

Psychosocial Issues

Washington State has a system to link people with HIV infection and AIDS to care and support services. Case managers in the HIV/AIDS Programs are the primary contact people for services. They can usually be found by contacting the local health department or health district. HIV infected or affected persons can be linked with medical care, insurance programs, volunteer groups, hospice, and other types of care and support services that may be needed during the course of a person, or family's, time of living with HIV. To find a case manager, contact the HIV/AIDS Program in your county's health department or district, or call the Washington State DOH at 1-877-376-9316.

Difficult realities

Persons with HIV and their families and friends face a multitude of difficult realities.

- Even with the advent of antiretroviral drugs, persons with AIDS still die prematurely.
- Men who have sex with men, and injection drug users, who may already be stigmatized and subjected to social and job-related discrimination, may encounter even more societal pressure and stress with a diagnosis of HIV or AIDS.
- 90% of all adults with AIDS are in the prime of life and may not be prepared to deal with death and dying.
- The infections and malignancies that accompany AIDS along with certain medications, can diminish and disfigure the body.
- People who are living with HIV face the need to practice "safer sex" and take medications for the remainder of their lives.

One thing that characterizes the grief around AIDS is the repetition of deaths that one person may experience. Many people working with or living with AIDS for years have gone to countless funerals and have seen a succession of their friends pass away. This is sometimes termed "chronic grief."

Chronic grief intensifies when one realizes that, before the grieving process for one death is complete, many more people may have died.

The idea of "cumulative" multiple loss or grief saturation is not new. The emotions felt by long-term survivors of HIV and the HIV-negative friends and families are similar to the emotions of the survivors of the Holocaust, survivors of natural disasters (earthquakes, tornadoes, etc.), and to battle fatigue described by soldiers.

Losses

HIV often produces many losses:

- Loss of physical strength and abilities
- Loss of mental abilities/confusion
- Loss of income and savings
- Loss of health insurance
- Loss of job/work
- Loss of housing, personal possessions, including pets
- Loss of emotional support from family, friends, co-workers, religious and social institutions
- Loss of self-sufficiency and privacy
- Loss of social contacts/roles
- Loss of self esteem

People experiencing multiple losses may feel:

- Guilt
- Grief
- Helplessness
- Rage
- "Numb"

Physical weakness and pain can diminish a person's ability to cope with psychological and social stresses.

Psychological suffering

Infection with HIV can cause distress for those who have HIV, their caregivers, family, lovers and friends. Grief can manifest itself in physical symptoms, including clinical depression, hypochondria, anxiety, insomnia, and the inability to get pleasure from normal daily activities. Dealing with these issues may lead to self-destructive behaviors, such as alcohol or drug abuse.

Disbelief, numbness, and inability to face facts occur for some. The "fear of the unknown," the onset of infections, swollen lymph nodes, or loss of weight (or unusual weight gain) can be accompanied by fear of developing AIDS, or of getting sicker.

Rejection by family, friends, and co-workers is often experienced. In some cases, guilt develops about the disease, about past behaviors, or about the possibility of having unwittingly infected someone else.

Psychological suffering

People living with HIV may feel as though their "normal" lives have completely ended, as they must plan detailed medication schedules and medical appointments. The cost of the medications for HIV may result in financial hardship, even if the person has

medical coverage. Call the Washington State DOH at 1-877-376-9316 if you or someone you know needs help paying for HIV care and medications.

Sadness, hopelessness, helplessness, withdrawal, and isolation are often present. Anger is common: at the virus, at the effects of the medications, or the failure of some of the medications, at the prospect of illness or death, and at the discrimination that can often be encountered. Some people with HIV consider suicide or attempt suicide, and some may kill themselves. Call your local Crisis Line listed in your phone book, or call the National Suicide hotline at 1-800-784-2433 or 1-800-273-8255.

Caregivers

Often feelings experienced by the caregiver will mirror those of the patient, such as a sense of vulnerability and helplessness. Caregivers may experience the same isolation as the person with HIV infection. Finding a support system, including a qualified counselor, can be just as important for the caregiver as for the person who has HIV disease. Support from co-workers can be especially important.

Stages of Grief

Grief has been described in a variety of forms. It may be best understood as a process that doesn't involve a straight line. People do not move predictably step-by-step through the various stages of their grieving, but progress at their own speed. There seem to be discreet phases of grief, including:

- shock and numbing
- yearning and searching
- disorganization and despair
- some degree of reorganization

The length of time it takes to move between these stages is determined by the individual, his or her values and cultural norms. In "uncomplicated grief," an individual is able to move through these stages and come out of the grieving process.

"Complicated grief" is described as an exaggeration or distortion of the normal process of grieving. People experiencing multiple losses are more at risk for complications. If an individual has been impacted by multiple deaths, it may be difficult for them to reorganize or "move on" with the process.

Caregiver Issues

Caregivers may find it necessary to acknowledge their own experiences and feelings when dealing with all aspects of this disease. Good self-care for the caregiver is important.

DO

DO meet with a support person, group, or counselor on a regular basis to discuss your experiences and feelings.

DO set limits in care-giving time and responsibility, and stick to those limits.

DO allow yourself to have questions. Let "not knowing" be okay.

DO get the information and support you deserve and need.

DO discuss with your employer strategies of performing your job in ways that reduce stress and burnout.

DO remember that UNIVERSAL and STANDARD PRECAUTIONS are for the patient's health and welfare, as well as your own.

DON'T

DON'T isolate yourself.

DON'T try to be all things to all people.

DON'T expect to have all the answers.

DON'T deny your own fears about AIDS or dying.

DON'T continue to work in an area where you "can't cope."

DON'T dismiss UNIVERSAL AND STANDARD PRECAUTIONS because you "know" the patient.

There are other issues for people who share a home with, or provide home care for persons with HIV or AIDS. Please refer back to the section on Transmission and Infection Control, starting page 6, for guidelines around safe home care.

Special populations

Although HIV infection affects people from all ethnic groups, genders, ages, and income levels, some groups have been significantly affected by the AIDS epidemic. These groups have included men who have sex with men, injecting drug users, people with hemophilia, women and people of color. The following information details how these different populations may be uniquely affected by the AIDS epidemic.

Men who have sex with men

American society has issues with homosexuality. Grief may not be validated when relationships are viewed through prejudice and considered "unacceptable." An example of this may be the reaction of churches to those who are living with, or have families living with AIDS. Many congregants report that they do not get the support they need from their church families because of the stigma attached to HIV, AIDS and homosexuality.

Self-esteem issues and psychological issues including depression, anxiety, diagnosed mental illness and risk-taking behaviors may also complicate the lives of these men.

Additionally, there are the issues with HIV-negative men who have sex with men. Most of the attention, resources and services are focused on HIV-positive gay men. As with any behavior change people can become "tired" with safer sex messages, and may make choices that place them at risk. Some may feel that HIV infection is inevitable (although it is not) and purposely engage in unprotected sex.

Men who have sex with both men and women (who do not exclusively self-identify as "gay") face additional challenges. It is more difficult to reach those men who do not identify as being "gay" with HIV prevention efforts and activities. Bisexual men face many similar challenges as "gay" men but may not have the social and community resources they need.

Injecting drug users

American society also has issues with illegal drug use and "marginalized" individuals such as those in poverty and the homeless. People who continue to use injecting drugs, despite warnings and information about risks, may be viewed by some as "deserving" their infection.

Injecting drug users

Harm reduction measures like syringe exchange programs, have been proven to reduce the transmission of blood-borne pathogens like HIV, HBV, and HCV. These programs are controversial because some people believe that providing clean needles and a place to exchange used needles constitutes "approval" of injection drug use.

In addition, poverty, self-esteem issues and psychological issues (including depression, anxiety, diagnosed mental illness and risk-taking behaviors) may also complicate the lives of injection drug

users. The desire to stop using illegal drugs may be very far apart from the ability to stop. The reality about inpatient treatment facilities is that while there is a large demand for spaces, very few are available. Many substance abusers are placed on "waiting lists" when they want treatment, and by the time there is a place for them, the individual may be lost to follow-up.

People with Hemophilia

Hemophiliacs lack the ability to produce certain blood clotting factors. Before the advent of antihemophilic factor concentrates (products like "factor VIII" and "factor IX," which are clotting material pooled out of donated blood plasma), hemophiliacs could bleed to death. These concentrates allowed hemophiliacs to receive injections of the clotting factors that they lacked, which in turn allowed them to lead relatively normal lives.

Unfortunately, because the raw materials for these concentrates came from donated blood, many hemophiliacs were infected with HIV prior to the advent of blood testing.

During the 1980's, 90% of severe hemophiliacs contracted HIV and/or HCV through use of these products. There is anger within this community because there is evidence to show that the companies manufacturing the concentrates knew their products might be contaminated, but continued to distribute them anyway.

Some people considered hemophiliacs to be "innocent victims" of HIV, but there has been significant discrimination against them. The Ryan White Care Act, funding HIV services, and the Ricky Ray Act, which provides compensation to hemophiliacs infected with HIV, were both named after HIV-positive hemophiliacs who suffered significant discrimination (arson, refusal of admittance to grade school) in their hometowns.

Women with HIV

Women in the U.S. and worldwide are becoming infected with HIV at higher rates than any other group of people. This is particularly true with women of color. Women who are infected with HIV, or who have family members who have HIV, face some unique challenges.

Women with HIV, continued

Women may become infected with HIV from a partner who either used injecting drugs, or who had other sexual partners. Many of these women assumed that the relationship was monogamous, or that they "knew" their partner's history. Many others are unable to discuss or implement safer sex practices due to issues of self-efficacy and/or domestic violence affecting their relationship.

Women may postpone taking medication, or going to medical appointments, in order to care for their children or other family members.

Women (and also men) may fear disclosing their HIV status to others, fearing loss of their jobs, housing, or other forms of discrimination. Single parents with HIV may feel particularly fearful because of their lack of support.

Many women have problems with lack of transportation, lack of health insurance, limited education and low income. They may have child-care problems that prevent them from going to medical appointments.

Many women who have HIV infection do not consider this to be their "worst problem". Their symptoms may be mild and manageable for many years. Meanwhile, they may have more pressing concerns, such as their lack of income, housing, access to medical care, possible abusive relationships, and concerns about their children.

People of Color

African Americans and Hispanics specifically have disproportionately higher rates of AIDS cases in the U.S., despite the fact that there are no biological reasons for the disparities. African American and Hispanic women make up less than 25% of the total U.S. population, but account for 77% of all reported AIDS cases in women. African Americans make up about 12% of the population, but account for 37% of all AIDS cases in the U.S. Hispanics make up about 13% of the population, but account for 20% of the AIDS cases in the U.S. In some areas, disparities also exist in the number of AIDS cases in American Indians.

People of Color continued

There is not one single reason that stands out as to why the disparities exist. One factor is health disparities, which are linked to socioeconomic conditions. Another factor is distrust of the healthcare system. Both legacies of the past and current issues of race mean that many people of color do not trust "the system" for a variety of reasons. Thus, even when income is not a barrier, access to early intervention and treatment may be limited. And HIV may be only one of a list of problems, which also include adequate housing, food, employment, etc.

Another factor may be the diversities within these populations.

Diversity is evident in immigrant status, religion, languages, geographic locations and, again, socioeconomic conditions. Getting information out in appropriate ways to these diverse populations is challenging.

There is a significant amount of denial about HIV risk, which continues to exist in these communities. As with other groups, there may also be fear and stigmatization of those who have HIV. Prevention messages must be tailored and presented in a culturally and linguistically appropriate manner. The messages must be carried through channels that are appropriate for the individual community. These channels may include religious institutions or through respected "elders" in the community. Ironically, it may be these institutions or elders who, in the past, have contributed to the misinformation and stigma associated with HIV. Many HIV prevention programs are recognizing the importance of working with diverse communities. Input from these communities must be included in planning, delivering, and evaluating HIV prevention activities.