: They were responsible for so many orphans among them that many were facing starvation. They did not have the time or capacity to tend the fields any longer, and crops were being engulfed by weeds.

The elders of the village were shocked, as the women themselves had been when they first began talking—each had thought the problem was hers alone because no one had ever discussed it publicly before. They were able to use that session to devise a plan for boys and young men in the community to help tend the fields so the women could feed their families again.

Training and support programmes need to focus on the needs of young girls who are nursing family members and supporting siblings. Many of these girls are invisible to service providers because they rarely enter the public health system. Programmes like SHAZ in Zimbabwe (see p. 15) are trying to build new models for providing emotional and financial resources to girls who are caretakers.[15] In Rwanda, NGOs and international agencies are providing vocational training and skill-building classes to youths—mainly girls—who are heads of household and helping to create support groups for them. In Uganda, where one family in four is looking after children not their own, the Uganda Women's Efforts to Save Orphans (UWESO) is working with girls who have become the main support of their families, providing training, paying school fees and helping them develop income-generating activities.[16]

Men are also playing an increasing role in taking on tasks and responsibilities within the household that are culturally perceived to be 'women's work'. As part of its strategy for addressing violence against women and its effect on HIV/AIDS, the Men as Partners (MaP) programme in South Africa (see p. 47) also focuses on the need to transform gender relations within the household. One MaP coordinator, Stephen Ngobeni, described the difficulties involved in getting men to take on responsibilities that traditionally have been viewed as women's domain: "When I stand up and challenge men's roles, I'm seen to be a rebel. People look at me and say 'how can he do things like this?'" When Ngobeni tried to get villagers to contribute to the cost of hiring trucks to distribute water, in order to ease the burden on women caregivers, villagers turned on him. "They said that was what women did traditionally. They said that women must bring this water. That women are sitting doing nothing." When Ngobeni took on the work with family members, carrying water to the village, others began to see how much work was

involved for women and agreed to hire trucks. "We need to stand up and talk even when people criticize us," said Ngobeni.[17]

These training programmes and activities are only the beginning of what must be a massive effort—the needs of families affected by AIDS are enormous and growing. Even as prevalence rates come down in countries such as Thailand or Uganda, the impact of AIDS will continue for years afterwards in terms of orphaned families, wages lost to caregiving and death, and resources spent on health care. The social services that will ease some of this burden are a critical part of HIV treatment.