

HIV Infection and AIDS

*Patricia J. Morokoff, Vickie M. Mays,
and Helen L. Coons*

In this chapter we provide an overview for the health practitioner of the psychosocial aspects of HIV infection and AIDS in women. We focus on prevention and treatment issues of special relevance to women. We begin with a brief epidemiological overview of relevant data and then present information on HIV transmission. We also discuss the provision of HIV and AIDS prevention services, including information about factors affecting women's decisions to obtain serotesting and issues in pre- and posttest counseling. Finally, we discuss the assessment of women's psychosocial needs and secondary prevention for women with HIV infection or AIDS.

Epidemiological Overview

Prevalence and Characteristics of Women With AIDS

In 1985, AIDS cases in women represented only 7% of the total number (Ellerbrock, Bush, Chamberland, & Oxtoby, 1991). By the year ending in June 1996, the proportion of AIDS cases in women had reached 19.5% (Centers for Disease Control and Prevention [CDC], 1996). For cases of HIV infection, reported by states with confidential HIV-infection reporting, women represent 24% of the cumulative total and 29% of the cases reported in the year ending June 1996 (CDC, 1996).

Women diagnosed with AIDS tend to be young women of color. A large percentage of women diagnosed with AIDS (84%) are between the ages of 15 and 44 (CDC, 1993d). More than half of American women with AIDS are classified by the CDC (1996) as Black (not Hispanic; 55%), whereas just under one quarter are White and one fifth are Hispanic. When one considers the rate per 100,000 population, Black women are 16.5 times more likely to be diagnosed with AIDS than White women and 2.4 times more likely than Hispanic women. Hispanic women are 6.8 times more likely to be diagnosed with AIDS than White women (CDC, 1994a). The CDC also classifies AIDS cases in the categories of Asian/Pacific Islander and American Indian/Alaska Native. Cases in these categories make up less than 1% of the total.

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The CDC classifies people with AIDS according to category. According to these data (CDC, 1996), the greatest percentage of women are classified as having been exposed through injection drug use (46%). The next most prevalent exposure category is heterosexual contact (38%). Of women infected through heterosexual contact, the most frequent transmission route is sex with an injecting drug user (IDU; 18% of the total). Thus, 64% of women with AIDS were exposed to HIV through injection drug use or having sex with an IDU.

Women are much more likely than men to be exposed to HIV through heterosexual contact. In contrast to the 38% figure cited earlier for women, only 4% of men are in the CDC's heterosexual-contact exposure category. If one looks only at individuals classified as exposed through heterosexual contact, women represent 66% of the total (CDC, 1996). A woman is at greater risk of infection from sex with an infected man than a man is from sex with an infected woman. The risk of transmission during unprotected sex with an infected man is believed to be 12 times greater than the risk to a man of having unprotected sex with an infected woman (Padian, Shiboski, & Jewell, 1990).

Sexual Orientation

Little data are available on the risk of female-to-female transmission (Kennedy, Scarlett, Duerr, & Chu, 1995). Although CDC data categorize only 0.8% of women with AIDS as lesbian (Chu, Buehler, Fleming, & Berkelman, 1990), subgroups of lesbians are likely to be at risk for HIV infection (Mays, Cochran, Pies, Chu, & Erhardt, 1996). These include lesbians who have unprotected sex with men or women at risk, lesbian IDUs who share needles or paraphernalia, lesbians who use unscreened semen for donor insemination, and the unprotected sharing of sex toys (Kennedy et al., 1995). In a study conducted by Magura, Kang, Shapiro, and O'Day (1993), 43% of a prison sample of women were found to be HIV-positive. Of these, 30% identified themselves as exclusively lesbian and another 23% identified themselves as bisexual.

Mortality

HIV infection and AIDS have become major contributors to premature loss of life in young adult women, most notably among young African Americans and Latinas. "Nationally, HIV infection was the fourth leading cause of death in 1993 among women 25-44 years of age" (CDC, 1995). Stratified by race, HIV infection was the leading cause of death for Black women in this age group in 1993 and the third leading cause of death among Hispanic women.

Sexual Networks

Although a woman may be exposed to HIV as a result of sharing drug equipment or sexual activity with an infected person, these behaviors pose

no such risk if the other person is not infected. A woman's risk is thus tied to the prevalence of HIV infection in members of her sexual network, defined as the set of her sexual partners and her partners' sexual partners. It may be difficult to determine the risk level associated with a woman's sexual network, especially because surveillance of HIV infection is not mandatory in all jurisdictions. As of June 30, 1996, 26 states had laws or regulations requiring confidential reporting by name of all individuals confirmed with HIV infection (CDC, 1996). Furthermore, there are many impediments, as discussed later, to widespread HIV diagnostic testing. Nevertheless, some idea of relative risk may be obtained from CDC information on AIDS cases in various localities. The higher the incidence of HIV and AIDS in a given locality, the greater the risk associated with failure to engage in appropriate preventive strategies. CDC guidelines allow health care institutions to take into account the HIV seroprevalence in the patient population in deciding whether to routinely offer HIV counseling and voluntary testing services (CDC, 1993b). Of course, even in areas with low rates of AIDS cases (e.g., North Dakota), there is some risk associated with unprotected sexual behaviors or sharing of drug injection equipment.

HIV Transmission

As can be seen from the routes of transmission for HIV infection, the most common sources of exposure to HIV are through injection drug use and sexual behavior with an infected person.

Risk Associated With Drug Injection Equipment

It is important for health care providers to understand changes in drug trends so they can understand women's risks for HIV infection. The four most commonly injected substances are heroin, cocaine, heroin and cocaine combined, and amphetamines. More IDUs have injected cocaine than have injected any other drug (Feucht, Stephens, & Sullivan, 1993).

Women can be exposed to HIV infection by sharing needles and other drug injection paraphernalia. Any equipment that comes in contact with blood, such as drug cookers used to melt heroin in water before use, cotton used to filter drugs, or water used to unclog needles, may transmit infection (Singer, 1991). Women may be especially vulnerable to infection as a result of their patterns of sharing drug injection equipment with a sex partner. The majority of women who inject drugs share drug injection equipment, and this tends to occur in a relational context. Women are more likely than men to have a partner who is an IDU (Feucht, Stephens, & Roman, 1990) and are more likely than men to have only one needle-sharing partner (Brown & Weissman, 1993), who is typically a sex partner. More women than men report sharing drug equipment with a sex partner (Stephens, Feucht, & Gibbs, 1993). Women report using drugs at home

more frequently than men (Stephens et al., 1993), again emphasizing the relational context of drug use for women. Women often use drug injection equipment after their male partner (Castro, Valdiserri, & Curran, 1992).

HIV transmission via injection drug use can be prevented if women do not inject drugs or if they clean drug injection equipment. Substance abuse treatment programs may not be readily available to women. Although there has been an increase in programs that accept women, availability is still limited for women who are Medicaid beneficiaries or for women with children. Even more limited are opportunities for substance abuse treatment to pregnant women (Kumpfer, 1991). Women and their partners can be taught to clean their own drug injection equipment with bleach. In some localities, syringe and needle exchange programs (NEPs) are available. As of September 1993, there were 37 active NEPs in the United States (CDC, 1993c). Studies evaluating these programs typically conclude that the NEP is effective in decreasing the rates of HIV drug risk behavior. A recent study of an NEP in San Francisco demonstrated that the program was rapidly accepted by male and female IDUs (Watters, Estilo, Clark, & Lorvick, 1994). It is important to recognize that there may be special barriers to women's use of NEPs. For example, child-care responsibilities may make it difficult for women to travel to the center to exchange syringes and needles.

Risk Associated With Sexual Behavior

Vaginal intercourse is the most common mode of heterosexual transmission of HIV infection worldwide. Research indicates that the co-occurrence of a sexually transmitted disease (STD) that produces genital ulcers is an additional risk factor for both the transmission and acquisition of HIV infection (Moss et al., 1991). Vaginal intercourse involving mucosal trauma further increases the risk of transmission. It is believed that anal intercourse is the riskiest form of heterosexual sex, probably because of mucosal trauma during insertion. Oral sex also is a possible route for infection, especially for the receptive partner when the insertive partner is infected and ejaculates.

One strategy for reducing the risk from sexual behavior is abstinence from sexual activities that could expose people to infectious bodily fluids, such as intercourse. This is the safest approach to preventing HIV infection. An alternative strategy is to begin using condoms during all insertive sexual activity. Condoms have been shown to be efficacious in preventing HIV infection and other STDs (Weller, 1993). It is important for health care providers to give women information on how to obtain and use condoms and how to be sexually assertive with respect to declining unwanted sex or initiating condom use. Women who are using oral contraceptives need to learn the importance of also using condoms to protect themselves from STDs.

However, there are significant barriers to the use of condoms that make it unlikely that providing information alone to women about con-

doms will increase their use. One barrier may be a monogamous relationship. It may be difficult to ask a steady sex partner to begin using condoms because of the implication that he is not trusted. Women who have multiple partners report a higher rate of condom use (Mosher & Pratt, 1993). A second barrier is that male condoms are a male-controlled method of protection. Because of this, women are in the position of negotiating with a male partner rather than being able to decide on their own when to use male condoms. In some couples (approximately one third according to Osmond et al., 1993), either condom use is never discussed or the male partner is the condom use decision maker. According to a study of condom use among Hispanic men and women (Mikawa et al., 1992), the use of condoms appeared to be a male prerogative rather than a female one, with men being much more likely than women to buy and initiate the use of condoms. If men are the decision makers concerning condom use, they typically decide not to use condoms. Only 12% of couples in which the male partner made condom decisions used condoms more than half the time compared with 32% of couples in which both partners made the decision and 49% of couples in which the woman made the decision herself (Osmond et al., 1993). Assertiveness concerning pregnancy and STD prevention has been found to be inversely related to a history of sexual abuse (Morokoff et al., in press).

A third strategy that could be used is adoption of the female condom. This disease prevention method is female controlled and thus potentially avoids some of the problems just identified. The female condom is a lightweight polyurethane pouch consisting of a soft, loose-fitting sheath and two flexible polyurethane rings. One of the rings is at the closed end of the pouch and is inserted into the vagina. The other ring remains outside the vagina after insertion. This product is marketed by Wisconsin Pharmacal as the Reality Condom. Research indicates that this product provides contraceptive efficacy in the same range as other barrier methods, especially when used consistently and correctly (Farr, Gabelnick, Sturgen, & Dorflinger, 1994; Trussell, Sturgen, Strickler, & Dominik, 1994). Because the female condom is obtrusive, it is apparent to a partner when it is used, and therefore its use may require negotiation with the partner.

From the perspective of female control, the best alternative, which is not currently available, would be a microbicide which could be used as a spray. Such a product could be used unobtrusively and would not require a partner's consent before use. Research is currently underway to develop such a product (Morokoff, Harlow, & Quina, 1995).

Social vulnerability: Race, gender, and poverty. In addition to examining barriers experienced by individual women in negotiating condom use with heterosexual partners, it is worthwhile looking at larger social issues that create conditions in which women have difficulty protecting themselves. The factors of poverty, racism, and gender inequality are fundamental social problems that foster risk taking and create conditions of risk for women both in the United States and worldwide (Population Council, 1994).

Ethnic minority and poor women. Although the rates and risk of HIV infection in ethnic minority women and poor women in inner cities is high, it is important to have accurate information about the nature of this risk. A national study that included a sample drawn from high-risk cities revealed that respondents were more likely to have had multiple sexual partners if they were more highly educated, were male, and were White or African American compared with Hispanic (Catania et al., 1992). Examination of data from women in the same sample revealed that 8% of White women reported multiple partners compared with 7% of Black women and 3% of Hispanic women (Grinstead, Faigeles, Binson, & Everley, 1993). Only two significant predictors of having a risky sexual partner were reported: income and gender. Individuals with lower incomes were more likely to report a risky partner as were women. It is thus increasingly evident that poor ethnic women are at higher risk, not because their own behaviors are riskier than that of others (i.e., they do not have more sex partners or use condoms less) but because their male partners are riskier (Hobfoll, Jackson, Lavin, Britton, & Shepherd, 1994).

Providing HIV and AIDS Prevention Services

The national health objectives for the year 2000 include increasing to at least 75% the proportion of primary care and mental health care providers who provide age-appropriate counseling on the prevention of HIV and other STDs; increasing the proportion of individuals with HIV infection who have been tested to 80%; and increasing to at least 50% the proportion of primary care clinics that screen, diagnose, treat, counsel, and provide (or refer for) partner notification services for HIV infection and bacterial STDs (Public Health Service, 1991).

The Context of Prevention Interventions

In what contexts should women receive messages concerning prevention of HIV transmission? It is important that information be available and counseling offered in any setting in which women are provided with health and mental health care. This includes (a) routine medical care checkups (e.g., in primary care or obstetrics-gynecology); (b) family planning clinics in conjunction with receiving contraception; (c) prenatal clinics; (d) STD clinics; (e) mental health clinics; and (f) substance abuse treatment facilities, including methadone maintenance clinics. It is recommended that hospitals and associated clinics encourage health care providers to routinely ask patients about their risks for HIV infection and to offer HIV counseling and voluntary testing services to patients at risk (CDC, 1993b). Other health care institutions, including drug treatment centers, mental health facilities, and private medical practitioners, are encouraged to consider offering these services. Furthermore, universal counseling and voluntary testing programs for pregnant women are recommended. Thus,

health care providers should ensure that all pregnant women are counseled and encouraged to be tested for HIV infection. Testing is especially important for pregnant women because administration of zidovudine (ZDV [also known as AZT]) early in pregnancy can substantially reduce the risk for perinatal HIV transmission (CDC, 1995). Because a growing group of younger and older women are at risk for HIV infection, prevention services should be offered whenever medical care is provided to women.

Primary care providers should be important sources of HIV prevention services to their patients. However, according to a survey of primary care physicians (CDC, 1994b), a substantial portion indicated they would not "usually" or "always" take sexual history information from a new patient. These results emphasize the lost opportunities to provide HIV risk counseling during encounters with patients. Furthermore, health care providers frequently do not assess sexual or drug risk behaviors. For example, only 49% of primary care physicians would usually or always ask about STDs, 31% about condom use, 27% about sexual orientation, and 22% about number of sex partners (CDC, 1994b). A barrier to assessment of such information was the physicians' concern (endorsed by 25% of the sample) that patients would be offended by questions about their sexual behaviors. For health care providers to feel more confident in providing risk assessment counseling, they need to be knowledgeable about HIV infection and its transmission (Gerber et al., 1993) as well as about sensitive strategies for assessing sexual and drug-related risks.

The CDC provides technical guidance on how counseling for risk assessment should be conducted (CDC, 1993b). It is emphasized that counseling must be client centered (i.e., tailored to the individual). It is specified that counseling be confidential, culturally competent, sensitive to issues of sexual identity, developmentally appropriate, and linguistically specific (i.e., presented in terms the client will understand).

Confidentiality. An important component to such assessment is a guarantee of confidentiality. This means that all information provided by the client will be kept private. This is especially important when patients are to be asked about sexual activity and drug use.

Cultural sensitivity. It is crucial to recognize that questions and information concerning transmission of disease are not received in a cultural vacuum. Individuals will interpret questions and information within the context of their cultural understanding of disease. For example, a study of traditional health beliefs among some African American women showed that most participants believed that there were other ways to acquire HIV infection besides sex and drugs (Flaskerud & Rush, 1989). Some medical practices may be seen as a threat to, or in conflict with, cultural or religious beliefs (Health Resources and Service Administration, 1993a, 1993b), and thus women may delay the use of prescribed medicines until they have become seriously ill. Health care providers may find it helpful to explore women's cultural beliefs during the clinical encounter.

Research has indicated that some African American women underes-

timate the prevalence of AIDS among African Americans (Mays & Cochran, 1995; Quinn, 1993). In addition, some African Americans and Puerto Ricans may be hesitant to participate in clinical trials or engage in a regimen of experimental drugs because of past encounters with federal and local public health officials that have left feelings of mistrust and neglect (Mays & Cochran, 1997; Health Resources Service Administration, 1993a, 1993b; Thomas & Quinn, 1991). Finally, as suggested by Mays and Cochran (1988), for poor ethnic minority women, HIV risk may be a less pressing threat than exposure to the elements, difficulty providing for dependent children, hunger, acute illness, trauma associated with physical or sexual assault, and other dangers.

Sensitivity to issues of sexual identity. As previously discussed, lesbian and bisexual women in some populations represent the majority of HIV infection cases (Magura et al., 1993). Furthermore, sex with bisexual men is a significant risk factor for HIV transmission in women. It is important that health counselors not presume that women are heterosexual, that their partners are heterosexual, or that heterosexuality confers greater risk for HIV infection in women. Health care providers should assess risk for HIV in lesbians or bisexual women in a manner similar to that of other women patients. Women who self-identify as lesbians may engage in sexual activity with men, suffer STDs, inject drugs, or engage in behaviors that may put them at risk for HIV infection. Although the biological mechanisms for female-to-female transmission are not known, for health providers with lesbian or bisexual patients it may be prudent to provide assessment and prevention counseling.

Developmental appropriateness. It also is crucial that risk assessment and risk reduction counseling be age appropriate. A particularly important but difficult group to reach is female adolescents, whose needs may be much different from those of women of other age groups. Girls and boys should be provided with sex education focusing on information about human sexuality, individual rights, and sexual responsibilities. It may, however, be difficult to reach those adolescents in most need of HIV prevention counseling, testing, and treatment services. Many at highest risk are school dropouts, who will not have access to school-based programs. For others without medical insurance or the ability to seek services without parental consent, accessing family planning clinics that have services may present a problem. Although adolescents are generally healthy, some do consult primary care or family practitioners for periodic health checkups. Health practitioners in these settings are encouraged to explore sexual concerns with these young women and to help them develop HIV prevention strategies, even if they are not currently sexually active.

Accuracy of information. Research indicates that the best information can be obtained by asking individuals to remember sexual behaviors with each partner individually rather than asking for a global estimate (Catania, Gibson, Chitwood, & Coates, 1990). It is also crucial to know the risk

status of each partner, including the gender of the partner and whether the partner has had multiple partners, has ever engaged in injection drug use, is bisexual, or has been diagnosed with HIV infection. Putting all this information together provides an estimate of the woman's overall level of HIV risk. It is also important to remember that many women may not know the truth of their partners' risk histories (Cochran & Mays, 1990; Mays & Cochran, 1993). Although many women may not know about a partner's risk behavior, others may know or suspect that their partner is not being monogamous or using drugs but not be ready to reveal or confront such information. Thus, health care providers may wish to discuss prevention strategies with women even in the face of no acknowledged risk.

HIV Counseling, Testing, and Referral for Women

The CDC (1994c) has identified several functions of HIV counseling. These include providing information on serostatus; providing prevention counseling to help initiate behavior change; providing referrals for additional prevention, medical care, and other services; and providing prevention services and referrals for sex and needle-sharing partners of HIV-infected individuals. Counseling and testing services offer an opportunity for health care providers to help women accurately understand their risk, to negotiate a relevant risk reduction plan, and to make appropriate referrals. It is crucial, however, that health care providers offer prevention counseling to all patients across the life span, paying particular attention to social class and ethnic group membership.

Most health care settings provide written materials (e.g., pamphlets) containing information on preventing HIV transmission. Research has indicated that this type of information alone rarely facilitates behavior change (e.g., Harlow, Quina, Morokoff, Rose, & Grimley, 1993). Therefore, to change sexual or drug use behavior, additional efforts are needed. These may include videotapes on prevention, individual counseling from a health care provider, or group sessions to discuss strategies for making changes in sexual and drug behaviors. Some research indicates that group sessions can be effective in helping women increase their frequency of protected sex. For example, Kelly et al. (1994) found that a three-session group was effective in increasing condom use among inner-city women from 26% to 56% of the time.

According to the CDC's standards and guidelines, the necessary components of HIV counseling, testing, and referral services include maintenance of confidentiality, risk assessment, prevention counseling, provision of test results, and provision of referrals (CDC, 1994c). Most HIV prevention counseling and testing for women is provided as an integrated part of health settings in which women receive care for their primary and reproductive health needs. A question faced by health care professionals, which is often determined by available resources, is whether primary care providers, clinic nurses, or social workers should provide services or

whether there should be a designated pretest–posttest counselor for these activities. Regardless of who performs these clinical interventions, it is important that the person is well trained not just in the biomedical aspects of transmission and risk reduction but also in the roles gender, culture, and social class play in women's abilities to initiate and sustain necessary behavior changes for risk reduction.

According to a national survey (CDC, 1993b), most physicians (66%) indicated that if HIV testing were appropriate for a patient, they would probably provide the test counseling themselves. However, various factors influenced physicians to refer patients for counseling and testing. These included a perception that counseling was too time-consuming (55%), a perception that information was insufficient to enable counseling (45%), and a preference for anonymous testing for their patients (42%).

Pretest counseling. According to CDC guidelines (CDC, 1993b, 1994c), HIV pretest counseling must include a personalized client risk assessment following the guidelines previously discussed. This assessment should lead to prevention counseling and, when appropriate, the development of a personalized plan for the client to reduce the risk of HIV infection and transmission. This plan should focus on barriers to safer behaviors and identify previous successes in making behavior changes. It is important that this plan be developed before test results are determined.

When appropriate, clients should be provided with information about the virus and how it is transmitted. The health counselor should discuss what the test results mean and indicate that there is a need to be retested after discontinuing high-risk behaviors. Anticipated reactions should be assessed and assistance provided in helping individuals to receive support from others.

During pretest counseling, it is important to discuss safer sex practices even if the woman indicates that she plans to become abstinent. It is still important to develop an HIV risk reduction plan in case she should become sexually active. In presenting safer sex practices, it is vital to consider and integrate the woman's religious and cultural practices, her sexual orientation, her individual sex habits, concerns she may have about changing her behavior with a particular partner, and the presence of coercion or physical abuse from that partner (Holman & McTague, 1995).

As discussed in the earlier section on prevention, it may be difficult for an individual woman to introduce the use of condoms to her partner. Discussing partner reactions, offering to counsel or present safer sex information to partners as well, and presenting women with information on alternatives that may provide some protection such as the use of the female condom or spermicidal agents is crucial to enhancing safer sex behaviors (Holman & McTague, 1995). Counselors need to be aware of the difficulty of providing individual options for a dyadic behavior. The more that men can be brought into the counseling process and made aware of their role and responsibilities for contributing to their partner's health, the greater the chance that dyadic options such as condom use will be adopted as a prevention strategy.

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Return for posttest counseling. Not everyone who receives HIV testing returns for posttest counseling. Research indicates that overall, only 63% of individuals who received testing returned for posttest counseling (CDC, 1993b). The lowest rates of return were recorded for adolescents, Blacks, and clients served in family planning and STD clinics (Valdiserri et al., 1993). These statistics may reflect difficulties in accessing the health care system for these subgroups. Overall, women were slightly less likely to return for HIV posttest counseling than men. CDC technical guidance indicates that HIV counseling programs should be active in addressing the problem of failure to return for HIV posttest counseling, determining whether specific barriers associated with the facility, such as long waiting times, deter clients. It is recommended that programs contact HIV-positive and high-risk HIV-negative clients who have not returned to learn their test results and who therefore have not received posttest counseling.

Posttest counseling. Posttest counseling, like pretest counseling, should be conducted by a provider who is trained in pre- and posttest counseling as well as gender- and culture-specific issues. In addition, whenever possible, posttest counseling should be conducted by the same provider who conducted the pretest counseling. For the woman who is HIV-negative, posttest counseling is another opportunity to provide and review information about HIV, safer sex practices, and the meaning of a negative test (Holman & McTague, 1995). For the woman who is HIV-positive, Holman and McTague reviewed the seven most important matters to cover during initial posttest counseling: (a) the test results; (b) the meaning of a positive test, review of HIV transmission, and its effects on the immune system; (c) the importance of maintenance of health, monitoring, early medical interventions, and antiviral therapies; (d) review and development of an individualized plan for safer sex and safer needle and drug paraphernalia practices; (e) issues of confidentiality of test results; (f) reproductive issues and pregnancy; and (g) identification of support persons. Additionally, at the time of posttest counseling it is important to provide referrals for whatever additional services might be necessary such as social, legal, psychological, and peer support services. Referrals or appointments for HIV antibody counseling and testing of partners and other family members should be given when appropriate. A follow-up visit should be scheduled within 1-2 weeks following a positive test result for support, continuity, medical treatment when appropriate, and psychosocial care. This visit should be sooner if requested by the client.

It is best to inform an individual of her HIV status at the start of the posttest counseling visit. However, for those who are HIV-positive, shock at the news of learning that she has a life-threatening illness may result in being unable to hear and recall information provided in the posttest counseling session. This can be due to the impact of trauma on short-term memory (Jaccard, Wilson, & Radecki, 1995). Therefore, verbal descriptions about HIV infection, treatment, and transmission should be supplemented with written and visual materials for some individuals. Women who are

less likely to read about the disease should be referred to additional services for follow-up.

When counseling an HIV-positive individual, the provider should go over information about the disease and strategies for reducing transmission. Sessions usually last 45–75 minutes when conducted by a dedicated HIV counselor. Much of the care women receive for HIV and AIDS is in the primary care setting, either hospital or community based. In these settings, it may be unrealistic for providers to offer the amount of time necessary for full counseling. Therefore, it is important to schedule a woman for a return visit soon or to refer her to specialized HIV services to follow up with additional information.

Health care providers must not underestimate the difficulty of making changes in women's sexual behaviors, however. Research indicates that the behavioral consequences of HIV counseling and testing are limited (Ickovics, Morrill, Beren, Walsh, & Rodin, 1994). Although the average level of sexual risk was lower for tested than nontested women, there was no change for either group from baseline to 3-month follow-up posttesting.

Some preliminary studies have examined the psychosocial sequelae of notification of HIV status. Data document the existence of depression in women blood donors who had been notified of their HIV-positive status (Cleary et al. 1993). Another study, however, showed that depression, anxiety, hostility, and other symptoms were just as high or higher in an HIV-negative group who had requested testing (Pergami et al., 1993). This result emphasizes that depression may be high among women who perceive themselves to be at risk for HIV infection, even if they turn out to be HIV-negative.

Barriers to HIV counseling and testing. Many barriers exist to sero-testing for women. A primary barrier is the reluctance of health care professionals to encourage testing despite the presence of relevant symptoms or risk factors. Physicians often encourage testing for groups that historically have been considered at high risk for HIV infection. In a national survey, 95% of primary care physicians indicated they would encourage gay men and IDUs to be tested. However, only 74% indicated they would encourage testing on the basis of an STD history, 57% on another drug or alcohol history, and only 40% would encourage testing of sexually active adolescents (CDC, 1993b).

A second barrier is that women may not want HIV testing for a variety of reasons, including the lack of perception of risk. Kalichman, Hunter, and Kelly (1992) found that minority women at risk perceived themselves to be less susceptible to HIV infection than nonminority women at risk. On the other hand, women may not want to know their HIV status for fear of having to tell others they are HIV-positive, leading to possible rejection from the family or other types of negative evaluation. Other factors that may inhibit women from seeking testing include fear of discrimination, effects on jobs, effects on children and ability to care for families, or fears about the implications of HIV and AIDS for health (Ethier, Ickovics, & Rodin, 1995). In a nationwide, population-based telephone survey of

more than 13,000 men and women, for women aged 21–34 who had had more than 10 partners in their life, only 38% had been tested for HIV (Berrios et al., 1993).

A third barrier is that women may have poor access to testing because of travel expenses or lack of child care, especially test sites and providers offering bilingual services.

Optimizing Health and Mental Health Outcomes in Women With HIV and AIDS

Health care providers can play a significant role in optimizing health and mental health outcomes of women who are HIV-positive or who have AIDS. The clinical and preliminary research literature suggest several strategies that may reduce morbidity as well as adverse psychosocial sequelae associated with HIV and AIDS in women.

Assessment of Psychosocial Stress, Symptoms, and Strengths Across the Disease Spectrum

It is important to assess the psychological and social service concerns of women as they progress along the disease spectrum. This evaluation must take into account the complex relationships between physiology and psychology. Women with HIV may be at greater risk for psychological and relational distress at specific times in the disease course (Coons, Spence, Walch, Harwell, & Striepe, 1995). The first significant stressor occurs at the time of HIV testing, when the individual may learn that she has a life-threatening disease subject to social stigma. Information on HIV status may precipitate depression, anxiety, or suicidal thoughts in some women. However, for other women, the diagnosis of HIV infection may lead them to take better care of themselves and take more control of their lives (e.g., by returning to work or school, stopping drug use, improving health habits).

Subsequent points of stress or anxiety include the development of HIV- and AIDS-related physical symptoms, hospitalizations for opportunistic infections, the diagnosis of opportunistic infections that signal a transition to AIDS, or a decline in daily functioning. As physical problems progress, social, psychological, and economic burdens may increase (Jaccard et al., 1995). It is important to remember that each woman interprets these markers according to her own set of meanings about their consequences. The perceived consequences of the disease will affect not only her own functioning but also the functioning of her family, partner, and children. Providers may find it useful to assess the impact of the disease on a woman's daily living and relationships. Providing information about the course and treatment of HIV infection and AIDS as well as its psychosocial impact will allow women to react on the basis of accurate knowledge rather than fears.

Responding to the Health, Mental Health, and Social Needs of Women With HIV and AIDS

Women coping with HIV and AIDS report a broad range of service needs for themselves as well as their family members (Coons et al., 1993). These concerns are likely to change throughout the course of the disease. Health care professionals can play a key role in referring women to appropriate hospital, community, and peer resources. These may include referral to specialists for medical evaluation and treatment; mental health providers; drug treatment programs; social workers or case managers to respond to housing and financial concerns; or legal aid workers to address custody, marital, property, or criminal issues. Clergy may be a valuable resource in providing support and addressing spiritual concerns. Participation in peer support groups for women living with HIV or AIDS that are sensitive to ethnic or cultural, sexual orientation, or religious concerns can also be encouraged.

Reducing Isolation and Increasing Social Support

Many women have little or no access through their own social networks to information about HIV or AIDS and therefore must rely on the medical setting for this knowledge. Many HIV-positive women may have never met another woman with HIV infection (Chung & McGraw, 1992). Disclosing HIV status, seeking support, and finding referrals for HIV-related problems often are more stressful when a person's social network is not very knowledgeable about HIV.

An important component of obtaining support is a willingness to disclose AIDS or HIV infection. One study of disclosure in women showed that rates were lowest for disclosure to extended family members, somewhat higher for immediate family members, and highest for lovers and friends. Spanish-speaking Latinas were the least likely to disclose their HIV-positive status (Simoni et al., 1995). Simoni et al. speculated that for these unacculturated Latina women, the cultural norms of *simpatía* and *familism* may have inhibited disclosure. Health care providers may find it useful to refer women who want to maintain closeness with their parents or other family members to counseling and supportive services that can help them to disclose their HIV status to their family.

Nearly two thirds of women of various ethnic or racial backgrounds in another study expressed a desire for information on how to disclose their HIV status to others (Coons et al., 1993). Furthermore, Simoni et al. (1995) found that women's reasons for not disclosing varied by target of disclosure. Nondisclosure to lovers and friends was attributed to a desire to avoid rejection or maintain privacy. Nondisclosure to parents was often attributed to a desire to protect the parent or concerns about stigmatization. It is clear that there are significant and varied concerns that prevent some women from telling family members and others of their illness and potentially gaining support. Women's perceptions of rejection or even

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physical abuse if others learn they are HIV-positive or have AIDS also may be realistic. These concerns underscore the need for change in societal attitudes to a more compassionate, less morally judgmental view of HIV and AIDS.

Some preliminary research has demonstrated that support groups for women with HIV or AIDS are helpful. Chung and McGraw (1992) found that a common problem identified by women was isolation. They found that women experienced shame and stigmatization because of their illness. Many believed that the only available support services were designed for gay men. It is important to reduce social isolation among women who have been diagnosed with HIV infection or AIDS. Health care providers can encourage patient participation in peer support groups by providing them with meeting times and contact information. Providing space or other resources at the hospital or community sites also can encourage participation.

Reducing High-Risk Behavior and Enhancing Self-Care

It is important for women with HIV infection to reduce high-risk behavior, including drug use and sexual behaviors, that put them at risk for additional STDs. However, research on the extent to which women modify risky behaviors after learning they are HIV-positive is lacking. For some women, the stress of being diagnosed with a chronic, life-threatening illness may be the precipitant for further risky behavior, especially if a woman tends to cope with stress through the use of drugs, alcohol, or sex. It thus is important for providers to assess drug use and sexual behaviors in women with HIV infection, to inform women about the potentially health-threatening effects of these behaviors, and to encourage training in stress reduction and healthful coping strategies.

It currently is unclear how drug or alcohol use in women with HIV infection affects immune functioning, viral activity, or disease survival, although research suggests adverse effects on these outcomes (Peterson et al., 1993). Furthermore, repeat exposure to HIV infection may lead to co-infection with a distinct HIV strain, a phenomenon that may occur more frequently than previously thought (Hu et al., 1996). Therefore, it is important to help women abstain from both drug use and sexual behaviors that put them at risk of exposure to another strain of the HIV, increased viral load (which could occur through infection by someone in a more advanced stage of HIV disease; Cohn, 1993), or another STD and to prevent the infection of others.

Health professionals can play a significant role in secondary prevention of adverse psychosocial and disease sequelae by providing appropriate counseling, referrals, and encouragement to abstain from drugs and increase safer sex behaviors. These activities, as well as improved nutrition, social support, and healthful coping strategies such as meditation or relaxation may also help women to feel they have increased control over their own health and well-being.

Identifying Women at Risk

The majority of women living with HIV or AIDS demonstrate a high degree of resilience. Many women with HIV infection or AIDS care for dependent children as well as other relatives. They may be working or attending school or participating in a drug recovery program. In addition, they are often coping with the stresses associated with poverty.

However, some women are at risk for more rapid progression of HIV infection toward AIDS. As discussed, research indicates that women who continue to engage in risky behaviors may be at greater risk for a faster progression toward AIDS. Correlates of these risky behaviors include a history of sexual abuse and physical abuse (Harlow et al., 1993). Women who are homeless or those with severe mental illness requiring hospitalization are at increased risk. It has been reported that 6.4% of hospitalized homeless mentally ill patients in New York City (1 in 16) were found to be HIV-positive (Empfield et al., 1993), as were 5.5% of predominantly domiciled patients admitted to two public psychiatric hospitals in New York City (Cournos et al., 1991). Women who are at risk require increased contact with support resources, including medical and mental health practitioners as well as social service and community-based programs. In addition, women who are caring for infected partners or other family members as well as themselves are under increased stress, which puts them at risk for a more rapid disease progression.

Conclusion

Many health care practitioners have learned that care and prevention are two sides of the same coin (Coates, 1994). Prevention of HIV and AIDS requires that HIV and AIDS assessment and intervention prevention services be offered whenever medical services are provided to women. Because there are significant barriers to receiving such services for women, it is important that the way in which services are offered be tailored to meet women's needs.

It is useful to remember that fighting HIV is as much about the social conditions that allow the disease to spread as the biological mechanisms that govern its progression. If researchers are to be successful in the prevention of HIV infection and AIDS, it is crucial that effective prevention, intervention, and treatment strategies are identified that are sensitive to the conditions of women's lives. Such issues range from women's reproductive desires in the face of HIV infection to the possibility that partner notification procedures may result in physical violence. It will be challenging for health care providers to structure care that integrates not only medical but psychological, relational, and social services needs for women at risk for HIV infection, women who are HIV-positive, and those living with AIDS. In providing HIV prevention services, health care providers must remember that women are diverse in their needs with respect to issues such as age, sexual orientation, and ethnicity.

It also is crucial that greater resources be invested in developing prevention methods that women can control. Because the only HIV prevention strategy for sexually active women is the use of condoms, women may not have direct control over their own health protection. Men should also be the target of behavior modification programs so that male norms for condom use are changed.

Health care providers play a crucial role in secondary prevention as well. Health and mental health prevention efforts must continue with women who have already been diagnosed with HIV infection. A growing body of evidence supports the interconnection of stress to immune functioning, emphasizing the need to reduce stress in women's lives associated with poverty and abusive living conditions, as well as the need to teach women healthful coping strategies. Such efforts will have long-lasting effects in promoting the physical as well as emotional well-being of women and their families.

In every phase of intervention, from primary prevention to provision of services to women with AIDS, significant barriers exist to the realization of women's health goals. It is the challenge of health care providers to work toward the elimination of these barriers so that the full goal of prevention of HIV and AIDS in women may be achieved.

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