The AIDS Epidemic: Casting Light Into the Darkness

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The human immunodeficiency virus (HIV) epidemic is a natural disaster comparable to earthquakes, hurricanes, and erupting volcanoes. This epidemic has eliminated hundreds of thousands of people throughout the world and threatens the lives of millions more. As devastating as the increasing number of lives lost in this epidemic is society’s reaction to those who suffer from the acquired immunodeficiency syndrome (AIDS). AIDS points out all the flaws in our society: hypocrisy, stigmatization, discrimination. All discrimination, whether racial or ethnic, whether against the physically handicapped or the mentally ill, or whether based on sexual preference, contributes greatly to people’s unwillingness to deal with the reality of AIDS. We need to change the public’s perception of this disease. We must bring AIDS out into the open, break the conspiracy of silence about it, destigmatize it. We must make people aware of their own risk and of just how prevalent this disease is now or the epidemic could continue to claim not only the lives of those who are strangers to us but also those who are dearest to us.

History has shown that epidemics of infectious diseases tend to hit hardest in urban areas. Epidemiologically, the communities of the urban poor at the time an epidemic strikes have more cases of that particular infection than other segments of the society. In the last century the great plague in the United States was tuberculosis. The urban poor who contracted this disease were mainly white European immigrants. The urban poor in America today are mainly other minorities, and these groups have been at great risk for HIV since the start of the epidemic in the early 1980s. Infectious disease in urban America has nothing to do with race or ethnicity; it is the phenomena of being poor, living in crowded conditions, and, especially relevant to AIDS, not having good access to health care and health care information.

While it is true that the HIV epidemic has hit urban America the hardest, it is also true that everyone in America is at risk for this disease. No one is immune. After nearly a decade of fighting this epidemic, one of our greatest obstacles remains the all too common belief that AIDS is a disease of gay men and drug addicts, of the amoral and the promiscuous. The general public in the United States still has no perception of being at risk for this disease. If we do not change this attitude, if we do not alter the public’s perception of personal risk, we will not be successful in our fight against this disease.

Changing people’s perception of their risk for a particular disease in order to effect change in their behavior to lower that risk is a battle we are constantly fighting in medicine. People who complete a questionnaire assessing, for example, their risk for coronary artery disease based on different factors listed generally will underestimate their risk by at least 50%, even given all the information. However, the battle against coronary artery disease is easy compared to the battle against AIDS. People will willingly compare cholesterol levels but not sexual preferences and practices. People will openly discuss the experiences of their friends and family members who have suffered massive heart attacks but remain silent about those loved ones who suffer from AIDS. Your risk for coronary artery disease is an acceptable topic of conversation but your risk for AIDS is not.

We are fighting an epidemic of a sexually transmitted disease in a society that still refuses to deal with the realities of human sexuality. To have a fighting chance against this epidemic, we must overcome our societal hypocrisy about sexual behavior. While we may wish that all people could be in mutually monogamous relationships and believe that this would be healthier psychologically, emotionally, spiritually, and physically, the reality of human nature is clear: we have never been and will never be a completely monogamous people. Furthermore, by not knowing or by failing to acknowledge what people actually do sexually, we fight the war against HIV blindfolded. We must know the routes by which the enemy is able to infiltrate our territory or we will lose this war.

We must bring AIDS out into the open. Each of us must realize at a gut level that we are at risk of this infection. By acknowledging that we are at risk, we can then change our behavior. Gay men have changed their behavior. There has been a decreased incidence to almost negligible levels of new HIV in a group of gay men who have been followed in San Francisco. That behavioral change started in the early 1980s, at a time when gay men were watching their friends die of AIDS. At that time, 10% to 20% of these men were already infected with the virus. Gay men changed their behavior, but it was too late for many. This is what haunts me about heterosexuals in the United States: Must peo-

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people watch a number of friends and loved ones die of AIDS to become convinced that they must change their behavior? Unfortunately, facts and statistics do not have much impact. Illness and death of someone one knows impresses people the most. How­ever, we know from the HIV epidemic among gay men in the United States and among urban heterosexuals in Eastern and Central Africa that by the time a person is seeing a number of friends of similar sexual lifestyle dying of AIDS, that person’s chance of already being infected is 10% to 20%. Will we have to wait until 10% to 20% of America’s general heterosexual population is infected before most heterosexuals will start using protection in sexual relations? When will most heterosexuals wake up?

We must bring AIDS out into the open, break the conspiracy of silence about it, destigmatize it. We must make people aware of their own risk and of just how prevalent this disease is now or the epidemic could continue to claim not only the lives of those who are strangers to us but also those who are dearest to us.

Somehow we must make people perceive that they are at risk, even when they don’t think they are at risk. As long as people think that no one they know has HIV or has died of AIDS—not their friends, not their colleagues, not their neighbors—they will continue to be unaware of the reality of the AIDS epidemic. The overwhelming silence in our society about those who have died of AIDS does nothing but contribute to the public’s continuing perception of being not at risk for the infection.

We must break this conspiracy of silence. The obituaries of AIDS patients rarely report that they died of AIDS because the stigmatization of AIDS is so great. In the early 1980s, I gave many televised talks because I was upset about the hysteria over AIDS in this country and I was trying, at least locally, to provide some rational explanations. I asked several of my African-American patients if they would be willing to go on television as people with HIV or AIDS, but they refused because of the triple discriminatory impact of being black, gay, and having HIV. Even when people are willing to go public, their normally supportive and loving families threaten to disown them if they do so. People refuse to admit to anyone but themselves that their loved ones are suffering from or have died of AIDS. We must work to overcome this prejudice. The realization that someone you knew had AIDS, someone who is just like you or someone with whom you may have shared some behaviors, such as having had sex with the same person, will have a tremendous impact on your behavior.

Unfortunately, some people will hold fast to their belief that they are immune to a disease such as AIDS because they live according to God’s rules or because they live clean, moral lives. All of us have heard someone infer or openly state that AIDS is punishment for “bad” or “sinful” behavior. Is death by torture an appropriate punishment for sexual activities or drug use? We must challenge people when they make these statements: Do you really believe this? Do you believe that your parents or your siblings or your children deserve AIDS and deserve to die because they are “bad” and use drugs or commit a “sinful” sexual act? Do people really believe that? I don’t think so. It is just another way to separate “them” from you, another way to remain convinced that you are not at risk.

It will continue to be a long, hard battle to change the public’s perception of AIDS, but we must not give up the fight. We must continue to educate the public and to increase awareness of AIDS prevention. State health departments and local community organizations are vital to fighting the battle against AIDS. A number of community groups have emerged in Detroit. We now have three local organizations specifically for minorities with HIV—one for African-Americans, one for Hispanics, and one for gay and lesbian African-Americans. Volunteers visit the common outdoor gathering areas to distribute condoms and to talk about AIDS prevention. Outreach to drug users includes information on cleaning needles with bleach. We need these organizations desperately. The AIDS Interfaith Network is now gathering a group of clergy of many different faiths who are interested in learning more about HIV and providing pastoral care to people with the infection. Their first official teaching conference (also done in Spanish) was held in the Southwest Detroit area in October 1989. When I first started taking care of patients with AIDS in 1983, I gave talks in gay bars and to gay organizations to raise money to finance pamphlets for AIDS prevention. I was shocked that there were hardly any African-Americans at the gay meetings or in the bars where I spoke in Detroit. The use of community organizations is therefore critical in finding ways to reach people who are not part of the vocal, mainly white, gay group of people with HIV and AIDS.

One of my dreams is that we will someday be able to advertise condoms on television. The power of the media is astounding and we must access that power. We need to use television to promote responsible sex by showing people discussing methods to prevent pregnancy and sexually transmitted diseases. The soap operas could set a great example. We need to work to influence some of our celebrities, whether they’re in the entertainment industry or in professional sports, to help us educate the public about AIDS and AIDS prevention. As long as condoms are viewed as promoting sex, when in fact they help to prevent pregnancy and AIDS, and as long as the distribution of free needles is seen as promoting drug abuse, when in fact it helps to stop the spread of AIDS, we will continue to be handicapped in our fight against this virus.

HIV and AIDS can be prevented. We already know how to prevent the spread of HIV. Condoms and the cleaning of drug injection paraphernalia will prevent almost all transmission of HIV in this country. The problem is how to get people to use these measures. Public education on the means of transmission of the virus and the techniques of avoiding the virus should pervade the community. Education will cast light into the dark corners of ignorance and lessen the risk of infection. Until that far-off day when we will have a vaccine (perhaps a decade from now), education to behavioral change will remain the only way of controlling the HIV epidemic.