The AIDS epidemic is taking a devastating toll on families and communities worldwide. In its wake lies a growing burden of caring for the sick, the dying, and those left behind. In countries hardest hit, most of the care for people living with HIV takes place in the home, and up to 90% of that is provided by women and girls. The inability of health systems to care for all those living with HIV who are in need of services has led many governments to rely on home-based care to fill the gap. Most of those who provide this care are unpaid and already quite poor, and the additional financial and emotional burden of administering care frequently pushes them into destitution. Therefore, caregivers, particularly women and girls, need more economic, technical, and social support for providing this essential yet too often unrecognized service – and this support must be made central to AIDS strategies. That is why the UNAIDS-led Global Coalition on Women and AIDS is making greater support for caregivers a top priority.

The social and economic burden of care on women

AIDS-affected households face both increased expenses – including health care, food, transportation, and burial costs – and decreased income, as AIDS often claims men and women in their most economically productive years. The cumulative financial burden on these households is substantial. A study in South Africa found that two-thirds of such households reported a loss of income, and a third of the remaining income was spent on health care – leaving little for clothing, electricity, food, and other necessities. Due to the demands of caring for others, many female caregivers have less time to earn an income, produce food, go to school, and maintain the rest of the household. This creates a vicious cycle, whereby women and their families are more likely to be malnourished, in poor health, or economically destitute – all factors that further increase their risk for HIV infection.

AIDS is severely stretching traditional coping mechanisms and extended family networks, often to their breaking point. As more working age women are living with HIV – struggling to provide for their families and often in need of care themselves – caregiving duties shift increasingly to older women and younger girls. In fact, older women are taking on caregiving on an unprecedented scale, assuming responsibility not only for their children and grandchildren, but for other children orphaned and made vulnerable by AIDS. In addition, AIDS frequently forces girls and young women to withdraw from school to fulfill caregiving duties and to help compensate for lost family income – heightening their risks of sexual exploitation and HIV infection.

In some countries, nongovernmental organizations (NGOs) and faith-based organizations (FBOs) have established home-based care projects using community volunteers, usually women in the community who receive minimal training and occasionally small stipends for transportation. Some of these programs are linked to formal care and support services, but most still need to be. The programs range from basic home visits to more comprehensive treatment and care programs. In many cases, home-based care starts with caring for a sick adult, but soon extends to helping others who are ill in the family, providing material support, and even helping with household chores. These programs can provide a significant burden of care, and many women find themselves working multiple jobs to support their families. In addition, many women are also responsible for caring for elderly parents, which can further strain their already limited resources.

The support of community volunteers and faith-based organizations can be critical in providing care for people living with HIV. However, these programs often lack the necessary resources to support the caregivers effectively, and many women find themselves struggling to provide for their families on their own. The support of the Global Coalition on Women and AIDS can help to ensure that these programs are sustainable and effective in providing care for those in need.
support for affected families, and services for orphans or other dependent children.1

• The UN Secretary-General’s Task Force on Women and AIDS in Southern Africa found that two-thirds of caregivers in the households surveyed were female, and almost a quarter of them were over 60 years old.5

• In Viet Nam, women and girls make up 75% of caregivers for people living with HIV.9

• Households headed by older women in sub-Saharan Africa are twice as likely to include orphans as households headed by older men,10,11 and only 3% of all households caring for orphans (excluding Eastern Europe) receive any public support.12 Studies show that in many countries, including Botswana, Namibia, Malawi, South Africa, Tanzania, and Zimbabwe, up to 60% of orphaned children, including those orphaned by AIDS, live in grandparent-headed households.13

Women caregivers need support and training

Home and community-based care for people living with HIV remains integral to the global AIDS response. Alongside dramatic expansions in access to antiretroviral treatment and HIV prevention, AIDS strategies must provide better and more coordinated support for caregivers, with particular attention to women and girls.

WHAT WORKS

Despite glaring gaps, innovative programs are working to support caregivers in AIDS-affected countries worldwide. These programs, often run by NGOs or FBOs, range from assisting older caregivers with the cost of providing medical expenses and support for orphans and vulnerable children, to improving access to HIV services for both caregivers and those they are caring for, to offering basic training in delivering home-based care.

The India HIV/AIDS Alliance supports NGOs to provide community-based care for people living with HIV, as well as children affected by AIDS. The program provides psychosocial support, health care, voluntary counseling and testing, economic and food support, and skills training.14 In Delhi, Tamil Nadu, and Andhra Pradesh, the program is being implemented by 38 NGO partners. In Tamil Nadu, the program has supported 4,224 people living with HIV, 5,521 family members, and 4,692 children affected by AIDS.15 Most of the caregivers are women.

• Women-headed households in Kenya (WOFAK), an AIDS support organization of some 3,000 women, supports caregivers who are providing home-based care. The caregivers offer nursing care, nutritional support, counseling, and accommodation for family members and communities. WOFAK is run largely by women living with HIV.16

• The Vietnam Women’s Union (VWU) works with older women caregivers affected by AIDS. Through the establishment of “Empathy Clubs” – self-managed organizations that encourage and support older women caregivers in their communities – the VWU has already profoundly improved the lives of those providing care and their families.17

• In Mozambique, older people have established support groups, called older people’s committees, to reduce the cost of care and increase their incomes. Money raised from small businesses is placed into a social fund run by the older people’s committees. This fund pays for transport to testing centers and AIDS treatment clinics, and covers the cost of applying for a poverty certificate – a government benefit that exempts children from paying secondary school fees.18

• The government of Swaziland, through a grant from the Global Fund to Fight AIDS, Tuberculosis and Malaria, and the World Bank, has supported the development of community-based care, and especially of female caregivers in the AIDS response. The program is being implemented by 38 NGO partners. It provides support, as well as access to training and referral backup support, basic supplies, and resources to support children orphaned and made vulnerable by AIDS. These resources should be tailored to those most likely to provide care – with a strong focus on women, including older women and girls.

• Expand economic support to caregivers by increasing their access to affordable basic shelter, land to grow crops or raise animals, and other income-generating opportunities.19

• Address the overall health and specific psychosocial needs of caregivers, in particular older women and young girls, through the provision of counseling and other assistance.

• Ensure that organizations and individuals working with caregivers are involved in the design, implementation, and monitoring of HIV prevention, treatment, care, and support programs at the national and community level.

• Encourage and support men and boys in sharing the responsibility of caring for those living with HIV.

WHAT’S NEEDED

Actions for National Governments

• Ensure that home- and community-based AIDS care is an integral and budgeted element of all national AIDS strategies and programs, through direct assistance to AIDS-affected families and political and financial support to community mobilization efforts to increase access to HIV information and support services.

• Ensure that caregivers have information on HIV prevention, treatment, care, and support, as well as access to training and referral backup support, basic supplies, and resources to support children orphaned and made vulnerable by AIDS. These resources should be tailored to those most likely to provide care – with a strong focus on women, including older women and girls.

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Actions for International Partners

• Ensure that bilateral and multilateral funding – from the Global Fund to Fight AIDS, Tuberculosis and Malaria, the U.S. President’s Emergency Plan for AIDS Relief, the World Bank, and other donors – supports programs for caregivers, and that these programs are adapted and responsive to the needs of women and girls.

• Increase support for families and communities that are caring for children orphaned and made vulnerable by AIDS, including basic health care, psychological counseling, school fees, succession planning, and access to HIV information and services.

• Increase support for individual caregivers, especially women, through access to economic, technical, and psychosocial support to sustain their work and secure their future. This includes support for training on the effective provision of care, continuing education and employment opportunities for young women caregivers as well as counseling, particularly for older women facing stress, stigma, or depression.

• Support the collection and analysis of data on caregivers to better inform AIDS policies and programs.

Providing enhanced support to caregivers is a key to fulfilling global commitments on AIDS. In particular, the 2001 UN Declaration of Commitment on HIV/AIDS – countries pledged to develop national policies and strategies that strengthen support for orphans and children affected by AIDS at the family, community, and national level. To meet these commitments, national governments and international partners should acknowledge the critical role of home- and community-based care, and especially of female caregivers in the AIDS response – and mobilize the financial and technical resources to support their work.

The Global Coalition on Women and AIDS is a worldwide alliance of civil society groups, networks of women living with HIV and AIDS, governments and UN organizations supporting AIDS strategies that work for women and girls. This brief is the fifth in a series that explores a range of key issues that particularly affect women and girls in the global fight against AIDS. All the briefings can be found at: http://womenandaidsoungaids.org.


Losing one or both parents to AIDS is not the only way that children are affected by the epidemic: other children are made vulnerable when a parent or other close family member becomes sick, when other orphans are brought into an already poor household, or when they themselves become infected with HIV. See UNICEF, “Children on the Brink,” 2004, http://www.unicef.org/publications/files/09 판단들-013.pdf.


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Ogden J, Eisim S & Growen C, op.cit.


R Monasch and JT Boemia, op.cit.


Email from Priya Mohanty, India HIV/AIDS Alliance, April 28, 2006.


