

are informal caregivers important in AIDS care?

what do caregivers do?

Informal caregivers of people with AIDS (PWAs) provide practical help and nursing care at home. They are often the lovers, spouses, friends, or family of someone with AIDS and are not professional care providers. The service they provide is essential to the scope of AIDS care services and saves society great expense.

AIDS care services in the US have shifted from hospital-based care to community-based and in-home care. Rising health care costs and many people's preference to receive health care, and, when possible, to die at home, have driven this trend. The percentage of AIDS deaths in hospitals decreased from 92% in 1983 to 57% in 1991. Informal caregivers have helped make this shift possible.

Caregivers provide practical support such as shopping, housekeeping, and transportation to clinics, as well as more basic assistance such as help with bathing, going to the bathroom, and feeding. As symptoms worsen, caregivers are also likely to take on more clinical roles such as keeping track of medications, giving injections, inserting catheters, and cleaning wounds.² Caregivers often provide front-line medical and mental assessment, being the first to note changes in health and to decide when to go for help. One study found the value of personal care tasks and housework performed by caregivers equaled a per capita value of over \$25,000 a year for caregiving.³

who are AIDS caregivers?

A national survey found that 3.2% of the entire US adult population have provided care to a friend, spouse, relative, or lover with AIDS. Almost three-fourths of caregivers were under 40 years old. Caregiving was equally distributed across gender, race and ethnic groups among the general population.⁴

Traditionally, parents, spouses and adult daughters have been the caregivers of people with terminal illnesses. With AIDS, family members still provide care in many cases. However, with gay men, it is more often the partners and friends who provide care. A study of 265 British men with AIDS found that 87% had a close friend or partner as primary caregiver.⁵

what are caregiver burdens?

AIDS is prevalent in young and middle-aged people; one in every four new HIV infections occurs in young people under the age of 22.⁶ Caregivers, also, are often in their 20s, 30s and 40s. At that age most people are traditionally building relationships and developing careers, not caring for sick people or preparing for the loss of their partner. The stress involved in this "off-time" caregiving can be enormous.²

Unlike professional care providers, informal caregivers are often on call 24-hours a day and are not protected by a limited work day or professional distance. Many informal caregivers have never cared for a seriously ill person, nor have they seen someone die. Also, caregivers must learn skills such as how to give shots or insert catheters, often under extremely stressful circumstances.²

Many caregivers of AIDS patients are also their sexual partners. This puts them at risk for HIV infection. For HIV-positive caregivers, disease progression symbolizes the loss of their partner as well as their own changing health status. Caregiving also raises the question of who will care for them when they become ill.

Informal caregivers may experience numbness, compassion fatigue, or burnout from losing multiple friends and loved ones to AIDS, or from caring for someone who has been ill for a very long time.

Says who?

1. Kelly JJ, Chu SY, Buehler JW. AIDS deaths shift from hospital to home. *American Journal of Public Health*. 1993;83:1433-1437.

2. Folkman S, Chesney MA, Christopher-Richards A. Stress and coping in caregiving partners of men with AIDS. *Psychiatric Manifestations of HIV Disease*. 1994;17:35-53. Contact: Susan Folkman 415/597-9156.

3. Ward D, Brown MA. Labor and cost in AIDS family caregiving. *Western Journal of Nursing Research*. 1994;16:10-22.

4. Turner HA, Catania JA, Gagnon J. The prevalence of informal caregiving to persons with AIDS in the United States: caregiver characteristics and their implications. *Social Science and Medicine*. 1994;38:1543-1552.

5. McCann K, Wadsworth E. The role of informal carers in supporting gay men who have HIV related illness. What do they do and what are their needs? *AIDS Care*. 1992;4:25-34.

6. Rosenberg PS, Biggar RJ, Goedert JJ. Declining age at HIV infection in the United States. *New England Journal of Medicine*. 1994;330:789-790.

7. Raveis VH, Siegel K. The impact of care giving on informal or familial care givers. *AIDS Patient Care*. 1991;39-43.

8. Schable B, Diaz T, Chu SY, et al. Who are the primary caretakers of children born to HIV-infected mothers? Results from a multi-state surveillance project. *Pediatrics*. 1995;95:511-515.

what are caregiver burdens?

In some communities there is still fear and stigma surrounding HIV disease. In addition, people greatly affected by AIDS are often already stigmatized populations: gay men, injection drug users, African-Americans and Latinos. Caregivers may fear social rejection, loss of job and/or housing and may thus conceal their caregiving status from family, friends, and co-workers.⁷

For women with HIV, having responsibility for children at home may pose a barrier to obtaining caregiving support for themselves. A study of HIV-infected mothers across the US found 46% were the sole caretakers of children. Only 30% knew about child care assistance services, and only 8% had contacted those services.⁸ Caregiving for mothers with HIV must include the children as well as the sick mother, and address the welfare of the children after a parent dies. According to one estimate, there could be over 80,000 AIDS orphans in the US by the year 2000.⁹

what can be done to help?

Helping caregivers benefits both the caregiver and the patient. Professional clinicians can include the caregiver in the "triad of care"—doctor, patient, caregiver—and train them in simple medical procedures to help improve patient care.¹⁰ Caregivers can benefit from psychological help (like support groups) to help them cope with the emotional roller coaster involved in caring for a terminally ill person. Caregivers may also need support in grieving the death of a loved one.

Some people may be unsure how to act around a person with AIDS, or confused about the best way to show love and support. A study of PWAs identified what they see as helpful and unhelpful actions in caregiving. Helpful actions included expressing love or concern, acting naturally, providing an opportunity for reciprocity and providing encouragement. Unhelpful actions included avoiding interaction, acting embarrassed or ashamed, breaking confidentiality, and criticizing their medical care decisions.¹¹

Doctors and clinical staff have an excellent opportunity for primary and secondary prevention with caregivers during medical appointments or home visits.¹² Informal caregivers may benefit from prevention education and assistance in staying HIV-negative. HIV-positive caregivers need information on early treatment of HIV in order to stay healthier longer.

Many organizations have emerged to provide care for AIDS caregivers. Kairos Support for Caregivers and Home Care Companions Inc. in San Francisco, CA, and Gay Men's Health Crisis in New York City, NY, provide training, educational and emotional support to caregivers with support groups, workshops, and classes. Some religious organizations, such as the HIV/AIDS Ministries Network and the National Episcopal AIDS Coalition, also provide support to caregivers.¹³

In Africa, many different community responses have helped AIDS caregivers. In Rwanda, a Red Cross project trains volunteers to train family caregivers in nursing skills, and to give emotional support. In Kamwokya, Uganda, where 20-30% of people 20-45 years old are HIV-positive, the religious community provides medical and material support to caregivers and also helps break down social tensions and unfounded fears in the community.¹⁴

The UCSF Coping Project, in San Francisco, CA, has been studying the physical and psychological well-being of gay male caregivers for over five years. The project found that while caregivers experience stress and depression, they also experience positive feelings associated with loving, caring and comforting. To sustain this positive well-being, the Coping Project suggests three techniques: define what is personally meaningful and valued by the caregiver; facilitate intimacy and conversation between caregivers and their partners; and help caregivers tune in to "brief human moments" that create positive feelings.² The UCSF Care Study has also been following the caregiving experiences of over 600 friends, partners and family members.¹⁵

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9. Michaels D, Levine C. Estimates of the number of motherless youth orphaned by AIDS in the United States. *Journal of the American Medical Association.* 1992;268:3456-3461.

10. Rabkin J, Remien R, Wilson C. *Good Doctors, Good Patients: Partners in HIV Treatment.* New York: NCM Publishers, Inc.;1994. Contact: Robert Remien 212/966-2375.

11. Hays RB, Magee RH, Chauncey S. Identifying helpful and unhelpful behaviours of loved ones: the PWA's perspective. *AIDS Care.* 1994;6:379-392.

12. D'Arrigo, T. When the caregiver has HIV: early intervention through home care. *Caring.* 1994;13:4,7,80. Contact: Caring Magazine 202/547-5277.

13. Contacts: Kairos Support for Caregivers 415/861-0877; Home Care Companions, Inc 415/824-3269; Gay Men's Health Crisis 212/337-3524; HIV/AIDS Ministries Network 212/870-3909; National Episcopal AIDS Coalition 202/628-6628.

14. Anderson S. Community responses to AIDS. *International Nursing Review.* 1994;41:57-60.

15. Contact: UCSF Care Study, Joe Mullan 800/350-8660.

Other caregiver resources:

Shelby D. *If A Partner Has AIDS: Guide to Clinical Intervention for Relationships in Crisis.* Binghamton, NY: Harrington Park Press;1992.