Secondary HIV Prevention
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Most HIV prevention efforts throughout the world have focused on primary HIV prevention, or preventing infection among susceptible individuals in the general population or in groups considered to be at risk. Little attention, however, has been devoted to secondary HIV prevention, which addresses preventing transmission from infected people to their uninfected contacts. The lack of research and interventions on helping individuals already infected with HIV to avoid risky behavior was noted at a recent National Institutes of Health Consensus Conference, which included a recommendation that HIV prevention programs be developed for seropositive people.1

The imbalance of primary and secondary prevention efforts with respect to HIV is revealed most starkly when compared to how other epidemic diseases have been controlled. A public health strategy focused on preventing transmission of disease by infected individuals freed the world from smallpox and dramatically reduced the incidence of syphilis. A balance between secondary and primary prevention has made great progress towards eliminating another health scourge, a parasitic infection called dracunculiasis, or Guinea worm disease. Ten years ago, Guinea worm disease seriously impaired health and socioeconomic development in India, Pakistan, Yemen, and 16 African countries. By the end of 1995, the World Health Organization estimated a 97 percent reduction in cases globally over the past decade, and the disease was reported eradicated from Pakistan. This remarkable public health success was achieved through balanced, dual efforts to detect new cases and prevent transmission by educating those infected not to enter or contaminate water sources, a secondary prevention intervention, as well as to prevent exposure by educating people to filter or boil all drinking water, that is, a primary prevention intervention.

There are several hypotheses explaining why secondary HIV prevention has escaped the interest or attention of HIV researchers, clinicians, and policy makers. The simplest theory is that the epidemiological concept of secondary prevention has never been made sufficiently clear, compelling, or perhaps palatable, nor has it been translated from its application in other infectious diseases to the context of HIV. Perhaps another factor is confusion about definitions: the term “secondary prevention” has been used in some HIV literature reports to refer to preventing disease progression from asymptomatic HIV infection to AIDS. The purpose of this article is to clarify the concept of secondary HIV prevention to mean preventing HIV transmission by infected individuals, as distinguished from primary prevention—preventing HIV exposure among uninfected individuals. We will then briefly review what has been done and could be done to further the secondary prevention of HIV.

Epidemiological Distinctions

The case of measles is a useful example to look at the ways in which epidemiologists conceive of infection and prevention. When children with measles return home, they bring the microbe with them. Each child then becomes an “index” or “primary” case in the context of viral transmission to other children in his or her “at risk” household. To measure such transmission, epidemiologists derive a “secondary attack rate,”* or the result of dividing the number of cases in the home

*The term “attack rate,” different from “secondary attack rate,” refers to the number of new infections in a population divided by the total number of people at risk in the population.
As an editor, I take the opportunity to listen to language in a way that most readers do not. This month, I was the one who got a lesson in precision and ambiguity. For years, the term “secondary prevention” has been used within the HIV community to mean two things. One definition encompasses interventions that target seropositives and focus on preventing transmission to seronegatives. People who apply this definition use the term “primary prevention” for strategies that target only seronegatives, which focus on preventing transmission to themselves. The Centers for Disease Control and Prevention (CDC), however, calls both of these kinds of intervention “primary prevention” and reserves the term secondary prevention solely for approaches designed to impede the progression of HIV disease in a seropositive person. One set of definitions distinguishes among the target populations of prevention interventions, while the other set distinguishes among the goals of the interventions.

In this month’s articles, both definitions are applied as authors use the term differently. But while Lydia Temoshok and Ralph Frerichs may not use the same terms or definitions as Walt Senterfitt does, they do make the same point. Whether we call it primary or secondary, it is clear that we need to develop interventions that speak to seropositives, enlisting their aid in preventing transmission to seronegatives.

It is important to notice two things in this context. First, with either set of terms, neither secondary prevention nor primary prevention aimed at seropositives is an alternative to primary prevention aimed at seronegatives; they work in concert. Unfortunately, prevention interventions aimed at seropositives have not received significant attention in the research literature or on the front lines of the epidemic.

Second, while prevention messages have been effective in protecting many people, undifferentiated prevention strategies are ultimately insufficient. We must ensure that strategies for each population, as well as for each goal, are sufficiently distinct and honed to find their targets. One last point. Secondary prevention may also encompass prevention against reinfection. Reinfection has always been a concern, but today it may transmit potentially drug-resistant strains of HIV, possibly confounding successful antiviral drug therapy.

The epidemic is a case study in the evolution of language, paralleling a rapid evolution of ideas. But language cannot obscure the real challenge: if we are to stop the spread of HIV, it is crucial to help seropositive clients learn their serostatus, disclose it, and appropriately practice safer sex.

References
4. FOCUS June 1998
to prevent this high level of transmission risk behavior.

Undifferentiated Prevention Strategies

Unfortunately, virtually all HIV prevention efforts have ignored the critical distinctions between primary and secondary prevention, and functioned as if the same “safer sex” guidelines applied to every individual and all populations. The basic message of most campaigns, “Protect yourself, use a condom every time,” is intrinsically illogical for partners in long-term, closed relationships, who have repeatedly tested HIV-negative. In such partnerships, the risk of infection is zero, irrespective of the “riskiness” of the sexual behavior.

The “condom every time” message makes the most sense for two people whose serostatus is unknown to themselves or to each other. In this context, both the virus and the risk of infection are abstract concepts; there is a statistical but largely unknown probability that either or both partners are infected with HIV. Using a condom every time is essentially an insurance policy: in case the partner is infected, consistent condom use reduces the risk of HIV transmission to within limits most people would find acceptable.

The implications for HIV prevention are very different when we consider a different context: when one person is HIV-infected and the other is susceptible (has tested seronegative or has unknown HIV status). The probability that one of the partners is infected is now 1.0 (or 100 percent), and using condoms consistently will reduce, more or less (more for oral, less for vaginal sex, least for anal sex), the probability that HIV transmission may occur. The actual risk of HIV infection is dependent on the transmission probability associated with the type and frequency of sexual behavior; the presence of other lesions such as ulcers or small tears that make it easier for the virus to be transmitted and genetic factors that lead to higher or lower resistance. Despite differences in transmission probability, public health efforts have been characterized by “undifferentiated,” but essentially primary, prevention approaches, neither recognizing nor addressing the significantly greater risk inherent in secondary attack rate contexts. Another problem with a message that begins, “protect yourself,” is that it is inappropriate to the situation of HIV positive people, who may then “tune out” the rest of the message, “use a condom every time.”

The First Challenge: Knowledge of Infection

It is important to remember that secondary prevention is logically dependent upon knowledge of HIV status. Despite remarkable progress in developing rapid, cheap, and noninvasive screening tests for HIV, there has been no discernible effort by the United Nations AIDS Program (UNAIDS) to encourage widespread and easy access to testing other than for blood transfusions or for surveillance. The model that UNAIDS recommends for testing individuals, which features labor-intensive forms of pre- and post-test counseling, is too costly and cumbersome for widespread implementation, especially in the developing world. Even when applied to the universally accepted goal of preventing mother-to-infant HIV transmission, the UNAIDS testing model will result in detecting the virus in only a small percentage of infected pregnant women in developing countries.

In order to reach more women, creative screening and assistance strategies that involve community or family planning outreach workers and simple screening tests, likely based on urine or saliva, will need to be developed and implemented, taking into account the factors of cost, coverage, and efficacy. In both developed and developing country settings, health care providers can normalize the notion of testing by underscoring the fact that knowledge of serostatus facilitates early detection and treatment as well as efforts to prevent further transmission to loved ones.

Innovative Secondary Prevention Needed

Developing and implementing effective secondary prevention strategies require innovative solutions at four levels. The individual level requires changing transmission risk behaviors and attitudes among people with HIV disease, as well as among HIV counselors, clinicians, and researchers. The social level requires continued efforts to destigmatize and normalize HIV infection, allowing people with HIV disease to function in society and in the workplace, as well as to more openly and honestly communicate their HIV status to others. The contextual level entails promoting structural changes that alter norms and behaviors in different risk contexts. Another problem with a message that begins, “protect yourself,” is that it is inappropriate to the situation of HIV positive people, who may then “tune out” the rest of the message, “use a condom every time.”
contexts, such as serodiscordant couples, casual partnerships, militaries, prisons, and needle-sharing partnerships. The institutional level necessitates enacting evidence-based public policy changes that support the various components and steps necessary for secondary prevention programs to be effective in real-world settings. Evaluation is a key tool, needed first to provide critical information about the extent and nature of the secondary transmission problems to be addressed, and then to provide feedback about the efficacy of secondary prevention strategies, a step often skipped by resource-strapped HIV counseling programs.

What describes a secondary prevention approach specific to HIV-infected individuals? Counselors, particularly those in HIV testing and counseling settings, might begin by emphasizing the responsibility of HIV-infected persons to help break the chain of transmission. It is important for risk reduction counselors to help their seropositive clients clarify attitudes, emotions, behavior, and values that promote or undermine sexual responsibility. This may include delving into “self-deluding” beliefs, for example, “Now that I’m on combination therapy, I’m not infectious,” or “If my partner isn’t infected after all this time, he or she must be immune,” both of which lead to the erroneous conclusion, “So, I don’t have to worry about safer sex anymore.”

The “one size fits all” approach of conventional counseling may be less effective in changing long-held patterns of behavior than a “custom-tailored” approach that is based on an assessment of each individual’s transmission risk profile. This approach entails inquiring about each current sexual partner and the specifics of drug use behavior. The mere fact of asking shows that the counselor cares about the possibility of another person getting infected, and this caring can be transmitted to clients. Step by step, the counselor can discuss and plan with each client the most effective ways to notify each partner (including future partners), deal with their reactions, and prepare for and engage in safer sex. Because incorrectly used condoms may break or slip off during sex (especially during anal sex), the counselor might also explore with the client satisfying forms of nonpenetrative sex as “truly safer” alternatives within serodiscordant relationships. Counseling should also consider risk context, such as whether the individual likes to go to bars to meet people, whether he or she travels on vacations to places where casual sex is likely to occur, or whether a problem with alcohol or drug use tends to undermine good intentions as well as the ability to practice safer sex.

Secondary prevention aimed at vertical transmission should seek to help seropositive women confront the reality of their infection, make informed choices about pregnancy, and learn about HIV treatment regimens that can greatly decrease the risk of mother-to-child transmission. In the context of HIV-related medical care, providers should consider every prescription to provide an opportunity to discuss transmission risk and adherence, and to reinforce the fact that successful treatment does not mean an individual is no longer infectious.

Conclusion
The confluence of recent biomedical advances in HIV testing and treatment offers the opportunity for setting up truly biopsychosocial diagnosis, treatment, and prevention services that engage people with HIV disease in lifelong health care partnerships. Incorporating secondary prevention into comprehensive programs creates shifts in attitudes and behaviors that not only benefit the individual and his or her close relationships, but also help reduce the size of the epidemic.

Clearinghouse: Secondary Prevention

References
New antiviral drug combinations allow much longer and fuller freedom from symptoms for most people with HIV disease, especially those who discover their infection early. Many people with HIV disease who were quite ill have become vigorous again. With dying less of a threat, needs for sex, intimacy, and love may be heightened. We are as yet uncertain what degree of reduced infectiousness the new therapies confer among people for whom treatment works. Meanwhile, many seropositives and seronegatives are playing and loving less safely. Motivating and supporting seropositives to care for and protect themselves, their partners, and their community while leading full and satisfying lives is likely to be one of the most efficient means of primary prevention—which simply refers to preventing new HIV infections, however that is achieved.

In 1997, a group of advocates and researchers began to network in Los Angeles and did not find even one prevention program in the city directed at HIV-positive people. In response, they began to organize. The earliest result of their actions was a commitment by the Los Angeles City Council of $180,000 for a pilot project targeting prevention needs of HIV-positive city residents.

**Chat Line and Groups Program**

A six-agency multicultural consortium of AIDS community organizations bid successfully to set up Positive Images. The Los Angeles Gay and Lesbian Center is the lead agency, with subcontracts to Being Alive and Women Alive, both organizations of and for people with HIV disease, Bienestar Latino AIDS Project, the Asian Pacific AIDS Intervention Team, and the AIDS Prevention Team of the Black Gay and Lesbian Leadership Forum.

Perhaps the most innovative component of the program is a telephone chat line for seropositives to talk anonymously about issues, problems, and feelings relating to sharing sex and intimacy as infected people. Safe drug use is also a welcome topic, but nearly all callers focus on sexual issues. The toll-free call-in number is staffed five hours a week by each of the consortium members. Chats—two sessions per week each lasting two-and-a-half hours—are facilitated by each agency’s part-time peer staff person, who has been specially trained and supported to be both a telephone and support group facilitator. The result is women’s chats, Latino and Spanish-language chats, and gay Asian men chats, among others. Each agency independently publicizes the chats for which it is responsible in its own outreach venues and media; and the Gay and Lesbian Center conducts general publicity about the program.

The telephone system can handle up to 20 callers at a time. The facilitators have the ability to go off-line to conduct private conversations with individual callers if they want to discuss special issues that require confidentiality, become distraught or inappropriate, or need urgent intervention. During the non-monitored hours of the week, callers may call in day or night and chat with whomever else is on the line.

The other component of the project is a drop-in support group program. Each consortium member agency is responsible for conducting at least one regularly scheduled group a week. Some groups establish and publicize discussion topics in advance.

Positive Images is in the latter half of its first year of operation. The City of Los Angeles will renew the contract for a second year. The year’s progress has been marked with impressive early results.
Responsibility is a loaded word; some suggest messages in terms of caring for one’s partner.

by the usual birth pangs and startup glitches. The first few months were dedicated to staffing the program, creating a working community advisory board, training facilitators, and finding software and hardware vendors.

The telephone system is finally running fairly smoothly, and there are currently more than 100 callers a week, about half in the chat groups and half at unmonitored times. The support groups at Women Alive and Being Alive are going particularly well, and women typically use the chat lines to stay in touch with other group members between group meetings. In addition, regular members who cannot attend a particular week’s in-person session find it useful to be able to stay in touch by telephone.

Discussion Themes

Facilitators report a difference in the main themes discussed among women compared to those discussed among men. In general, women come to the groups not feeling free to engage in sexual activity, having been hammered with messages by medical providers and others that they are very infectious. This message may strike a particular resonance with women socialized to put the welfare of others first. Much of the Positive Image discussion among women has stressed the fact that the women who participate are in general less infectious to others than they believe, and that it is valid and ethical for people with HIV to want to have sex and to value the sexual components of intimacy and love.

Many of the male participants, on the other hand, seem to need reminding that they really do need to think carefully about disclosure of their serostatus to potential partners, rejection and the fear of rejection, the role of anonymous sex, and the level of responsibility they wish to assume for protecting partners who may be seronegative. It is not uncommon among these men that denial and rationalization alternate with despair and depression, leading to transmission-prone behavior.

The group or chat discussions are often heated and contentious, reflecting how close the issues raised come to a person’s core being and his or her sense of vulnerability as HIV-positive. Many seropositive people think, for instance, that they are already targets enough of implicit blame by seronegatives and society in general that they do not wish to assume any special responsibility to protect seronegatives from infection. Others say that “responsibility” is a loaded word that invites reaction and rebellion, even though they may, in fact, feel constrained to act in ways that can be considered responsible. Some have suggested that the messages can be couched better in terms of caring for one’s partners, or that serodifference is only one issue in the larger struggle to learn the skills required to sustain individual relationships and find a supportive social milieu.

A seropositive woman peer facilitator says she has most success posing the issues in terms of choices: “You have a choice as to what role you take on in protecting yourself, your partner, your community.” Facilitators do discuss the issues of “re-infection” and the potential hazards of acquiring new sexually transmitted diseases (STDs) and other infections, but an appeal to self-protection alone is not credible or adequate as a central message.

In this first year, Positive Images is conducting some simple process evaluations as well as assessments of self-reported behavior change or intent to change among callers and group members who have participated in at least several sessions. We are exploring ways of more rigorously evaluating this exciting exploratory project.

Conclusion

Positive Images is a powerful step toward effectively enlisting seropositives in the primary prevention of HIV. Its premise is to validate and support needs for sex and intimacy as well as to enhance the ability of seropositives to love and play with care. By offering easy access to facilitated discussion of an emotionally charged issue that has gotten little attention, the program can deepen the understanding of attitudes and behaviors we need to change and can yield ideas for further intervention.

Authors

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Recent Reports

Prevention for HIV-Infected Youth


A two-step process—consisting of an ethnographic study and pilot testing in three cities—led to the development of a 30-session, three-module, group intervention focusing on secondary prevention and quality of life. According to a review of the design process, preliminary intervention outcomes for the first module included decreases in alcohol, marijuana, and injection-drug use, increases in rates of consistent condom use, and decreases in missed medical appointments.

Researchers collected ethnographic data from 85 HIV-infected youths in New York, Los Angeles, and San Francisco, and inferred four preliminary observations: peer-leadership programs need increased training and support services for at least one year; HIV-infected youths may not understand or adhere to drug regimens or may follow folk beliefs about HIV disease; patterns of substance abuse and associated risk behaviors vary in different settings; and substance-abusing HIV-infected youths often present to health care providers when crashing from a high. (One finding related to the first observation was that peer leadership programs may decrease self-esteem, lead to role conflicts with providers and poor modeling by adolescent leaders, and place unreasonable expectations on the youth leaders.)

Researchers piloted interventions among four to five youths in each city. All pilot participants were 20-year-old gay or bisexual men, injection-drug users, or women.

The resulting intervention model consists of three modules, each made up of eight to 12 two-hour sessions. Modules are psychoeducational and are delivered in interactive small groups (although concerns about anonymity and logistical challenges suggest the need for individual sessions as well). The sessions aim at improving skills, attitudes, and knowledge to encourage change in risk-taking behaviors. To enhance motivation for behavior change, participants are asked to set goals, review their progress at each session, and compare their accomplishments to a standard set by their peers, group leaders, parents, or themselves. They set new goals at the end of each meeting.

The first module aims to increase behaviors that encourage participants to keep medical appointments and maintain HIV medication regimens. In increasing motivation for self-preservation, Module 1 also helps youths deal with HIV-related stigma and serostatus disclosure to family, friends, and sexual partners. It applies daily diaries and storytelling techniques.

The second module focuses on reducing substance abuse and increasing safer sex. Module 2 attempts to interrupt the pattern of “trigger, thought, crave, use” by teaching participants to avoid triggers and to prevent the escalation of thoughts that may lead to substance use. It covers ethical dilemmas such as risking having an HIV-infected baby, intimacy through unsafe sex, refusing sex without a condom, disclosing serostatus even when it might result in a break-up, and refusing unprotected sex with an otherwise loving and giving partner. Each dilemma is introduced through a role-play. Participants also role-play behaviors that support safer sex and resolve interpersonal conflict, brainstorm ways of making condom use more attractive, practice disclosing serostatus, and focus on the concurrence of sex and substance use.

The third module centers on personal responsibility, ethics, and improving quality of life. Module 3 seeks to increase personal satisfaction and strength by reducing negative thoughts, attitudes, and emotional responses and by encouraging participants to accept difficult situations as part of life.

Counseling and Disclosure of Serostatus


Repetition of secondary prevention messages from different sources promotes disclosure of HIV status from seropositive men to their seronegative sex partners, according to a study of 255 sexually active men. Disclosure increased with the frequency of counseling and led to safer sex.

Researchers used written questionnaires to survey 273 men recruited from a health maintenance organization clinic (HMO) and 304 men recruited from a public health clinic. The majority of subjects from the HMO were White with college experience or a college degree, while the majority of subjects from the public health clinic were Latino men with a high school diploma, GED, or less education. Of the 577 men recruited for the study, 255 had engaged in sexual behavior in the previous two months. Researchers divided participants into four groups: those counseled during the post-
Self-Disclosure of HIV Seropositivity


A very small study in rural New Mexico shows that self-disclosure of HIV seropositivity does not necessarily lead to safer sex. Participants agreed that self-disclosure to sexual partners is necessary, especially in long-term relationships, but they also reported that even after disclosure, their partners often did not want to practice safer sex.

Researchers conducted a focus group in which three seropositive women and one seropositive man discussed self-disclosure. The participants were all in their late twenties or early thirties; three were White, and one was Latina. Two of the focus group members had AIDS, and two of the women were former injection drug users. The man was married but sexually active with both women and men; one of the women was in a homosexual relationship but also had sex with men; the two other women were in heterosexual relationships. The focus group discussed five basic topics: a partner’s need to know, nondisclosure combined with safer sex practices, disbelief and denial among seronegative or untested partners, strategies for evaluating partners for potential disclosure, and the reaction of partners upon disclosure.

In some cases, a desire for intimacy prevented disclosure, and in other cases seropositive individuals felt that imposing the use of safer sex practices negated the partner’s need to know, especially with casual partners. Although fear of rejection was also a major reason for not disclosing, only the male focus group member had experienced rejection from a primary partner, his wife. Indecision about disclosure was common among the group, and participants described using their intuition to decide if, when, and how to self-disclose and to judge probability of rejection.

Even after disclosure, participants reported that their seronegative or untested partners often chose not to use protection, confirming that despite widespread knowledge about HIV, many people deny their own HIV risks. One female participant who had disclosed her seropositivity to a long-term male partner said he did not believe her for six years, during which time the couple practiced unsafe sex and had a baby.

Because of previous negative experiences with counselors and the health care system, participants did not rely on counseling professionals for help with self-disclosure. Asked to offer advice to others in situations calling for self-disclosure, they offered no specific tips, only general advice such as “follow your feelings.”
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