Challenges Facing Women with HIV

Denice J.D. Benson, MFCC and Catherine Maier, MA

In the United States, the medical and psychosocial needs of women with HIV disease remain largely unclarified. This is particularly true in urban regions where the incidence of HIV infection is high, but the prevalence among women is low. The absence of common social group identification, of visibility in the larger HIV community, and of research and service delivery focusing on women's specific needs compounds the isolation, denial, and ultimately the premature death these women face. The psychosocial responses of women with HIV disease and the appropriate clinical interventions for them must be seen in the context of these broader social and environmental issues.

This article begins by defining the psychosocial conditions under which women face the epidemic, and then, using three case studies, explores specific situations and clinical responses to the psychological concerns women raise.

The Invisible Woman

Society has not adequately responded to the needs of women with HIV disease. Women comprise "only" 9 percent of frank AIDS cases in the U.S. Four years ago, "only" 4 percent of these cases were among women. In fact, women proportionately represent the fastest growing segment of people with AIDS in the U.S. This increase has included women who have had sexual contact with bisexual or intravenous (I.V.) drug users, as well as women who have been I.V. drug users themselves. At the same time, women remain undereducated about HIV risk, testing, and treatment. Many are unaware of their own risks and of their HIV antibody status, and are vulnerable to misdiagnosis by medical practitioners who remain ignorant of the clinical manifestations of HIV disease in women, which can include vaginal infections, pelvic inflammatory disease (PID), and cervical dysplasia.

The diverse needs of women with HIV disease remain largely uninvestigated. In San Francisco, for example, there has never been a comprehensive assessment of the needs of this population. The inclusion of women in clinical trials and research protocols continues to be limited. An unfortunate outcome of this discriminatory process, beyond the obvious ramifications for individuals, is that the medical picture and psychosocial needs of women with HIV disease remain unstudied and unrecognized.

Psychosocial Aspects of Women's Lives

There is no single socioeconomic or psychological profile that describes all women affected by AIDS. Case experience, however, suggests that women with HIV disease are predominantly poor, and that a disproportionate number are women of color.

Many women lead lives with significantly limited resources, complicated by child-rearing, their own or a family member's substance abuse, psychological problems, encounters with the criminal justice system, and homelessness and other manifestations of poverty. These women are accustomed to discriminatory treatment and therefore do not readily seek or trust service providers in a system they perceive as hostile and punitive. In the end, HIV disease is one more challenge for these women; basic needs usually take priority over HIV prevention and treatment. These factors lead women to come to the attention of care providers later in disease processes of all kinds, including HIV-related ones.

There are an increasing number of women who, prior to their HIV infections, were not struggling to meet basic needs. With the introduction of HIV disease, however, these women wrestle with their fears of becoming not only stigmatized, but also economically and physically dependent upon their families or the social service and public health care systems should they become ill. Their anticipated or realized loss of economic independence or loss of status as a caretaker raises fears of abandonment, of becoming the person in need of care. They wonder, "Will anybody—my partner, my family, my doctor—be there for me?"

Women are taught, explicitly and implicitly, to care for others first. Many women face the task of learning the difference between healthy nurturance—something they may never have experienced themselves—and codependent caretaking, that is, pathologically putting the needs of others before their own.

The biggest challenge in counseling HIV-infected women—often isolated and expecting second-class treatment—is first to find them and then to gain their trust.

Finally, many people in the social underclass of U.S. society, which includes most HIV-infected people, live with the burden of society's disdain. Consciously or unconsciously, they internalize the prevailing homophobia, misogyny, racism, and classism. AIDS becomes an excuse for society to express hostility toward and separate from those most affected by the epidemic. For women with HIV disease, in particular, issues of isolation, trust, and empowerment continue to be central, regardless of their class or cultural backgrounds, or alcohol- or other drug-abuse histories.

Sonja: Meeting Basic Needs as a Foundation for Change

Sonja, who was diagnosed with AIDS five years ago, is a 48-year-old White woman with a long history of substance abuse. She had not sought health care before her AIDS diagnosis because earlier encounters with the medical delivery system had taught her to expect sub-standard and discriminatory treatment.

Upon discharge, she was referred by the hospital to a social worker for case management. Sonja told her case worker that she was homeless, without financial resources, friends, or hope of living much longer. The social worker immediately provided assistance in obtaining housing and financial benefits. The social worker then identified other issues challenging Sonja, including substance abuse, low self-esteem, hopelessness, isolation, loss, and grief; Sonja's child and partner had both died of AIDS. Due to Sonja's distrust of "the system," her social worker offered individual counseling sessions on an as-needed basis to allow Sonja to determine the frequency of contact. After two months of encouragement, Sonja joined a women's therapy group.

Shortly after she joined the group, Sonja began her recovery from addiction, and has had continued success in this process for four-and-a-half years. Citing her AIDS diagnosis as her impetus, Sonja developed her own recovery plan instead of entering a continued on page 2
Challenges for Women... continued from cover

formal program. As her confidence and knowledge of HIV disease increased, Sonja's counselor arranged for her to speak publicly. In telling her HIV story, Sonja was able to make contact with people whom she respected and who respected her. This public support and validation led to increased self-esteem and sense of purpose.

Therapeutic intervention began by resolving a hierarchy of Sonja's basic needs. Sprunging from consistent and non-judgmental support, Sonja learned to trust her counselor and, increasingly, herself in making beneficial decisions about her life. Sonja learned to see other people's interest in her story as nurturing rather than as suspicious and leading to manipulation. Her interactions with other women with HIV disease and her public speaking empowered her and enabled her to feel good about herself for the first time.

Rose: Overcoming Isolation

Rose is a thirty-five year old Asian woman who was diagnosed with AIDS three years prior to her first meeting with a social worker, and five years after a transfusion. She and her husband are both professionals, but she is currently receiving disability benefits.

Rose called her social worker two-and-a-half years ago to join a group for women with AIDS. Rose was concerned that, by approaching the agency or the group, she would identify herself as a woman with AIDS. She and her husband had told their friends and relatives that she had cancer. After three individual counseling sessions, Rose talked about her extreme isolation and the guilt she felt about lying about her condition. She said she distrusted other women with AIDS, whom she characterized as having contracted HIV through I.V. drug use or unprotected sexual activities.

With her social worker's support and encouragement, Rose attended one group meeting, but did not return. In addition, Rose did not answer her social worker's phone calls, which the social worker continued over the next year. When Rose responded, her social worker validated both Rose's feelings about being different from other group members and the experiences and worth of the other women in the group.

Eventually, Rose began weekly individual counseling, during which she discussed feelings of isolation, discrimination, shame, and powerlessness. Rose decided to rejoin the group, and in time was able not only to share common feelings but to nurture other group members. The group's non-judgmental, supportive, therapeutic environment has decreased her sense of isolation.

Robin: The System Fails

Robin, a 25-year-old White woman with a history of drug addiction, homelessness, and social isolation, was hospitalized with Pneumocystis carinii pneumonia (PCP), toxoplasmosis, and other HIV-related conditions. Six months earlier, after Robin collapsed in the street and was unable to care for herself, a church group arranged "foster" care for her in the home of an older couple. At the time of her second hospitalization, the couple decided they were unable to offer Robin continued housing because her health and illness, particularly among women, meant "too little too late."

Conclusion

The stories of these three women exemplify some of the therapeutic interactions counselors may have with women with HIV disease. The biggest challenge in delivering counseling to HIV-infected women—often isolated and expecting second-class treatment—is first to find them and then to gain their trust. But the response necessary to change this situation goes beyond the traditional realms of counselors.

The medical establishment, most notably the Centers for Disease Control (CDC), continue to base their recommendations on clinical and research data about HIV disease in men. Currently, the CDC does not recognize as indicators of HIV disease the gynecologic conditions with which infected women often present. This means that women are often incorrectly diagnosed and that the number of AIDS cases among women is underreported. It is notable that women's societal invisibility is not only an effect, but also a cause of this phenomenon.

The appropriate clinical response to this situation is to create therapeutic environments that address the hierarchy of human needs, from food, shelter, clothing, and medical care to psychological and interpersonal issues such as trust, autonomy, self-esteem, and intimacy. In many cases, this means adopting a team approach in which case managers, health care practitioners, and counselors plan interventions together. In areas where women with HIV disease are fewer in number, it may be necessary to extend the recruitment period for groups and begin with groups with smaller numbers of participants.

Finally, the AIDS care community must accept some challenges to improve treatment for women with HIV disease. They must begin to look at women as individuals affected directly by AIDS, and not simply as "vectors" for infection. Researchers must examine and publicize quickly to the AIDS care community, as well as the medical establishment, their findings concerning the medical, social, and psychological manifestations of HIV disease in women. Counselors cannot wait for researchers to decide that women are worthy of study or to prove that women are affected by the epidemic, or for a "critical mass" of women to apply for services like group therapy; they must begin by offering low cost or free counseling services to women, demonstrating that women's concerns are considered and their lives are valued.

Denice J.D. Benson, MFCC is Acting Coordinator of Training and Women's Services at the UCSF AIDS Health Project. Catherine Maier, MA is Coordinator of the Women and Children's Services at the San Francisco AIDS Foundation.

References


Request for Submissions and Comments

We invite readers to send letters responding to articles published in FOCUS or dealing with current AIDS research and counseling issues. We also encourage readers to submit article proposals, including a summary of the idea and a detailed outline of the article. Send correspondence to: Editor, FOCUS: A Guide to AIDS Research and Counseling UCSF AIDS Health Project, Box 0884 San Francisco, CA 94143-0884
A Global View of Women and HIV

Helen Schietinger, RN, MFCC

Much of what is written about women and AIDS focuses on women’s capacity to transmit HIV to male sexual partners. This perspective, however, is at least partially based on misconceptions. First, the facts suggest that HIV is more efficiently transmitted from men to women than from women to men. Second, most women in the world have not been able to control their exposure to HIV, because male sexual partners have been unwilling to follow prevention guidelines. Research indicates that women will protect themselves if they can.

To develop appropriate prevention and care strategies, educators and researchers must focus, not on women as vectors of transmission to men and children, but on women themselves and the psychosocial impact of HIV. Data on the epidemiology of HIV disease among women and on the sociocultural and economic situations of women at risk forms a basis for this examination.

Global Epidemiology

The World Health Organization (WHO) estimates that, as of 1990, there are eight to 10 million people worldwide with HIV disease, 75 percent of whom were infected through sexual activity. Three million of those infected are women, 82 percent of whom live in Africa.1 The global pandemic is actually a series of regional epidemics, each with its own pattern and rate of spread. The patterns have changed significantly in the first decade of the pandemic, with the most dramatic increases in new infections occurring in developing countries.

In North America, Europe, parts of Latin America and the Caribbean, and Australia and New Zealand, the predominant modes of transmission are unprotected sex between men and I.V. drug use. However, there has been an increase in the prevalence of heterosexual transmission, particularly in Latin America and the Caribbean. This is especially true in urban populations with high rates of other sexually transmitted diseases, I.V. drug use, or both.

In sub-Saharan Africa, 80 percent of all adult HIV infection is transmitted heterosexually among equal numbers of men and women. In some cities, up to 30 percent of sexually active adults are infected. In rural areas, where the majority of the population of most African countries lives, HIV infection is increasing.

Transmission via transfusion of infected blood comprises about 10 percent of all HIV infection in Africa.2 Routine HIV antibody screening of blood for transfusions is being implemented more widely but remains a problem for many health systems with inadequate resources. Since women in Africa are more frequently transfused—due to a combination of blood loss during childbirth and anemia—they are at greater risk of HIV infection via transfusion.

While seroprevalence has been low in most of Asia, the Pacific, North Africa, and the Middle East, over the past few years there has been an alarming increase in HIV infection among specific populations in Asia and the Pacific. Research indicates this to be true particularly among populations with high rates of sexually transmitted diseases, I.V. drug use, or both.3 Studies of the HIV disease process have focused primarily on men, who over the past 10 years have made up the bulk of available subjects. Based on information collected from short-term studies of women and men in various parts of the world, however, WHO has found no difference between men and women in terms of HIV disease progression. In addition, researchers have not found that pregnancy accelerates the onset of AIDS among HIV-infected women.4

Women’s Socioeconomic Status and HIV Infection

The global epidemiology of HIV disease is determined not only by how HIV is transmitted but also by socioeconomic and cultural factors, which make women more vulnerable to infection initially, and to poor health once they are infected. Among these factors, the most significant is that many societies value men more than women. This inhibits the abilities of women to control sexual relationships, achieve economic parity, and obtain quality health care. For example, in Bangladesh, researchers found 14 percent of girls—compared to 5 percent of boys—to be malnourished. Families in India’s rural Punjab spend more than twice as much on medical care for male infants as they do on care for female infants.5

In many societies, a woman’s social value is related to her ability to have children. This cultural norm reflects complex sets of socioeconomic factors, such as the need to have large families to succeed in labor-intensive farming, the need to be cared for in old age, and the need for social approval. Under such conditions, it is not surprising that seropositive women become pregnant despite a 25 to 40 percent chance that their children will be HIV-infected and the probability that such children will be orphaned.

In most cultures, men are the sexual decision makers. Because of this, women generally are not able to stop their partners from having other sexual relationships or to insist that the couple use condoms during sexual intercourse.

Limited resources in the developing world, where most HIV-infected women live, impair health care systems and disproportionately affect women. As a result, the maternal mortality rate in the developing world is 12 times that of the industrialized world;6 the AIDS survival rate is six months, compared to two years in the industrialized world. Women have fewer options for economic survival than men, and this is reflected in the fact that women have lower incomes, lower literacy rates than men,7 and limited access to health care. Yet, in many societies, women are responsible for supporting not only themselves but their children.

Conclusion

Women in areas of high HIV prevalence are vulnerable to HIV infection because of poverty and because of their dependent sociocultural roles, particularly their lack of control over sexual relationships. Once infected, they frequently have poor access to health care and economic assistance. Successful HIV prevention programs must empower women economically and socially, so they can avoid infection, gain access to health care, and improve the quality of their lives.

Helen Schietinger, RN, MFCC was, through 1990, a Technical Officer at the World Health Organization Global Programme on AIDS, located in Geneva, Switzerland.

References

Recent Reports


A review of how HIV disease affects women, in terms of diagnosis, treatment and pregnancy, states that many health care providers fail to consider HIV-related conditions when diagnosing symptoms of disease in women, and that, although women present with gynecological symptoms as early signs of HIV infection, health care providers often do not perform gynecological examinations. It concludes that clinicians must become more familiar with gynecological examinations and that gynecologists must be trained to diagnose and treat HIV infection.

HIV infection may be a factor in a variety of conditions disproportionately or exclusively affecting women. For example, women have a higher incidence of urinary tract infections, breast cancer, and human papilloma virus (HPV), have special problems arising from gonorrhea and chlamydia infection, can die of complications related to pregnancy and of cancers of the reproductive tract, and seem to have more respiratory problems than men.

Women with HIV have more severe episodes of sexually transmitted diseases (STDs) than non-infected women. Women are also prone to developing chronic conditions, such as abdominal abscesses and pelvic inflammatory disease (PID), that do not respond to medication. Repeat episodes of STDs and other infections that are difficult to treat may indicate underlying problems and should lead clinicians to investigate more thoroughly.

Clinicians should regularly screen for a number of gynecological conditions—including syphilis, chlamydia, herpes, penicillin-resistant gonorrhea, vaginal warts, and HPV—among women at high risk of HIV infection. Vaginal infection is a sign of lowered resistance to disease and may indicate compromised immunity.

Psychiatric Health of HIV-Infected Women. Wilford Hall Medical Center, San Antonio, Texas, and Uniformed Services University of the Health Sciences, Bethesda, Maryland (General Hospital Psychiatry, January 1990).

A group of 20 HIV-infected women without AIDS showed an overall absence of major depressive disorder and drug dependence 14 months after they learned they were HIV-infected. The subjects, almost all of whom were active duty Air Force personnel, had discovered their HIV antibody status as part of a mandatory military screening program.

The women were educated, middle class, employed, and had been infected almost exclusively through heterosexual contact. Annual examinations since November 1987 consisted of psychiatric history, mental status examination, and ratings of depression, anxiety, alcoholism, and social support.

Researchers diagnosed 20 percent of the women with hypoactive (reduced) sexual desire disorder, 15 percent with adjustment disorders, 10 percent with mild organic mental disorders, and 20 percent with personality disorders or specific developmental disorders. None of the women had required psychiatric hospitalization since seroconversion, but 20 percent had sought outpatient psychiatric support. Two women reported suicidal ideation. No subjects reported suicidal gestures or attempts. Other studies of similar male populations show significantly higher rates of major depressive disorders, alcohol dependence, and suicidal ideation.

Most of the women experienced disruption of sexual activity. Several women who were sexually active never used condoms during intercourse, while 40 percent consistently used condoms during intercourse. There was no correlation between psychiatric diagnosis and the occurrence of unprotected sex. In addition, follow-up examination found no correlation between disease progression and psychiatric diagnosis.

Reproductive Decisions and HIV. State University of New York Health Science Center at Brooklyn (Obstetrics and Gynecology Clinics of North America, September 1990).

HIV-infected women and seronegative counterparts with similar demographic backgrounds become pregnant at similar rates, and, after counseling on the risk of HIV transmission to fetuses, at least half these women choose to continue their pregnancies. According to a review of the literature, a variety of factors—including psychological concerns, perceptions of risk, barriers to abortion, personal health, drug use, and religious, ethical, and cultural beliefs—influence seropositive women's decisions to have children.

Chief among psychological factors is denial: women may deny the implications infection has for pregnancy and the fetus. They may also perceive the psychological benefits of having children as outweighing the risks of bearing children who might die shortly after birth.

Religious and ethical beliefs may play a role in determining whether women will continue pregnancies. But, even when they choose abortion, women may face barriers in access to services, such as lack of financial resources, lack of child care during hospitalization, refusal of outpatient services to women on methadone maintenance, and discrimination among abortion providers against seropositive women.

The role of cultural influences is a strong one in the decision-making process. In certain cultures, a woman's role is strengthened by having children. In environments where unemployment is high and social status is low, women may find childbearing their most fulfilling role. Finally, male partners influence not only choices to continue or abort a pregnancy, but also contraceptive use, and may enforce their wishes through physical and emotional abuse.

Next Month

It has been clear since early in the epidemic that caregiving is a crucial element of the health care model for treating AIDS. Up to now, less attention has been paid to the issues of informal caregivers—families, friends, and partners—who offer emotional, practical, and spiritual support to people with HIV disease. In the January issue of FOCUS, Ken Pinhero, LCSW, Program Coordinator, and Cathy Cassel, LCSW, Program Psychotherapist, both at the AIDS Family Project of Operation Concern in San Francisco, define the psychosocial challenges for caregivers and present a group therapy model for approaching these issues.

Also in the January issue, Ian Barlow, MD, Psychiatric Consultant at the UCSF AIDS Health Project, examines the degree of appropriate emotional involvement between professional and volunteer caregivers and their clients.