A PERSONAL PERSPECTIVE: CARING FOR HOMELESS PEOPLE WITH AIDS

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In inner-city neighborhoods, AIDS (acquired immunodeficiency syndrome) has become rampant as drug users and their partners, women, and young gay men of color account for an increasing proportion of AIDS cases. As the gay community has been decimated by the disease, a similar fate possibly awaits many inner-city residents. Service providers in the urban setting must confront the issue of homelessness among clients who have AIDS: it is no easy task to provide care to individuals living with AIDS who may also be struggling with multiple problems, such as poverty, drug addiction, mental illness, social isolation, or abuse. For some providers, the challenge may be overwhelming; they instead may choose to work with other groups of individuals affected by AIDS. For those who are prepared to commit themselves for the long haul, however, opportunities for personal growth and job satisfaction may overshadow the difficulties inherent in working with this population group.

A PERSONAL LOSS

My decision to work with disadvantaged people with AIDS resulted from losing my 52-year-old father to the disease in 1994. My father had been sick for some time; no one had been able to determine the cause until he was given a test for human immunodeficiency virus (HIV). The news that he had full-blown AIDS came as a complete shock to my family; to make matters worse, my parents, who lived in South Africa, had limited financial means and no medical insurance.

During this period, my father suffered constantly, and I was frustrated over not being able to help him. My mother managed to hold down a full-time job and care for my father without outside help. Soon, after my father's condition worsened and he developed dementia, my mother finally succeeded in getting him accepted into a local hospice. However, the day after he moved in, the family

was called back to the hospice because his condition had deteriorated. He died around midnight.

The loss of my father and the strength, love, and devotion demonstrated by my mother will remain with me forever. My father's death affected me deeply, much more than I had anticipated, and it changed my perspective. I felt that it was important not to forget the ordeal my family endured; further, I felt that it was essential to be around people who were dealing with AIDS in their lives. Because I remembered my family feeling isolated, alone, and alienated in our pain and grief, I was determined to do something to help families like my own. Therefore, I explored job opportunities in AIDS service organizations in New York City. Several people tried to discourage me, including my employers, and many were concerned that my grief would interfere with my effectiveness as a caregiver. For me, however, such work was not so much a choice as something I was compelled to do.

In early 1994, I took a position in the South Bronx as director of a housing program for people affected by AIDS. I remained in this position for 4 years. This paper summarizes what I learned from this experience and is offered as potential insight to others.

CHALLENGES

HOUSING: DIRECT ISSUES

My task was to help establish an apartment program and a congregate facility in the Bronx for homeless people with AIDS. The first few months were overwhelming; it took me some time to appreciate fully the magnitude and the complexity of my clients' needs. It is difficult for most people to imagine a life-threatening illness and even harder to understand what it must feel like to have AIDS, in addition to being homeless, alone, and addicted to drugs. It is important to be aware of one's motives for engaging in this work and to understand the complex systemic and clinical challenges that lie ahead. These realities can be intimidating, and if one is not clear about one's motives, they may be overpowering.

One of the first things I realized was that the number of people with AIDS who are in need of housing is alarming. Some clients may wait for several years, and as their condition deteriorates, so does their hope that they will ever find a place of their own. Most homeless people living with AIDS are housed temporarily in welfare hotels, which limit stays to 90 days. As soon as their 90 days have passed, clients are shunted to another hotel, and the process continues.

Conditions in some of these "hotels" are appalling: residents must share dirty bathrooms, rooms are small and depressing, and there is the constant fear of being assaulted or having belongings stolen by other residents, many of whom are just out of prison. These are hardly suitable places for very sick individuals. One grows accustomed to hearing people tell how depressed they became living in such places and how they could not wait to move out.

The outlook is bleaker for people with HIV who are not yet diagnosed with AIDS. Many of them have little chance of securing housing, since many applicants with AIDS are still waiting for housing; these individuals are given priority. HIV-infected asymptomatic persons must wait until they become sick before they have a reasonable chance of being housed suitably.

In New York City, homeless individuals with AIDS may live in apartments provided by community-based organizations, and these apartments come with supportive services provided by these organizations. However, the number of these housing units, called *scattered-site apartments*, is limited, and because there is an ever-increasing number of infected people who need housing, there are many applicants for each opening.

In the beginning, it was heartbreaking for me to turn people away. I felt (and still do) that it was unconscionable not to be able to provide decent, safe housing for vulnerable and seriously ill people. I also was acutely aware, during my first year, that if I was not careful, I would burn out. As time passed, I was able to cope better with the demands and limitations of my work, but maintaining professional detachment always was difficult.

Providers are frustrated constantly by limited funds, which makes it difficult to find suitable apartments in safe neighborhoods for clients. Most community-based organizations in New York City that are contracted to provide housing services to homeless people with AIDS receive no funds for annual rent increases. Consequently, apartments are lost after a few years, and organizations must hunt frantically for other apartments for displaced clients. Every year, fewer affordable apartments are available to organizations serving clients with AIDS.

Fundamental systemic changes are needed in the provision of housing and supportive services for both HIV-infected and AIDS-diagnosed persons. Measures to reduce the waiting time, as well as to improve the quality of staff at city agencies, are essential. Furthermore, there needs to be better coordination by community organizations and groups to advocate and demand better housing services for homeless people with HIV and AIDS. They must be the voice for this silent and vulnerable group.

ASSOCIATED ISSUES

The new AIDS treatments have little chance of working when people are homeless and not connected to services. Approximately 75% of the people referred to me for housing either did not have a medical provider or did not see a physician regularly. Among those taking medications such as protease inhibitors, most reported that they had missed doses and had great difficulty adhering to the medication regimen. There is a crucial gap in the service system, resulting in many people with AIDS going without care or being unable to navigate the medical system effectively. The only time some people have contact with a physician is when they need to be taken to the emergency room. By providing supportive housing services to AIDS patients, providers usually can monitor medications, accompany people to their primary physician, and make sure that they do not fall through the cracks. They can provide a safe living environment for people, as well as help them get the treatment they need.

The clinical challenges associated with this client population also need to be addressed. Working with seriously ill individuals who may have addiction and/or psychiatric problems is difficult for even the most skilled and seasoned practitioner. Nothing can prepare a person for the demands of working with people with substantial drug and behavior problems. For example, my staff and I struggled repeatedly with resistance from clients; for whatever reason, many individuals do not want help or are not ready to accept it. Providers must be prepared to invest the time required to help clients to overcome deficits in basic life skills and must be aware of the complexity of addressing the impact of severe emotional problems and addiction issues, especially as they relate to treatment compliance.

I have witnessed many dedicated, competent staff come and go over the years. Those who work with the homeless usually receive low pay, work in difficult environments, and do not always receive the recognition and respect that they deserve from both clients and supervisors. One can become demoralized and fatigued within a short period. Burnout in supervisors is also common because they have to struggle with inadequate resources, demoralized staff, and problems arising from client behaviors. There are no magic solutions to address stress and burnout among personnel who choose to work in this setting; higher pay, improved working conditions, and staff support programs are necessary, but are beyond the means of many AIDS service organizations.

REWARDS

Despite difficulties and stresses, this work can be immensely rewarding, particularly when one is able to offer people places of their own. I will never forget one

of the first clients who moved into our new AIDS residence. Elizabeth, a 58-year-old grandmother, had been homeless for a number of years. Within a few days of moving in, she had decorated her room and proudly took me on a "tour," showing me how she had arranged her collection of assorted knickknacks and personal belongings.

Unfortunately, several weeks later, Elizabeth had to be hospitalized. She did not have much time left. Elizabeth accepted the news with strength and dignity, and she decided to return to the residence, where she died several days later. The only thing that she had possessed of any material value was a large television, which she bequeathed to the residence. The residents donated a few dollars and bought a plaque in her memory.

Even though she lived for only a short time in the residence, Elizabeth had a place where she felt she belonged and where she was safe. As another client said to me: "This is my own place. Nobody is going to take it away from me, unless I mess up." This sense of ownership is new to many people who have never had a place of their own. On days when the medications do not seem to be working as well as they should and when everything seems overwhelming, knowing that one has a place to call one's own makes all the difference in the world.

My personal journey, from losing my father to AIDS in South Africa to working with homeless people with AIDS in the South Bronx, has been an experience that cannot be described adequately in one word, sentence, or paragraph. My father's death gave me a renewed appreciation of life and of the importance of helping people who are enduring difficult times, both of which were reaffirmed in my work. I met many people who had immense tragedies in their lives, yet their concern, love, and faith in others was not diminished. People can endure much in their lives, yet retain the capacity to survive.

With new advances in medical treatments, death from AIDS is not as pervasive as it once was. There is hope and the possibility of a future for many. Nevertheless, in this new era, a new challenge faces providers: complacency. There is a growing public perception that the AIDS crisis is over; this may result in the needs of particularly vulnerable people with AIDS being ignored. More attention needs to be focused on addressing the psychosocial needs of disadvantaged people with AIDS who may be homeless, drug addicted, or mentally ill, but more resources are needed to focus that attention. Failure to address the social context of AIDS adequately may diminish the impact of recent treatment advances for these individuals.