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RECOGNIZING HIV INFECTION— THE ROLE OF HOME TESTING

RALPH R. FRERICHS
University of California at Los Angeles (UCLA)

ABSTRACT

Early detection of HIV is important, both to start timely treatment and to avoid further viral transmission. Yet for many people, discovering possible infection is overly cumbersome and time consuming. To learn early of viral presence, sexually active persons would need to take time off from work to repeatedly seek clinic-based testing and counseling, perhaps every three to six months. Testing for HIV at home is more convenient and certainly is more anonymous. Home HIV tests serve as personal screening tools for those concerned with HIV risk, indicating when positive the need for additional confirmatory testing and counseling in medical settings. If used widely, home HIV tests would enable many more HIV infected persons to learn of their infection, come for medical care, and to use preventive actions to avoid further viral spread. To this end, promoting home HIV testing is an important assistance strategy for both medicine and public health.

INTRODUCTION

If early detection of the human immunodeficiency virus (HIV) is to become a reality, we need to develop simple testing schemes that more effectively respond to the wants of the consuming public. The Food and Drug Administration (FDA) has licensed several home-collection tests for HIV antibodies (Food and Drug Administration, 1996), offering alternatives to those who do not favor current testing programs. While many have admired provider-based counseling and testing sites for their high standards of confidentiality and care, others found such clinic-based systems to be complex, non-accessible, and intimidating. Such persons might prefer home-based testing, done at periodical intervals in a more private setting. If infected with the virus, many would want to know early so that

they could request new therapeutic drugs or avoid opportunistic infections that may hasten death (Havlir & Richman, 1996). Those with a high sense of love or social responsibility would want to offer early warning to sexual partners, persons having contact with their blood, or to protect their newborn child (Bayer, 1996). So how should people respond to home tests that promote individual responsibility and self-empowerment, but have only limited conventional face-to-face counseling? Will more infected persons who use home tests come forward and demand care and warn sexual partners, or will they hide their identity, acting as if nothing had happened? Will people be as careful with sexual partners as they are with blood donations, demanding home test results before intimate contact? These questions and others will need to be addressed as home-based tests become widely available.

In this article, I will briefly address the unrecognized HIV problem in the United States, the importance of early detection, the value of testing for risk reduction, the notions of government-protection versus self-protection, and the hope for home tests. I will conclude with a call for public health professionals to promote early detection of the virus and to stimulate efforts to improve the image of newly recognized HIV infected persons in the society.

UNREPORTED AND UNRECOGNIZED HIV/AIDS

Three recent estimates of national HIV prevalence suggest that 600,000 to 900,000 persons in the United States are carriers of the virus (Rosenberg, 1995; Anonymous, 1995; Holmberg, 1996). Many of these persons likely do not recognize they are infected, although the numbers are difficult to estimate. With the arrival of new therapeutic agents, there is much hope for HIV infected persons of extended survivorship (Collier et al., 1996; Simonds et al., 1995). Transmission can also be reduced from an infected mother to a newborn child, but only if testing identifies the presence of the virus before birth (Connor et al., 1994). Lacking awareness of their infection, however, HIV carriers would have no reason to seek medical assistance and would continue unknowingly to expose others to the deadly microbe. Included among those exposed are their sexual partners, persons sharing drugs mixed with their contaminated blood, and their newborn infants.

In the largest study to date of persons in the United States with AIDS, Wortley and associates (1995) found that about half had not learned of their infection until one year or less before their AIDS diagnosis. Thus, for seven to nine years this group unknowingly exposed others to the virus. Among female AIDS patients, more than 60 percent had remained unaware of the virus until the year before they were diagnosed with AIDS, offering many opportunities for viral spread. Given these findings of delayed detection, it explains why the virus is able to move from one person to another, allowing the epidemic to continue.

All fifty states report AIDS cases and deaths to the United States Centers for Disease Control and Prevention (CDC), but only twenty-six report HIV infections, with two (Connecticut and Texas) limiting reports to children less than thirteen years old. In the other twenty-four states, public health officials have less knowledge of who is infected, who needs medical care, and who wants help in preventing further transmission. Likely about half or more of those carrying the virus do not know they are infected. Through 1995, CDC reported 254,861 persons living with HIV infection or AIDS (Centers for Disease Control and Prevention, 1995). This group represents only 28 to 43 percent of the 600,000 to 900,000 estimated as infected. Another study in an urban outpatient HIV clinic found that 60 percent did not suspect that they were infected until they received a positive HIV antibody test result (Wenger et al., 1994). Among pregnant women in Tennessee, the prevalence of known seropositivity at delivery approximately doubled after an HIV screening program was started, indicating that half likely did not know they carried the virus (Lewis et al., 1995). Even among younger homosexual and bisexual men who have received much information about HIV/AIDS, a recent study in Northern California reported that serostatus was unknown to 70 percent who were infected (Lemp et al., 1994). Finally, in Los Angeles County, 36 percent of heterosexuals coming to sexually transmitted disease (STD) clinics, and thereby defined as high risk, did not accept the offer of a confidential HIV test, and thus did not learn of their HIV status (Simon et al., 1996). These disparate studies from throughout the United States suggest that current HIV counseling and testing sites are not effective at identifying HIV infection, and therefore do not serve either the medical interests of HIV infected persons or the public health interests of the nation.

TESTING AND RISK REDUCTION

Our most successful HIV control strategy in the United States remains testing of donated blood. As a result of blood screening programs, the risk of HIV infection from a contaminated transfusion has been reduced to one infection per 450,000 to 660,000 donations (Lackritz et al., 1995). Blood testing programs remind us that susceptible persons are only at risk when intimately exposed to the virus. While condoms are highly effective at reducing HIV transmission, consistent (or always) condom use has remained low in the United States, especially among trusted sexual partners (Catania et al., 1995; Choi & Catania, 1996). When condoms were not regularly used among heterosexual couples discordant for HIV, the virus moved from infected to susceptible at a rate of five to seven per 100 person-years (Saracco et al., 1993; De Vincenzi, 1994). Among steady discordant homosexuals the rate of infection is even higher, depending on the frequency of unprotected anal intercourse. Fortunately, with knowledge of HIV status, many discordant couples either abstain from penetrative sexual intercourse, or protect themselves by using condoms. It is to such couples that home

HIV tests offer the most benefit, allowing them to decide with full disclosure how much risk they are willing to accept.

GOVERNMENT VERSUS INDIVIDUAL PROTECTION

Central to the mission of public health is the protection of communities from communicable diseases. Included as typical public health strategies are mandatory immunization programs, outbreak investigations, case finding, and for some sexually transmitted diseases, partner notification. When such programmatic efforts are working well, the public feels confident that they are being protected from undue harm. Yet the situation is less certain with HIV. In twenty-four states no attempt is being made to identify those who are infected, or to notify even long-term sexual partners that they are at risk. Instead the prevailing public health philosophy has become "protect yourself." Recognizing the perilous nature of contemporary sexual relationships and the inability of public health agencies to identify those who are HIV infected, many people will likely view home HIV tests as but another tool to protect themselves, and if infected, to seek early care.

As new testing technology becomes available, various authors have accepted the notion of home HIV testing for those who favor the convenience and anonymity of this approach (Frerichs, 1994; Bayer, Stryker, & Smith, 1995; Merson et al., 1997). While HIV counseling and testing sites have been established in all metropolitan areas of the United States, only 24 percent of Americans have ever had an HIV test (Anonymous, 1995). Among those who wanted a diagnostic test, public testing sites were less popular than private sites. Moreover, counseling was not an important feature of testing at the private sites. Only 28 percent of those being tested at private sites reported counseling, in contrast to public sites where 61 percent were counseled. This disparity suggests that, when given a choice, formal counseling was not an important feature of the testing process. Instead, 72 percent of people who went for testing at private sites seemed only to want the results (Anonymous, 1995).

When viewed with the same standards we use for assessing test validity, institution-based testing sites would not fare well. The term *sensitivity* is used to describe the percentage of persons with HIV who a diagnostic test correctly identifies. Typically the sensitivity for high-quality enzyme-linked immunoadsorbent assays (ELISA) is in the 98 to 99.9 percent range. A test that has a sensitivity of less than 95 percent would be viewed with great concern, and rightfully so. When people are tested, they are given a blood sample and are asked to return one week later for their results. Many never come back, ranging from 17 percent non-returnees among HIV infected teenagers in Houston (Ilegbodu et al., 1994), 18 percent among HIV infected attendees at CDC-funded testing and counseling sites (Valdisseri et al., 1993), and 30 percent among HIV infected postpartum women in New York (Sorin, Tesoriero, &

LaChance- McCullough, 1996). Thus, in these three studies, the sensitivity of the HIV notification system ranged from 70 to 83 percent, far below the acceptable sensitivity levels of HIV antibody tests.

So will people be willing to use home tests now that they are becoming available? In a 1992 National survey of nearly 21,000 adults, 29 percent responded that they would be very likely or somewhat likely to use home HIV tests (Phillips et al., 1995). Among those reported to be at higher risk of HIV, 42 percent showed a willingness to use home tests. What is remarkable is that such high interest was reported four years before home-collector tests were even available in the marketplace. Once the media, public debate, and advertising stimulate interest, the percentage who would accept and prefer home tests for self-screening will likely continue to rise.

DESIRED PUBLIC HEALTH RESPONSE

Above all, the goal of public health professionals should be to reduce the burden of illness in the society. With HIV, early detection leads to both treatment and prevention of future infection. Yet testing, whether at home or office or of blood donations, is only one aspect of HIV control efforts. To be successful, public health officials need to continue to deliver educational messages that favor delayed first intercourse for teenagers, premarital abstinence, and use of condoms for sex with partners not confirmed as HIV negative. They also should continue efforts to prevent the use of illicit intravenous drugs and to support needle exchange and sterilization programs to ensure that drug addiction, which can be treated, does not lead to infection and premature death.

The goal of public health should further be to help society develop a more realistic view of HIV infection, recognizing that the disease is caused by a virus and not by sinful behavior. With people's keen sense of individual rights and personal decency, most will not accept public humiliation and harm of HIV infected persons. Instead they have gone to great lengths to pass legislation that prohibits discrimination based on HIV status. Moreover, for widespread testing to become successful, effort must be continued to reduce the fear and loathing that many still show toward those who are infected. To do so requires the active efforts of the media, concerned citizens, public health professionals, and people living with HIV. Home testing will help bring the problem out in the open, and lead to public awareness that HIV infected individuals can function in a normal manner in our society (Frerichs, 1995).

The FDA will probably continue to license other HIV home-collection kits, creating competition over test quality, price and convenience, much as has occurred with home pregnancy tests. While offering easy access to persons who can afford such home tests, groups such as homeless people, intravenous drug users, sexually active street children, or inner city sex workers may hardly notice their arrival. Instead, when infected by HIV they likely will remain untested and

unaware of the intruding virus. To help such people and ultimately to control the epidemic, public health professionals will need to develop innovative testing strategies, while creating a social climate that accepts and supports those who are willing to address their disease.

Over the years, I have been working with colleagues in Asia to evaluate simple, low-cost screening tests for HIV that use the non-invasive medium of saliva rather than blood (Frerichs et al., 1994). Rather than screening, I prefer the term "HIV indicator" since being positive indicates the need to seek formal counseling and confirmatory testing with blood. HIV indicators featuring saliva or blood spots would be used on a regular basis by those who feel at high risk, but only occasionally by others who worry they might be infected. Since most would be negative, they would remain home and not burden the health care system with the expense of testing. Such cost savings for HIV testing programs could then be used for extended contact and care with HIV infected persons, as proposed years earlier by Francis and colleagues (1989).

CONCLUSION

If we are to control HIV, we must offer the public a more realistic view of transmission and separate notions of sin and social discrimination from recognition of viral infection. HIV infected persons need to be identified early in the course of the disease, so that treatment and care can be offered, along with ways to avoid viral transmission. Due to the complexity of the HIV problem, many intervention and prevention strategies are needed. Yet widespread testing that includes home HIV tests has not been successfully tried. To promote such testing, public health officials will need to consider various approaches, including routine testing in medical care settings, premarital testing, pregnancy testing, and home testing with simple HIV indicators that point to the need for follow-up counseling and confirmatory testing. Gaining public acceptance for such a strategy becomes a major challenge in our struggle to improve society's health.

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Direct reprint requests to:

Ralph R. Frerichs
Department of Epidemiology
University of California at Los Angeles (UCLA)
Los Angeles, CA 90095-1772