AIDS and HIV Infection

BACKGROUND

GLOSSARY

AIDS
Acquired immune deficiency syndrome. A person is considered to have AIDS if in addition to HIV infection, s/he has one or more of 29 opportunistic infections or a CD4 cell count (a measure of cells important to the immune system) of 200 or fewer per cubic centimeter (cc) of blood.

Antiretroviral
An agent (e.g., AZT, d4T) used to suppress the activity or replication of retroviruses such as HIV.

ARV drugs
Antiretroviral drugs administered to HIV/AIDS *patients.*

HIV
Human immunodeficiency virus, a retrovirus that causes the body's immune system to deteriorate.

MAP
Michigan Abstinence Partnership. Promotes abstinence from sexual activity and tobacco/alcohol/drug use among youths aged 9 and older.

Opportunistic infection
A serious and unusual disease, e.g., rare type of cancer or pneumonia, that is virtually absent among people with a healthy immune system.

PLWA
Person (people) living with AIDS.

PLWH/A
Person (people) living with HIV or AIDS.

Retrovirus
A virus that stores its genetic information on a single-stranded RNA molecule instead of the usual double-stranded DNA. HIV is a retrovirus.

Viatical life-insurance settlement
An arrangement whereby a person sells his/her life insurance policy for cash; the buyer pays all future premiums and receives all benefits when the seller dies.

The human immunodeficiency virus (HIV) deteriorates the body's immune system. Most people with HIV look and feel healthy for many years but can transmit the virus to others. Previously, most developed Acquired Immune Deficiency Syndrome (AIDS), the most serious form and final stage of HIV infection. However, due to advances in therapeutic regimens (see below), more are remaining free of AIDS longer (but the effect's duration is unknown). AIDS is the clinical definition of illnesses associated with HIV; a person is considered to have AIDS if s/he has one or more of 29 opportunistic infections (serious and unusual diseases, such as rare types of cancer and pneumonia, that are virtually absent among people with a healthy immune system) or a CD4 cell count (a measure of cells important to the immune system) of 200 or fewer cells per cc of blood.

HIV is *communicable* (capable of being transmitted) and *chronic* (of long duration or slow progression). No vaccines to prevent HIV infection currently are approved for use, but some are under development. Medical treatment is available, but there is no cure for HIV or AIDS.

- Worldwide, the World Health Organization estimates that approximately 31 million adults and children are living with HIV infection; by the year 2000, if the current transmission rate holds, the figure will be 40 million. In 1997 more than 2 million people died of AIDS, and an estimated 16,000 new infections occurred daily. More than 90 percent of people with HIV live in the developing world.
- In the United States, an estimated 650,000–900,000 people are believed to be infected with HIV (December 1996), and a reported 232,820 people are living with AIDS (July 1997).

Michigan Facts

The following information is based on 1996 data, unless otherwise specified. Trends are derived from 1991–96 data.

- An estimated 8,500 to 11,500 Michigan residents are HIV positive (January 1998); of these, documented cases include 3,730 persons living with AIDS (PLWA) and 4,049 people with HIV that has not yet developed into AIDS.
- Michigan ranks 8th among states and territories in population, 17th in AIDS cases (1981–97), and 33d in cases per 100,000 population.
- From 1981 to 1998, 9,228 AIDS cases were reported in Michigan; 5,498 have died.

- About 80 percent of people with HIV/AIDS are men.
- AIDS cases among females are increasing faster than among males.
- Heterosexual transmission is increasing significantly (12 percent of AIDS cases in 1997), with women accounting for two-thirds of heterosexually acquired infections.
- Seventy percent of Michiganians with HIV/AIDS reside in Wayne, Oakland, and Macomb counties, which are home to 42 percent of the state's population.
- African-Americans account for nearly 60 percent of total infected persons, while making up just 14 percent of the population; AIDS cases are increasing faster among African-Americans than Caucasians.
- There were 36 percent fewer deaths in 1996 than in 1995; this mirrors the national trend.
- AIDS is the second leading cause of death among young (aged 25–44) African-American males (1996).
- AIDS is being diagnosed at a higher rate among people aged 40 and older than among people who are younger.

The Michigan Department of Community Health (MDCH) publishes detailed HIV/AIDS statistics quarterly.

Transmission

HIV enters the bloodstream through open cuts, sores, or breaks in the skin, direct injection, and mucous membranes. Only blood, semen, vaginal secretions, and breast milk have been implicated as HIV transmitters. In the United States, HIV is most commonly spread through sexual contact (vaginal, anal, or oral) and sharing dirty needles during illegal intravenous drug use. Babies born to untreated HIV-positive women are infected 20–25 percent of the time, but the incidence is greatly reduced when pregnant women adhere to specific therapies. Transmission from HIV-positive blood transfusions is virtually nonexistent in the United States today due to blood screening.

Although 75 percent of the world's AIDS incidence has been traced to heterosexual transmission, for the majority of U.S. persons living with HIV or AIDS (PLWH/A) transmission is traced to men having sex with men. In Michigan, behaviors listed in the exhibit account for the specified percentages of HIV and AIDS as of January 1, 1997.

Percentage of Known Transmission Behaviors among Michigan Residents with HIV or AIDS

Transmission Behavior	*Percentage among* PLWH/A
Male-to-male sex	51%
Injecting drug use (IDU)	26
Heterosexual	13
Male-to-male sex + IDU	6
Blood products	2
Perinatal	2

SOURCE: Michigan Department of Community Health.
NOTE: Total number of PLWH/A *with a known risk factor (transmission factor) is 6,540.*

Prevention

Currently, avoiding certain behavior (or, put another way, engaging in safe behavior) is the only way to prevent new HIV infection; there is no vaccine. Many prevention programs attempt to elicit safe behavior; examples are counseling, needle-exchange programs, education, peer training, HIV testing (because counseling accompanies it), health education and risk reduction, and media campaigns.

In 1994 the federal Centers for Disease Control and Prevention, which is the agency principally responsible for supporting HIV prevention efforts nationwide, required states to begin implementing community-based HIV prevention planning as a condition for federal funding; Michigan has eight regional and one statewide community planning groups, and their primary purpose is to determine the at-risk populations' needs and advise the MDCH about appropriate prevention measures. The regional planning groups include local health officers, PLWH/A, service providers, public health professionals, behav-

ioral and social scientists, evaluators, and health planners. In FY 1998–99 the State of Michigan has budgeted roughly $3 million for HIV-prevention efforts.

HIV Testing

The presence of HIV in one's body is determined by a test that identifies HIV *antibodies* (protein substances developed in response to and interacting with the virus). Until recently, testing occurred only through blood samples taken at roughly 450 sites in Michigan—local health departments, hospitals, or other qualified agencies (licensed physicians also may run tests); test results are available in about two weeks. Only about 65–75 percent of people who are tested in this way return to learn the results. In 1997 more than 65,000 state residents received such testing and counseling (required under state law before testing and after results are disclosed), at a cost of approximately $4 million (federal and state).

The arrival of other testing options in the state in 1997 could increase the number of people being tested and/or the number who know their HIV status. Home test kits, which cost approximately $40, allow people to prick a finger, put blood drops on a card, mail it to a lab, and telephone the lab in one week for the results. People with positive results are counseled by phone and referred to local HIV/AIDS care agencies. An alternative to blood tests is a product called OraSure, which draws HIV antibodies to a special collection pad placed between the lower cheek and gum for two minutes; the test is administered (with counseling) in a clinic or physician's office and sent for analysis to a laboratory that reports the results back to the physician/clinic in about three days.

Treatment

In 1996, for the first time in the epidemic, the number of Americans with AIDS declined, reflecting advances in treatment and successful HIV prevention and education. Treatment slows the progression from HIV to AIDS, which historically averaged ten years. Currently, the most promising treatment for HIV/AIDS is triple therapy—combinations of three antiretroviral (ARV) drugs, including a *protease* (a protein-splitting enzyme) inhibitor. These therapies cost $1,000 to $1,500 a month and require a rigorous regimen and high patient adherence (15–20 tablets daily, with periods of fasting). Pharmaceutical companies justify the prices, reporting an average of 12 years and up to $359 million for a drug to get from laboratory to pharmacy. Although the per patient cost is high, at least two studies show that by reducing the necessity for hospitalization and other expensive services, such therapies lower the overall PLWA treatment costs.

Low-income PLWH/A without adequate health insurance have access to drug therapy through AIDS drug-assistance programs that are funded with federal money (and sometimes, although not currently in Michigan, additional state money) and administered by the state. The federal funds are made available through the Ryan White CARE Act (Title II), passed by Congress in 1990, which also directed that states establish HIV care consortia—bodies that determine the needs of PLWH/A and their families and allocate the federal (and state) resources to address the needs. In Michigan, there are eight regional, one statewide, and one prison consortia. The consortia—which consist primarily of PLWH/A and representatives of service planners and providers in the region—fund case-management/care-coordination services, mental health services, substance abuse treatment, emergency financial assistance, outpatient primary care, transportation, buddy-companion services, home health care, support groups, and food-delivery programs, as well as other support services. (This is an example of devolution; that is, responsibility for decision-making has devolved—been delegated—from the federal government to the states and local communities.)

Annual state spending for HIV/AIDS-related care is approximately $7.6 million, some of which is required as a condition of receiving federal funds.

State HIV/AIDS-Related Laws

Michigan has a substantial body of law pertaining to HIV/AIDS; the major provisions are summarized here.

- HIV infection is a serious communicable infection that must be reported to the MDCH.
- Public schools must teach the principal modes by which dangerous communicable diseases (including HIV and AIDS) are spread and the best methods for preventing them. Abstinence from sex as a responsible method and as a positive lifestyle for unmarried young people must be included; school boards must approve curriculum changes.
- HIV testing (both confidential and anonymous) through local health departments is free to Michigan residents and nonresident college students; pre- and post-test counseling is mandated.
- With a few specified exceptions, written informed consent must be obtained before administering an HIV antibody test.
- Provisions to ensure patient confidentiality are specified (e.g., people with HIV may omit their name and other identifiers from reporting papers; local health departments are prohibited from maintaining a roster with names of people with HIV) and exceptions noted (e.g., to prevent further HIV transmission).
- Marriage-license applicants must be counseled about sexually transmitted diseases and HIV infection and offered HIV testing; if either applicant tests HIV positive, both must be informed.
- At their first prenatal examination, pregnant women must be counseled and tested for HIV, hepatitis, and venereal diseases, *unless* they refuse or such tests are medically inadvisable.
- Sex- and/or needle-sharing partners of HIV-infected people must be contacted and counseled; confidential partner-notification programs are operated by local health departments.
- Upon court order, people arrested and charged with certain sex crimes must submit to testing and examination for HIV/AIDS and other sexually transmitted diseases; positive results must be reported to the defendant, victim, MDCH, local health department, and court.
- Persons with HIV are prohibited from donating blood.
- Engaging in sexual penetration without informing the other person of one's positive HIV status is a felony.
- MDCH and local health department representatives may petition the court for specified actions if a person with HIV/AIDS engages in behavior identified as a "health threat to others" (e.g., continued high-risk sexual behavior).
- Donated blood, tissues, organs, and other specimens must be tested for HIV antibodies prior to transfusion/transplantation, unless the test cannot be performed during the time when the specimens are viable and the potential recipient is so notified; sperm donors also must be tested.
- If exposed to an emergency patient's blood, body fluids, or airborne agent, police officers, fire fighters, and licensed health professionals may request (in writing) information from the treating health facility regarding the patient's HIV status; confidentiality requirements apply.
- Police officers, fire fighters, corrections officers, and county and court employees who have undergone training in avoiding blood-borne disease transmission may request that a prisoner be tested for HIV if the employee was exposed to the prisoner's blood, body fluids, or airborne agent; confidentiality requirements apply.
- Incoming prisoners at state-run corrections facilities must be tested for HIV antibodies; prisoners who are HIV positive and engage in risky behavior while incarcerated must be segregated.
- Physicians who know that a deceased patient had an infectious condition (including HIV) must advise the mortician of appropriate infection control precautions.

Civil Rights of PLW H/A

The Americans with Disabilities Act of 1990 (ADA) protects 43 million Americans who have physical or mental disabilities, including AIDS and HIV, by providing them with legal recourse when they experience discrimination. The ADA, which has nearly the same provisions as Michigan's older Handicappers' Civil Rights Act, forbids discrimination in employment,

government-provided services, public transportation, and public accommodations. Two other protective measures are the federal Fair Housing Amendments Act (prohibiting disability discrimination in housing) and the Rehabilitation Act, which applies only to federally funded entities and executive agencies. The future of the ADA's protections for PLWH/A is under question, however; the U.S. Supreme Court currently is deliberating it first case directly involving HIV or AIDS. In question is whether asymptomatic HIV meets the definition of a disability under the ADA. A ruling is expected in summer 1998.

DISCUSSION

Prevention

Measuring either behavior change or the number of HIV infections prevented by such change is difficult because of the personal nature of HIV transmission and biased self-reporting. Battles among policymakers, health authorities, and the public regarding HIV-prevention programs are common because of differing values, misunderstandings about HIV and AIDS, and distrust.

Sexual Abstinence versus Safer Sex

Some people advocate abstinence-only education in schools while others promote abstinence-based education plus safer-sex education (e.g., effective condom use). The federal government recently offered states sizable grants for abstinence-only programs, and Michigan was awarded $1.9 million to expand the Michigan Abstinence Partnership (MAP), which promotes abstinence among youth aged 9 and older from tobacco, alcohol, and other drugs as well as from sexual activity. As evidence of the success of abstinence-only education, MAP supporters point to Michigan's significant drop in its teen pregnancy rate since the MAP began in 1993. (In 1992, there were 93 pregnancies among every 1,000 females aged 15–19; in 1996, the rate was 77/1,000, the lowest since such reporting started in Michigan, in 1980.)

Opponents of abstinence-only education argue that Michigan's declining teen pregnancy rate could be due to factors other than the MAP and that it is based on assumptions that are inconsistent with the behavior of a majority of youth; they contend that teens are engaging in sex and, to prevent pregnancy as well as sexually transmitted diseases, those who do should be educated about how to protect themselves. Michigan's 1997 Youth Risk Behavior Survey indicates that 49 percent of Michigan public high school students have had sexual intercourse (9th graders—32 percent, 10th graders—46 percent, 11th graders—58 percent, 12th graders—65 percent); of these, half reported having had only one sexual partner, and 16 percent reported having four or more. Supporters of abstinence-only education fear that teaching students how to engage in safer sex promotes sexual activity; opponents point to a recent study showing that New York youths increased condom use but not sexual activity after being educated about condom use.

Syringe and Needle-Exchange Programs

Since intravenous drug users make up a sizable proportion of the PLWH/A population, prevention among this group is vitally important in slowing HIV transmission. Syringe/needle-exchange programs are proven successful in reducing the risky behavior (sharing dirty needles and syringes) among intravenous drug users. However, such programs rarely are supported with public funding because the risky behavior involves illegal drug use. More than 100 syringe/needle programs are believed to exist nationwide, including a demonstration site in Detroit, but they operate with private funding. In support of public funding for those programs, advocates point to the programs' success; opponents argue that the programs, by providing drug paraphernalia, are at the very least evincing a benign view of illegal and destructive behavior if not actually promoting it.

HIV Testing, Reporting, and Patient Confidentiality

Testing

The new testing options, including home test kits and clinical oral tests, can greatly increase the number of people know their HIV status. Many health experts welcome the new options because they think more people will be tested, but others warn that further misunderstanding about HIV and increased risky

behavior could occur. For example, Michigan requires pre- and post-test professional counseling, but people testing themselves at home will not receive prevention information as they would at a clinic. If a home-tester's result is negative, s/he may not learn how to reduce the risk in the future. Furthermore, a negative result obtained within six months of being exposed to HIV is not conclusive, as antibodies can take as long as six months to develop and be detectable. If the result is positive, s/he will have heard it by telephone (or discovered it instantly, if home test kits yielding instant results become available in the United States as they are elsewhere), impersonally, and without benefit of counseling.

The oral tests, which are available at some clinics, are an alternative for people who dislike having blood taken, but the test's nature has led some to believe mistakenly that HIV easily can be transmitted orally (there is only one such documented case on record). Marketing and counseling associated with the oral tests need to make clear that this test identifies *antibodies*, which do not transmit HIV.

Reporting and Confidentiality

All states require that AIDS cases be reported to public health authorities, but only 30 (including Michigan) require HIV cases to be reported as well. Some health authorities and others are calling for national HIV reporting (using names or codes), but others, and many PLWH/A, are concerned that it could erode confidentiality rights. Proponents of wider reporting argue that the absence of a full HIV surveillance system deprives health authorities of reliable information about the incidence, prevalence, and trends in HIV infection, types of behavior that increase transmission risk, or trends within specific subpopulations (e.g., minorities, women). Opponents fear that stricter monitoring and reporting could increase the risk of discrimination in housing, insurance, and employment, as well as invade personal privacy. For example, it could be that within local or state health departments there would be established a master list of every PLWH/A; in the wrong hands, such information could be devastating to those infected. Furthermore, opponents worry that increased monitoring and reporting will deter people from being tested, which could result in more transmissions, delayed treatment, and higher costs.

Treatment, Insurance, and Cost of Care

Treatment

The decline in U.S. AIDS cases in 1997, due to the new ARV drugs and prevention efforts, is promising, but health experts are concerned that people, and policymakers in particular, could interpret this to mean that the AIDS epidemic is over or at least its threat is diminishing. Reducing commitment to prevention efforts and HIV treatment could result in a resurgence of cases.

Cost of Care and Insurance Issues

Given HIV's long duration, the current practice of early treatment with expensive drugs, and the care required for end-stage illnesses, HIV and AIDS are expensive. This cost, the young age at which most AIDS patients die, and the lack of health insurance among intravenous drug users—who represent a significant proportion of the at-risk population—raise questions about who should be responsible for the health care costs of AIDS. Some believe that private health insurers can and should assume a greater role by offering comprehensive benefits at affordable premiums to more of the working population and that employers should continue to insure employees even when they are too sick to work. Opponents contend that insurers would assume far too much risk by covering people at high risk for HIV/AIDS and that it is unfair to force others to pay higher premiums due to the increased costs of insuring AIDS patients. They also contend that the government (through Medicare, Medicaid, and other programs) should be the payer of last resort.

Some health insurance companies, in this era of health care cost containment, have reacted to the costs of HIV and AIDS by requiring HIV tests from applicants. The Michigan Insurance Code does not prohibit testing potential policyholders for HIV, but the Insurance Bureau interprets some sections of the code as prohibiting insurers from testing selectively, meaning that if an insurer requires tests of one appli-

cant for a particular coverage, then all applicants for such coverage must be tested. Insurance companies may not ask applicants about sexual orientation or make coverage determinations based on marital status, living arrangements, HIV status of family members, or past history of HIV testing.

In 1997 the federal Health Insurance Portability and Accountability Act took effect, which prohibits insurer discrimination based on health status. A PLWH/A thus is able to obtain individual health insurance coverage so long as s/he had 18 months or more of health insurance under a group plan prior to applying, is not eligible for any other group coverage, has no other insurance, and is not without insurance because s/he failed to pay premiums. However, under Michigan's Patient Rights Act, most insurers are allowed to exclude pre-existing conditions for up to 12 months, and Blue Cross and Blue Shield of Michigan and HMOs are allowed to exclude pre-existing conditions for up to six months, depending on how long a person had insurance prior to applying for group or individual coverage. Furthermore, the ADA permits differential treatment of persons with disabilities in insurance coverage, provided that the differences are based on sound actuarial data. A current lawsuit against one major insurance company claims that the insurer violated the ADA by "capping" lifetime benefits for HIV-related conditions at an amount less than imposed for other medical conditions.

Other insurance issues pertaining to HIV and AIDS include *viatical* settlements and disability insurance. The former allow terminally ill people to sell their life insurance policies for cash; the buyer pays all future premiums on the policy and receives all benefits after the insured's death. The benefit of this practice to PLWH/A is that it gives them immediate funds with which to obtain medical treatment, pay debts, or maintain their quality of life. The drawbacks are that payments from viatical settlements may be taxed under federal and state laws, reducing their value, and the cash received may reduce one's eligibility for public assistance. The Health Insurance Portability and Accountability Act now allows viatical-settlement proceeds to be tax free if the seller is thought to be within 24 months of dying and the viatical company purchasing the policy is licensed in the state in which the seller resides.

Disability insurers historically expected PLWH/A to remain disabled until their death. However, the new protease inhibitor drugs enable some PLWH/A to return to work. The problem is that returning to work means a PLWH/A might lose disability benefits and also could mean—if s/he goes to work for a small company and has to reapply for disability coverage—that s/he will be individually underwritten. For PLWH/A who receive Social Security income and Social Security disability income in Michigan, incentives are offered to help them return to work while still providing needed financial assistance. However, some don't know about the incentives, and they fear that welfare reform has eliminated all assistance. Moreover, the current success of one's treatment does not guarantee continued effectiveness. Also, some PLWH/A have not been able to work for years, and their skills are outdated. Several private insurers are offering retraining courses or no-risk trials in the work force, and advocacy groups are assisting PLWH/A regarding legal issues and work force re-entry. A 1996 report states that nationally, more than $1.5 billion a year in disability benefits are paid by private insurers and Social Security to about 100,000 PLWA and other diseases related to HIV (less than 4 percent of the disability market).

Civil Rights of PLW H/A

Although federal and state laws have been enacted to protect the rights of people with disabilities, including PLWH/A, discrimination still exists and confidentiality is not always upheld. There is concern that confidentiality rights, in particular, could be eroded by more extensive HIV monitoring and reporting.

Although not universal, some courts (including the Michigan Supreme Court, in 1992) have ruled that a person may not be discriminated against because of a misperception that s/he is infected with HIV or has AIDS. That is, merely being regarded as having an impairment triggers the ADA's protections. It also is unlawful to discriminate against a person because s/he associates with a PLWH/A.

See also Civil Rights; Health Care Access; Substance Abuse.

FOR ADDITIONAL INFORMATION

AIDS Education Global Information System (AEGIS)
www.aegis.com
[Largest HIV/AIDS database in the world]

AIDS Partnership Michigan
2751 East Jefferson Avenue Suite 301
Detroit, MI 48207
(313) 446-9800
(313) 446-9839 FAX
www.aidspartnership.org

Detroit Community AIDS Library
4325 Brush Street
Detroit, MI 48201
(313) 577-8943
(313) 577-6668 FAX
www.libraries.wayne.edu/dcal/aids.html

HIV/AIDS Information Center */and/*
Journal of the American Medical Association
American Medical Association
www.ama-assn.org/special/hiv/

HIV/AIDS Prevention and Intervention Section
Michigan Department of Community Health
3423 North Martin Luther King, Jr. Boulevard
P.O. Box 30195
Lansing, MI 48909
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HIV/AIDS Surveillance Section
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HIV InSite */and/*
Center for AIDS Prevention Studies
University of California, San Francisco
74 New Montgomery, Suite 600
San Francisco, CA 94105
(415) 597-9100
(415) 597-9213 FAX
http://hivinsite.ucsf.edu/
www.caps.ucsf.edu

HIV, STD, and Adolescent Health
National Conference of State Legislatures
1560 Broadway, Suite 700
Denver, CO 80202
(303) 830-2200
(303) 863-8003 FAX
www.ncsl.org

Michigan Aids Fund
Riverview Center Building
678 Front Street, N.W., Suite 265
Grand Rapids, MI 49504
(616) 451-2394
(616) 451-9180 FAX

Michigan Protection and Advocacy Service
HIV/AIDS Advocacy Program (HAAP)
29200 Vassar Boulevard, Suite 501
Livonia, MI 48152-2116
(800) 414-3956
(248) 473-4101 FAX
www.mpas.org