CROSS-CUTTING ISSUES

Women and AIDS

Introduction

In 1983, the Assistant Secretary for Health appointed a Public Health Service Task Force on Women's Health Issues. The charge to the Task Force was to identify those issues related to the health of women that were important in our society, and to prepare a blueprint for meshing them with the priorities of the PHS. The Task Force report, published in the winter of 1985, provided a clear picture of the issues that were critical at that time. However, many of what were then the most compelling concerns of women have since been eclipsed by a new threat to public health, namely AIDS.

While certain health issues and concerns are unique to AIDS, many of the factors identified by the Task Force as affecting women's health are pertinent to women with AIDS, and have an important bearing on how successfully women at risk for HIV infection are identified and are able to seek and receive treatment. These include:

- cultural/social values and attitudes;
- economic status;
- labor force participation;
- family, household structure, and social support systems; and,
- interactions with the health care system.

It has long been recognized that these factors can exert a negative impact on the overall status of a woman's health. AIDS and the risk of HIV infection compound that effect. Concerns about HIV infection also intermingle with a woman's roles as spouse or sexual partner, mother, family provider, health care provider, and worker. In many cases, the women most affected by HIV are economically disadvantaged and/or IV drug abusers.

Although the number of women with AIDS is relatively small in relation to the total number of cases (fewer than 6,000 of the more than 74,000 cases reported by late September 1988 were diagnosed in women), the rate of increase in women is alarming. Between January and September 1988, the proportion of AIDS cases occurring in women was 10 percent; prior to 1988, the proportion was about 7 percent. It is estimated that between 1 million and 1.5 million Americans are now infected with HIV; approximately 100,000 of these are thought to be women of child-bearing age.

Women are most likely to become infected with HIV through direct intravenous (IV) drug use (more than half of the women with AIDS have a history of drug abuse) or through heterosexual contact (about 30 percent have contracted AIDS through sexual contact with men who are infected--IV drug abusers, bisexual men, or men with hemophilia). Women who engage in prostitution are particularly at risk. A smaller but significant group of women who are at risk for HIV infection are those : 1) with diseases that require therapy with blood or blood products (Cooley's anemias, sickle cell anemia, neurangioedema, clotting disorders, thrombocytopenia, etc.), or 2) who undergo surgery that requires transfusion.

The spread of AIDS from women to their fetuses is also a major concern. By mid-September 1988, more than 1,100 cases of AIDS had been reported in children. It is estimated that, by 1991, the number of infants and children infected with HIV will reach 10,000 to 20,000. (The vast majority --77 percent--of children with AIDS have come from families where one or both parents were IV drug abusers.) The predominant paths of HIV transmission from mother to child are not understood. The effect of pregnancy on the health of the infected mother is uncertain, as are the effects of the infection on the outcome of pregnancy.

Although the issues, goals, and recommendations developed at the PHS meeting in Charlottesville are important for women, several are particularly relevant. We have singled those out in order to formulate a current agenda for the PHS on the subject of women's health as it relates to AIDS.

Epidemiology and Surveillance

Most of the issues identified by the workgroup on epidemiology and surveillance are geared to the general population. However, several key concerns pertain more specifically to heterosexual transmission and the special needs of minorities and women. These are:

- To ensure completeness of surveillance data and the accuracy of the surveillance definition, conducting supplemental studies focusing on specific groups, including women;

- To determine current incidence and prevalence, monitoring trends of HIV infection in the heterosexual population, and paying special attention to specific subgroups, including women;
- To characterize and establish the distribution of risk behaviors, including IV drug abuse and sexual behaviors;
- To establish rates and determinants of HIV transmission through various modes, including type of sexual contact, IV drug use, mother-to-newborn transmission, occupational exposure to blood, and receipt of infected blood or blood products;
- To expand knowledge of the natural history of HIV infection in various populations; and,
- To stratify projection data based on such factors as sex, race, and ethnicity.

Prevention: Information, Education, and Behavior Change

For at least the next several years, the most effective mechanism for significantly reducing the spread of HIV infection will be education. Because the numbers of women at risk for HIV infection are rapidly increasing, education must be targeted at risk reduction in women, particularly women whose behaviors place them at high risk for AIDS. Educational efforts must also be aimed at the health professionals who treat individuals infected with HIV.

Since there is such diversity among the groups of women at risk for HIV infection, education and prevention activities will need to be directed to specific subgroups (e.g., adolescents, minorities, pregnant women, health care workers, IV drug abusers, etc.). AIDS health education campaigns, targeted to women through the mass media, should emphasize individual responsibility and behavior. They should also address the social, political, economic, and environmental factors that influence the behavior of women.

Clinical Manifestations and Pathogenesis

Much remains to be learned about the natural history of HIV infection and opportunistic infections. Issues that need further study include the characterization of HIV infection in women, the transmission of HIV from mother to infant, the effects of HIV infection on pregnancy, and vice versa, the possible relationship between certain sexually transmitted diseases and the heterosexual transmission of HIV, and the possible risks to pregnant health care workers caused by exposure to opportunistic infections in HIV-infected patients.

Therapeutics and Vaccines

Development of vaccines and therapeutic agents for HIV infections relies on information obtained during clinical trials. However, for numerous ethical and legal reasons (such as the potential effect of experimental agents on reproduction or development), women and children are often not included in clinical trials. While it is important to take steps to protect the well-being of women and children, it is equally important to structure clinical trials so that all categories of patients, including women and children, have an opportunity to participate.

The prevention of infection among persons at high risk of HIV infection is another important problem. Such individuals include children of infected mothers, victims of rape, and health care personnel and laboratory workers accidentally exposed to HIV. It is important to identify and test drugs that can prevent infection among persons at high risk or accidentally exposed to HIV.

Blood and Blood Products

A number of the issues associated with the transmission of AIDS in blood and blood products are specifically related to women. These include: transfusion-associated AIDS, HIV transmission via donated tissue, women as sexual partners/spouses of hemophiliacs and blood transfusion recipients, and worker safety.

Transfusion-associated AIDS, which represents only 2 percent of AIDS cases in men, accounts for 11 percent of the cases among women. Inasmuch as women choose to undergo elective surgery more often than do men, information on the risks of infection by HIV from blood transfusion should be available and clearly explained to all potential blood recipients and their health care providers. Similar information should be available for women undergoing tissue or organ transplantation or artificial insemination.

As of late September 1988, 701 adults with hemophilia--approximately 5 percent of the population of HIV-infected hemophiliacs--had developed

AIDS. The sexual partners of 28 of these patients had also developed the disease.

Another aspect of hemophilia-related AIDS, though less well known, is the impact of discrimination on the lives of hemophilia patients and their families. Fear of discrimination has led patients and their families to avoid HIV testing.

Educational materials should be developed and provided for women regarding the use of condoms and other practices to reduce the risk of HIV infection from a sexual partner. Also, counseling for hemophilia patients regarding possible HIV infection should involve spouses and family members.

The recognized occurrence of HIV infection in health care workers, laboratory personnel, and workers in the blood banking and plasma industry, although infrequent, has led to a need to examine biosafety in these areas. Since 97 percent of nurses, 86 percent of health aides, and 71 percent of health technicians are women, worksite AIDS education and prevention efforts in the health care setting should be sensitive to their particular needs.

Intravenous Drug Abuse

As of late September 1988, the cumulative number of AIDS cases in female IV drug abusers was more than 3,100--52 percent of all the AIDS cases reported in women. Moreover, heterosexual and perinatal transmission of HIV are largely associated with IV drug abuse.

Significantly, the number of IV drug abuse associated AIDS cases is on the rise. From January to late September 1988, 29 percent of adults with AIDS had a history of IV drug abuse, compared with 26 percent previously. The nationally recognized problem of increased IV drug use among teenagers is also a serious consideration in the heterosexual transmission of HIV infection. Because of the large number of women (and infants) becoming infected with HIV as a direct result of drug abuse, any recommendations for treatment programs or for information/education programs for drug abusers must be targeted to women.

It is especially important to integrate drug abuse treatment services with other health and social services that could contribute to rehabilitation. In addition, it is of critical importance to consider the integration of drug abuse treatment services with child care and other primary health care services, such as family planning, that a woman might require.

Research to improve the effectiveness of drug abuse treatment and recruitment and retention for treatment must be tailored to women, and must be sensitive to racial and ethnic needs. In addition, risk-reduction and prevention strategies must target women who are drug abusers, the sexual partners of drug abusers, and prostitutes.

While the relationship between IV drug abuse and AIDS is commonly recognized, the role that the use of alcohol and other drugs may have on rendering individuals more vulnerable to AIDS due to changes in the immune system and changes in risk-taking behavior is less well understood, but obviously need to be addressed.

Neuroscience and Behavior

HIV infection can affect both maternal behavior and infant development. However, there is little information on the effect of maternal behavior (as influenced either by HIV infection or by drug abuse) on the neurological, cognitive, affective, and behavioral development of infants. There is clearly a need to develop such information.

Patent Care/Health Care Needs

Few health care services are targeted to women with AIDS and their families. Those that do exist are presently not well coordinated to provide a system of comprehensive care. There is a pressing need to provide for women a wide range of family-centered prevention and treatment services. These should be mainstreamed into existing community health care centers such as maternal and child health centers, and should be sensitive to the special needs of certain groups of women, including minorities, abused women, runaways, homeless women, adolescents, IV drug abusers, and women caring for family or friends with AIDS.

A woman's access to HIV-related health care can be complicated by problems arising from her economic status, lack of adequate insurance, geographic location, availability of transportation and/or child care, and fear of discrimination. In some situations, language and ethnic or cultural beliefs may also be barriers to care. These barriers need to be considered in the development of comprehensive care programs.