In spite of, or maybe because of, the vision and passion of AIDS caregivers, overwhelming stress is a major by-product for both formal and informal caregivers, who often care for HIV-infected lovers, friends, family members, or neighbors. Rather than responding because of professional responsibility, they become caregivers as a direct result of their involvement with individuals or with their communities, or because of their commitment to the cause of HIV-related care.1 This means that informal caregivers have a large emotional and social stake in their caring. Leonard Pearlin, Shirley Semple, and Heather Turner suggest that this degree of emotional involvement places informal caregivers at great risk of stress and burnout.2 This article focuses on informal caregivers: what they do, sources of their stress, and attributes that may prevent or heal the effects of stress. In its exploration of stress, it identifies gender differences, isolation, and the availability of professional support as factors that exacerbate or relieve stress.

The needs of each caregiving situation are different. The information and skills required by caregivers may cover a wide range of needs including personal care activities such as how to bathe and feed another; basic and advanced nursing techniques, for example, giving bed baths, changing dressings, and monitoring pain control; learning how to access research studies for up-to-date treatment modalities; and registering for medical and financial support. Caregivers may also find they need to observe and practice new skills with more experienced caregivers, either informal or professional.

Gender and Caregiving

In response to past epidemics or endemic chronic illness, informal caregivers have predominantly been women. In all societies, women have been reared to nurture and care for those with illnesses in the family and the community. Support services for caregivers in North America, albeit inadequate, have focused on women and their needs. Little is known about the stressors that men, especially gay men—who are the most frequent HIV caregivers discussed in the literature—experience when they become primary caregivers.

In addition, it would be easier to identify stressors and coping strategies related to HIV disease if all patients and caregivers were gay men. In many HIV caregiving relationships, however, one or more of the people involved—as patients or caregivers—may be heterosexual. On the other hand, gay men have received the most attention in the literature of HIV-related, informal caregivers. Until a 1991 study, little, if anything, had been published about the needs of informal caregivers of other people, for example, those who had acquired HIV disease through heterosexual sex, injection drug use, or blood product transfusion.

A 1988 study that compared male and female caregivers of people with chronic illnesses identified a few of the special issues male caregivers face. The study found that, unlike female caregivers, most male caregivers had little experience with the intimate physical and emotional contact caregiving demands. The basic skills many women learned in childhood, such as bathing and feeding another, had to be learned by adult males. For many male caregivers, the reversal of normal domestic and emotional relationships also added to the stress of caregiving. Male caregivers frequently had to redefine as their new...
The history is well-known; forced by circumstance to assume the care of their own, gay men and lesbians in places like New York, Los Angeles, and San Francisco, banded together to respond to the epidemic when government failed to provide services. It became the norm for people with HIV disease to find their best caregivers in volunteer "buddies." The result was a well-developed system of home care that kept patients in familiar surroundings at dramatically lower costs of treatment.

But over the past few years, the volunteer networks have begun to weaken, overcome by an underfunded and inaccessible health care system, and multiple loss, grief, and hopelessness. Tragically, as the health care system continues to fail, HIV-related care requires even more role what society had usually defined as the nurturing side of women's work.

Caregivers find that their public lives—careers and outside interests—come to a standstill as they concerns become focused on caring for up to 24 hours a day. While a major concern for all, most women have at least considered that at some time in their lives they might be called on to leave the workplace to care for another. Most men have never been socialized to this possibility and are often profoundly shocked by the reality.

Gay men who provide care may experience many of the caregiving stressors ascribed to heterosexual men. Observation of those in the gay community has identified a number of other HIV-specific stressors: the existence of unexpected, untreatable manifestations of HIV disease; the effects of the multiple loss of friends and community members; homophobia both inside and outside the gay community frequently resulting in a lack of support and respite care; the fact that caregivers, themselves may have HIV disease; and frequently that, informal caregivers in the gay community—both men and women—are also formal caregivers and face HIV-related stressors on the job as well as at home. In addition, gay men may not have had the opportunity to raise children or care for aging parents and thus may not have learned caregiving skills in adulthood.

Isolation

While gender differences may make caregiving more difficult for men, caregivers also share many of the same burdens regardless of gender, for example, isolation and the absence of professional support. People who care for loved ones at home frequently report feeling isolated and abandoned by their friends and family. The expected and needed support from the surrounding community is often absent. Fear of HIV-related discrimination leads to secrecy about HIV disease and exacerbates the stress associated with caregiver isolation.5

A 1991 study examined the support needs of caregivers of HIV-infected people with hemophilia. Of the 23 caregivers interviewed, 15 were the spouses of the people with hemophilia. The researchers assumed that the majority of these caregivers were women. The study did not support people with HIV infection.

The result is that none of the populations affected by HIV disease is adequately supported by the overextended volunteer networks that once served as the model for HIV-related care. While "informal" caregivers—friends, lovers, and family members—have always functioned as a crucial part of the home health care system, the weakening of AIDS volunteer networks requires them to accept an even larger role in caring for people with HIV disease.

Therapists represent an important resource for those clients who must seek care and those who must provide it to their HIV-infected friends, lovers, and family members. In this issue of FOCUS, Shirley Paton and Denny Paterno describe the roles and challenges of informal caregiving and offer some prescriptions for the training and nurturing of caregivers.
identify the genders of the other eight respondents, who were parents and other relatives. The stressors identified by these caregivers were very similar to those identified by gay men caring for their friends and lovers.

Caregivers reported that many friends and family actively or passively avoided offering support. Problematic interactions—especially with insensitive or prejudiced professionals—limited access to helpful information. Subjects cited most often anticipated rejection and lack of trust as reasons for not confiding in others, and those factors prevented almost two-thirds of the caregivers from seeking needed emotional and physical support.

**Professional Support**

The nature and range of informal caregiving activities and the psychological and physical toll exacted by them are also related to the availability of formal support. Stress increases in the absence of such professional support.

The availability of professional support, however, is often limited. In large urban centers where the formal health care community is responding to the epidemic with a full range of services, the burden of care is exacerbated by the continuously growing number of ill people. In rural areas or urban centers with smaller numbers of people with HIV disease, formal support services are frequently limited. Informal caregivers, isolated by distance or by real and perceived concerns about confidentiality and discrimination, must provide the full range of supportive care.

**The Attributes of Those Who Care**

Caregivers choose this role because it makes sense to them at that particular time in their lives. However, simply being willing to provide care is not enough. While the following list of attributes that enable caregivers to handle stress is neither exclusive nor exhaustive, it appears to be pertinent to most caregivers—gay or heterosexual, male or female.

Initially, AIDS care attracted many whose intentions were good, but whose technical skills and knowledge were minimal—in part because no one knew what treatments, therapies, or techniques would relieve HIV-related suffering. Today, there is a growing body of knowledge about the physical and emotional care of HIV-infected people. Caregivers, fortunate enough to be in large centers of HIV-related care may access responsive professionals or participate in wide-ranging self-help groups. Others, in smaller centers or those who feel too inhibited to reach out, need active encouragement and help to obtain information from distant AIDS agencies. The most adaptive caregivers are those who are resourceful enough to seek and access this support and counsel.

Such counsel comes from experienced formal and informal caregivers who must attempt to balance the desire to be “honest” and prepare a caregiver for every possible situation with the need to avoid overwhelming informal caregivers and leaving them feeling defeated rather than empowered. The following training approaches should enable informal caregivers to provide safe and effective care: functional support from formal caregivers; practice under the observation of experienced caregivers; information given in response to asked and unasked questions; and an open-ended invitation to return for more information and practice.

Rapid change remains a part of the HIV epidemic. The physical and emotional state of an infected person can quickly improve or deteriorate. Treatment modalities change continuously: therapies believed effective one moment are labeled dangerous the next. The community of people who are ill and who provide care is expanding. Caregivers who have an ability to accommodate change smoothly will experience less stress than those who cannot. Once again, responsive professionals or self-help groups may provide the support caregivers need in order to anticipate and handle change.

Unlike most other adult relationships, but similar to the fulfilling relationship between the mother and child, the caregiving relationship is primarily unidirectional. Both people focus on the needs of only one, the one who requires care.

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**References**


Subtle feelings of disappointment and disillusionment may arise when caregivers realize that the ill person is not able to meet the emotional needs of the caregiver. These emotions are hard to identify and express because of the very reason they developed: all energy in the relationship is focused on the person who is ill. Effective caregivers will be able to seek and find mutual relationships in other parts of their lives.

The more intimate the relationship between caregiver and the person with HIV disease, the more the caregiver will experience pressure to place his or her own life on hold for the duration of the illness. Caregivers must come to realize that even in the most intimate of relationships, the fate of the ill person is uniquely his or her own and cannot be shared by the caregiver. The caregiver who overidentifies with the experiences of the ill person will ultimately fail to provide a supportive caring environment. When ill people are deprived of both the joy and hardship of assuming responsibility for their own lives, they may also lose energy for living. The most successful caregiver will be able to accept the place of illness in the loved one’s life. To do this, the caregiver needs to develop interests and relationships apart from the ill person.

Finally, caregivers who laugh easily can bring healing to themselves and to those for whom they care. Caregivers must actively cultivate a sense of humor that allows them to laugh with their peers, the person with HIV disease, and by themselves. To cultivate a sense of humor, read or listen to humorous stories, books, or songs—before the dream withers.

Many times the ill person is able to identify and share the humorous aspect of a situation when a caregiver is unable to see beyond the pain.

The Rewards of Caring

Like so many other skills, caregiving improves with practice. As these skills improve so does confidence, and stress may decrease. Caregivers will find that as time goes on, they can move their loved ones more gently, change their bandages more quickly, or feed them soup without dribbling it all over the bed. The “What if...?” fears—What if he falls? What if he can't swallow? What if I hurt him when I move him?—diminish as knowledge and experience grow.

Caregivers may also find that confidence comes as they advocate for their patients’ medical treatment, financial aid, or other services. This experience can have positive personal results when caregivers find themselves in situations where they must ask for services for themselves.

Walking alongside someone facing death has its rewards. On the way the caregiver may, if open to change, lose some of his or her own fears about living or dying. Because of the caregiving experience, the caregiver may decide to act on a dream—return to school, travel, or write a song—before the dream withers.

Caring for someone with HIV disease is stressful, and the stress of HIV caregiving will not “just go away.” Caregivers, no matter how lofty their initial motivations, must actively choose to decrease stress or be overwhelmed by it. If they do, the rewards of caring can change their lives.
I took care of my lover, Michael, for two-and-a-half years after he was diagnosed with PCP and before he died. During much of that time, we lived normal, active lives, but these times were interrupted by bouts of fatigue, fever, pain, nausea, diarrhea, drug intolerance, weight loss, anemia, melancholy, fear, frustration, and three hospitalizations.

There were frequent tests ranging from blood draws to magnetic resonance imaging (MRI). There were medical procedures including the implant of a blood line catheter and daily infusions to control cytomegalovirus (CMV) retinitis. There was constant vigilance for signs of new opportunistic infections.

During his last four months, Michael was confined to the house. In addition to CMV, he was diagnosed with mycobacterium avium intracellulare (MAI). This caused intense pain, recurring bouts of spiked fevers, wasting syndrome, and extreme fatigue.

The Demands of Caregiving

The demands on a caregiver during the final stage before death are physically intense and emotionally draining. I decided to take a medical leave from my job so that I could deal with these stresses and spend all of this time caring for and being with Michael. I knew this was our final time together. I was too aware that there would be a time when I could no longer sit and hold his hand or help to ease his fears.

I always tried to be aware of Michael's physical capabilities and not his limitations when I considered the level of assistance I would offer. I encouraged him to do many tasks for himself. During periods of extreme fatigue, I helped by anticipating what items he wanted or needed. At his bedside, I placed a low easy-to-open chest and stocked it with daily medical needs, changes of clothing, reading and writing materials, a cordless telephone, and favorite snack items. I also hung an easily seen calendar and a clock on the wall. This helped to make Michael feel more independent and saved me many steps.

My focus during this entire time was to make Michael comfortable and to give him the emotional support I could. As he became weaker, as more symptoms...

It was important to take care of Michael's mind as well as his body. I spent the better part of each day holding his hand and recounting our history.
appeared, and as the pain became more intense, his range of interests diminished and centered only on maintaining comfort. This shift was one of the most difficult things for me to witness: all of his efforts had to be concentrated on fighting merely to stay alive.

It became necessary for me to track and administer daily medications, to make most decisions, and to be alert for changes in his physical condition. I had to coax him to eat and often fed him. I had to learn to be satisfied with getting one or two bites of food into him at a meal.

Responses

There were some activities that I found helped me to cope with the caregiving demands and the emotional issues surrounding Michael's decline. First, running and exercise provided me with time to ponder and sometimes even solve problems. This also helped to diminish the effects of stress.

Second, Michael and I shared our fears and concerns regarding AIDS, Michael's physical deterioration, his eventual death, and how I would face life without him, and this sharing created an increased openness of communication. In Michael's words, "By confronting your demons, you take away their power over you."

Third, we were fortunate to have a wonderful nursing assistant who was skilled in performing the mechanical tasks of caregiving such as changing the bedclothing with Michael in the bed, bathing Michael while he remained in bed, and repositioning Michael to prevent bedsores. The nursing assistant was also compassionate and intuitive in recognizing that there were tasks that I wanted to do. His presence provided a feeling of security as well as the opportunity for a respite if I desired it.

The Final Days

When Michael's pain became overwhelming, about three weeks before he died, the doctor prescribed liquid morphine. This caused a coma-like state. The emotions this raised in me seemed more than I could handle. I searched for a way to cope—I needed a way to help myself through this, but I knew I also needed to ease Michael's mind.

It became clear that it was important to me to communicate to Michael how much he had given me. I also believed it was important to care for Michael's mind as well as for his body. From that point on, I spent the better part of each day holding his hand and recounting our history. I told him the many things I would always remember. I told him that although his body would no longer be, these memories of him—of us—would remain alive with me.

I talked of how we met, our first apartment, our first meal, our first Christmas, our shared love for Joni Mitchell music, and how we always said that we would grow old together. I told him the many things I learned from him including patience and caring for others. I promised him I would be okay after he died. I told him it was okay for him to let go.

Even though he was not able to respond, I know he heard me. The day before he died, the infusion nurse stopped by to check his catheter. I was sitting on the bed, and Priscilla was just buttoning Michael's pajamas. He opened his eyes for a moment, looked at me, and said in a shaky voice, "Thank you for everything, Den, I love you." His final words told me I had done the right things.

As I reflect back to that April day when Michael was diagnosed with PCP, I have to struggle to remember specific events just like I struggle to remember events that occurred in the days right after he died. But, I remember the events of caregiving. Yes, it was difficult. It was stressful. It was scary and draining. But it provided a time for Michael and I to show each other the depth of our caring and love for each other.

AIDS Health Project Book on AIDS and Alcohol

Risk and Recovery: AIDS, HIV and Alcohol, a new handbook for mental health and alcohol service providers, explores the connection between HIV disease and alcohol use, puts this information in the context of culture, attitude, and sexuality, and focuses on providing HIV-related education and counseling in recovery settings. The book is $16.95 (plus tax and handling) and includes training modules for recovery programs.

For information on ordering the 256-page book, write: UCSF AIDS Health Project, Box 0884, San Francisco, CA
Characteristics of Informal Caregivers

A British study of informal caregivers found that their needs for emotional support were often unrecognized and unmet. Of the 125 caregivers researchers interviewed, 45 percent were close friends of the patients, 42 percent were partners, 8 percent were family members, 2 percent were "buddies," and 3 percent were other people. Seventy-seven percent were men, and 62 percent were between the ages of 30 and 45. About 15 percent had health problems of their own that affected their ability to provide care, and 10 percent were HIV antibody positive.

Care included assisting with personal and household tasks as well as offering emotional support; 70 percent of the study participants did both. Much of this care was offered continuously over the course of months, although personal caregiving, including bathing, dressing, going to the toilet, and feeding, was of shorter duration. Caregivers also assisted with hospital stays and outpatient appointments, and provided ongoing emotional support.

Thirty percent of respondents said while they would have liked more help themselves, they had not obtained it. Fifteen percent recognized a need for more emotional support, and 13 percent desired more practical help, especially transportation assistance, shopping support, financial and legal help, and help that would have allowed them to continue paid employment. Caregivers also desired moral support, particularly from friends and family, but were often unwilling to ask for it. Among the reasons for their reticence were: caregivers did not know where to go to get support; they were too busy or tired; they did not want to involve outsiders; and the HIV-infected person for whom they were caring did not want to involve outsiders.

Training and Support of Caregivers

A review of the literature and of case examples establishes clear parallels between programs to recruit, train, and support volunteers who work with people with HIV disease and those who work in the hospice movement. It also clarifies the unique demands of HIV-related caregiving.

Hospice training programs prepare volunteers to deal with high levels of stress. Volunteers learn about the hospice goal of a “peaceful, good death,” basic communication skills, pain control, and the stages of dying, as well as a wide range of emotional issues—such as death anxiety, dependency, and loss. Hospice volunteers typically participate in ongoing support groups in order to share their feelings, lessen stress levels, and find support.

To increase the number of AIDS volunteers to meet the growing need for HIV-related support, recruitment programs must address the fears and concerns of heterosexuals and other volunteers drawn from outside the gay and lesbian community. Among these concerns are negative attitudes about gay “lifestyle,” sexuality, and the fear of contagion. Volunteers require education about the social realities facing gay men with HIV disease who may be estranged from their families of origin, and about the non-traditional gay family and friendship circles. Volunteer training must also address special HIV-related demands, including AIDS Dementia Complex, physical disfigurement, and social isolation.

The researchers suggested a training model including two components. The didactic component consists of providing information about all aspects of HIV disease, legal and financial planning, the stages of death, crisis intervention, communication skills, and other practical skills.

The affective component involves small group discussions and exercises to deal with emotions ranging from generalized anxiety about AIDS to fears of rejection by friends and co-workers. The purpose of the exercises is to decrease social distance and heighten empathy for people with HIV disease. They also work as a screening mechanism to weed out volunteers whose own emotional makeup and unresolved issues make them inappropriate caregivers.

Caregivers can mediate the uncertainty of HIV care by anticipating caregiving as a transitional period marked by major changes and a new perspective on life.
Who Are AIDS Hospice Volunteers?


A comparison of 60 AIDS and 40 traditional hospice volunteers revealed major demographic and psychosocial differences.

AIDS hospice volunteers were primarily gay or bisexual (63 percent), and male (63 percent), and they were employed in a variety of occupations. Their mean age was 38. In contrast, traditional hospice volunteers were more homogeneous: 83 percent were heterosexual women, and 34 percent were either homemakers or retired. Their mean age was 50.

The two groups were similar in personality and ways of coping. Both were extroverted, intuitive, and feeling, and tended to rely more on emotion than problem-solving to cope with stress.

They differed, however, in their perception of threats related to hospice volunteer work. The AIDS hospice volunteers, including those who were heterosexual, perceived greater threat to all aspects of their lives, including employment, health, physical safety, and social interactions.

The Uncertainty of AIDS Caregiving


AIDS family caregivers, from both families of origin and families of choice, function in an environment of total uncertainty. According to the theory of AIDS family caregiving developed by the researchers, caregivers can mediate this uncertainty by anticipating caregiving as a transitional period marked by major changes and a new perspective on what is important in life.

The investigators interviewed 53 family caregivers in Seattle. A third were partners, 43 percent were friends, and 13 percent were parents of someone with symptomatic HIV disease. Most caregivers were White gay men who lived with their ill partners or friends. Interviewers asked a series of questions about what it was like to live with and to take care of someone with AIDS and, using “grounded theory,” qualitatively analyzed the subjects’ interpretations of their social interactions.

Caregivers reordered their lives in response to the cycle of crisis and calm periods that characterize the HIV disease process. These transitions were divided into five categories.

“Managing and Being Managed” by the Illness is characterized by vigilant monitoring of the course of the disease and responding to the demands for care. “Living With Loss and Dying” requires reassessing life plans and accepting the possible death of a loved one. “Renegotiating the Relationship” means revising ways of relating, coping with dependency, minimizing conflict, and clarifying expectations.

“Going Public” is the process of revealing the caregiving role to others and experiencing the unpredictability of the reactions. The authors examine this unique aspect of AIDS family caregiving in their second article. This analysis reveals that caregivers perceive themselves as sharing the stigma associated with AIDS because of their close relationship with an HIV-infected person. To move through this process, caregivers must balance secrecy and assertiveness and the risks and benefits of going public.

Finally, “Containing the Spread of HIV” is related to the fear of contagion to others and to oneself. In this process, caregivers face their own HIV serostatus and mortality.

The magic bullet—the AIDS vaccine-dominated last year’s international conference in Florence, as researchers presented 13 vaccines, all at the stage of human safety trials. The U.S. National Institutes of Health recently unveiled plans for large-scale human trials to determine whether vaccines that are safe are also effective. In the December issue of *FOCUS,* Dennis Osmond, PhD, an epidemiologist at the University of California San Francisco, discusses the vaccine development process, and focuses on the ethical and psychological issues involved in human trials.

Also in the December issue, Joyce M. Johnson, DO, MA, Acting Director of the Division of Epidemiology and Surveillance at the U.S. Food and Drug Administration and Assistant Clinical Professor of Psychiatry at the Georgetown University School of Medicine, discusses the counseling approaches practitioners can use in helping clients make decisions about participating in vaccine trials.
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