HRSA CARE ACTION

PROVIDING HIV/AIDS CARE IN A CHANGING ENVIRONMENT MARCH 2003

Prevention Is Treatment: Prevention With Positives in Clinical Care

Today, HIV-positive individuals are living longer, healthier, lives. Yet, maintaining safer sexual and drug use behavior can become increasingly challenging for some HIV-positive individuals. Indeed, unsafe sexual behaviors and sexually transmitted diseases are increasing in certain subgroups of people living with HIV disease.[1] For example, studies have shown rising rectal gonorrhea rates among men who have sex with men (MSM) in San Francisco, a population among whom HIV prevalence is known to be high.[2] Other evidence suggests that risk-taking behaviors among people who are HIV positive may increase after initiation of highly active antiretroviral therapy (HAART), a development due in part to what has been termed "treatment optimism"—that is, an overconfidence in today's treatments that results in complacency.[3]

HIV transmission has long been known to involve the behavior of both the HIV-negative and the HIV-positive person, but only in recent years has prevention among HIV-positive individuals in care emerged as a national priority.[4] The goal of prevention among positives is both to reduce the spread of HIV and other consequences of risky behavior and to prevent exposure to opportunistic infections among people living with HIV disease.

HIV/AIDS prevalence in the United States is between 850,000 and 950,000, and approximately 40,000 new HIV infections occur every year.[5,6] As prevalence continues to grow, each behavior in which an HIV-negative person engages carries more and more risk.[7] Thus, the danger of ignoring the need for prevention interventions among people living with HIV disease is greater than ever before. Clearly, more, not less attention to prevention is needed.

From 350,000 to 528,000 people with HIV make use of the clinical setting and receive HIV care each year. Although linking them with prevention services could—and should—be a logical component of any comprehensive prevention strategy, that is not the situation today, as data from a variety of sources indicate.[8,9] A wide range of barriers must be overcome, a review of standard practice must occur, and implementation of national guidelines (under development) for providing prevention for HIV-positive people in clinical settings is necessary if prevention is to become a standard part of clinical HIV management.

Importance of the Clinical Care Visit

The clinical care visit offers an important opportunity to help prevent the spread of HIV disease. The opportunity is especially valuable for Ryan White Comprehensive AIDS Resources Emergency (CARE) Act providers, whose client base of underserved populations have historically lacked access to health care and related information and may be most in need of prevention services. This opportunity must not be ignored: Most CARE Act providers have ongoing, trusting partnerships with their patients

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and are in a unique position to provide risk reduction and prevention services in clinical settings. Providing these services on an ongoing basis is crucial, because episodic counseling and testing do not appear to alter high-risk behaviors.[10]

The goal of prevention among positives is both to reduce the spread of HIV and other consequences of risky behavior and to prevent exposure to opportunistic infections.

The HIV/AIDS Bureau (HAB) has made prevention with positives a priority in light of evidence that documents ongoing high-risk behavior among people living with HIV disease and emerging evidence of practical, successful interventions. Through programs such as those currently being initiated through the CARE Act's Special Projects of National Significance (SPNS) program, models for delivering preventive services in the clinical setting will be investigated. In the words of HAB Chief Medical Officer Dr. Laura Cheever, "Prevention, considered a part of primary care, is a fundable service under the Ryan White CARE Act, and grantees should take every opportunity to incorporate prevention into routine clinical practice."

Prevention Works

Current surveillance information indicates that although prevention interventions have not been equally successful across all populations, important strides have been made:

- Seroprevalence among white MSM in the United States declined by 50 percent between 1988 and 1993.
- Seroprevalence among injection drug users (IDUs) in New York City declined dramatically in the 1990s.[11]
- Perinatal transmission declined by 75 percent from 1992 to 1998.
- HIV prevalence among young people in the Job Corps was cut by one-half.[12,13]

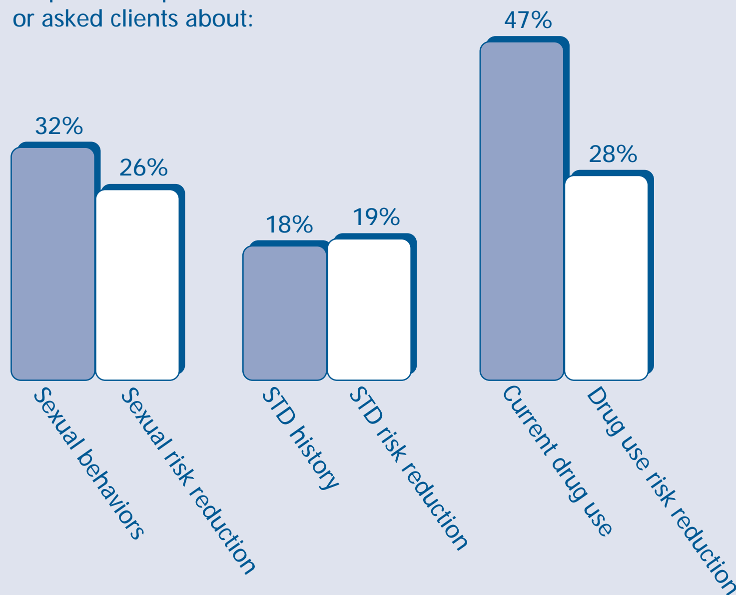
Many HIV prevention efforts that have historically targeted HIV-negative persons can be extrapolated for use among people living with HIV disease in various clinical and treatment settings. Experience shows that HIV prevention programs that are comprehensive in nature are most effective.[14] A brochure and a condom are not enough: People engaging in HIV risk behaviors need an array of prevention messages, skills, and support to help them reduce sexual and drug-related risks.

Drug injectors, for example, not only need strategies to help them stop sharing needles and to help them protect their HIV-negative sexual and drug using partners; they also need to learn ways to protect themselves from reinfection. HIV prevention interventions for the vast majority of substance users who are not in drug treatment also must address the sexual risks that are common among people who use drugs, including "crack" cocaine, marijuana, and alcohol.[15] HIV prevention interventions must occur in the larger context of a comprehensive approach to resolving problems often associated with risk behaviors. This approach must reflect not only the public health goal of eliminating risk behaviors but the reality that immediate elimination may be neither probable nor possible. Thus, for some individuals harm reduction strategies that can support the movement of individuals to safe behaviors based on what they are able to achieve today may be more effective than strategies that promote only the ideal.

The resources required for creating and implementing effective prevention programs are considerable, yet they are cost-effective when compared with the cost of treating HIV disease *and* the opportunity lost when an individual is not able to contribute to family and community. And with the rising costs of treating HIV, effective prevention is more cost-effective than ever. New estimates from the Centers for Disease Control and Prevention (CDC) are that if only 1,255 infections are prevented each year, CDC's federally funded HIV prevention efforts in the United States achieve cost-effectiveness. If only 3,995 infections are prevented, our Nation's investment in HIV prevention actually saves money.[16]

Episodic counseling and testing do not appear to alter high-risk behaviors.

Seattle Survey Shows Shortage of Prevention Interventions in Clinical Settings
(n = 74)



Source: Natter J, et al. Integrating HIV prevention and care services: the Seattle "Collaboration Project." *J Public Health Manage Pract.* 2002;8(6):15-23.

Barriers to Implementing Prevention in Clinical Settings

Published accounts of validated, effective prevention interventions for people living with HIV in clinical care have been scarce. Several demonstration projects are underway, but recent data confirm that the concept of prevention with positives, much less the process, is still not well defined or understood by providers and patients in many care settings.[17] This lack of understanding is one of many important barriers to implementation of new prevention initiatives.

Barriers to implementing prevention with positives programs can be loosely grouped into client-related, provider-related, and system-related factors. Despite some overlap, this grouping provides a framework in which to understand, address, and overcome these barriers.

Client-Related Barriers

With the lines between prevention and treatment fading, the care system for people who are HIV positive must attend to both the medical and support services related to HIV treatment and the behavioral and social supports needed to prevent the spread of infection. However, several barriers prevent implementation of a balanced approach.

Stigma. The stigma of HIV disease often transcends all other barriers to care and prevention services. Stigma plays a role in every aspect of the adequate management of HIV and is a factor in the structural divide between prevention and treatment. The fear of stigmatization may have relegated the role of exercising prevention strategies primarily onto uninfected people and inadvertently removed responsibility from those who are HIV positive.[18] For example, fear of stigma can lead people living with HIV disease to not inform their partners of their serostatus, thereby encouraging risky behavior. Overcoming stigma is a monumental problem that requires intense education and cooperation among all stakeholders.

Treatment Optimism. Complacency about the need for HIV prevention may be among the strongest barriers communities face as they plan to meet the prevention needs of the new century. One contributing factor is "treatment optimism," or excess enthusiasm for HAART in managing HIV and the resulting view that HIV is a chronic, manageable disease.[19]

The success of HAART is good news for the people living longer, better lives because of it, but the availability of treatment may lull people—both those who are HIV positive and those who are HIV negative—into believing that preventing HIV infection is no longer crucial. The success of treatment may be especially misleading to younger generations, who may have not seen the most devastating effects of the early years of the epidemic. The reduced viral loads that result from effective treatment with HAART lead to the belief among some people that the probability of HIV transmission is lessened.

The problems of treatment optimism extend beyond its effects on risk-taking behavior: Many people do not realize that we are still learning about HAART's long-term effects on the body and effectiveness against HIV. Moreover, just as safe behaviors are difficult to maintain, so are treatment regimens; poor adherence is fueling the development of drug resistance. And when drug resistance is coupled with a relaxation in preventive behaviors, treatment-resistant strains of HIV evolve and spread. Confusion and misinformation about the need for prevention add a new dimension of complexity for both program planners and individuals at risk.

Prevention Burnout. Similar to the concept of treatment optimism—and equally lethal—is "prevention burnout," or burnout in people hearing the same prevention message for more than two decades.[20] People long affected by the epidemic may feel that they have heard all there is to hear about prevention and may grow frustrated with prevention behaviors. They may also be reluctant to change behaviors, including notification of partners, particularly with casual partners. In addition, they may be resigned to eventual seroconversion.

Changing Demographics. The cultural, sociodemographic needs of emerging high-risk groups require messages and interventions that differ from those used two decades ago. Today, a person diagnosed with AIDS is more likely than ever to be African American, Latino, or female. One-half of all new HIV infections are estimated to be among people under age 25. Heterosexual contact is an ever-increasing risk factor. Preventing new infections through prevention with positives interventions requires a detailed understanding of the cultural context of HIV today, including knowledge about the behavioral patterns of HIV-positive individuals

Comorbidity. The health and social problems that commonly coexist with HIV infection have increased in both frequency and number over the past decade. The HIV care community has struggled to create comprehensive systems of care that respond to these problems, which must be considered when developing prevention with positives programs. For example, common comorbidities like mental illness and substance abuse make both treatment adherence and prevention adherence more difficult. And just as treatment adherence is exacerbated by poverty, poor housing, lack of employment, and poor access to health care, so, too, is prevention. Effective prevention with positives programs cannot be implemented without simultaneously dealing with those problems.

System-Related Barriers

Prevention with positives has emerged as a unique, identifiable set of services targeted to a well-defined subset of the population only in recent years. Previously, prevention interventions targeted the HIV-negative community to a much greater extent than they did people living with HIV disease. Consequently, the prevention with positives concept was only a small part of the collective approach to prevention in the United States and was not a significant component of health policy agendas.

Moreover, preventive medicine is only a sometime component of the American health care system. The approach to health care in the United States continues to be one of treatment rather than prevention, and this quality has been manifested in the system that has emerged to care for people living with HIV disease. For example, until its reauthorization in 2000, the CARE Act placed prevention largely outside the realm of fundable services in order to reserve resources for medical care and support. In the past, prevention was not effectively incorporated into the biomedical model of HIV care; funding sources usually reimbursed for prevention or treatment, but rarely both.

Fallout from the separation of prevention and care in the American medical system has resulted in lack of coordination between providers of prevention and care services. With diverse funding streams and spending authorities, this lack of coordination is understandable. In the fields of HIV prevention and care, Federal agencies are taking steps to improve the level of coordination. New policies of the U.S. Department of Health and Human Services reflect that prevention and care run along a continuum and

Prevention with Positives: Resources on the Web

Visit the Web site created to support the SPNS HIV Prevention Initiative to find a wide array of resources: *http://ari.ucsf.edu/policy/pwp.htm.*

that care providers can play a role in bridging this gap. However, an approach that reflects the prevention–care continuum is still relatively new and is only beginning to be reflected in many care settings.

Provider-Related Barriers

Several studies indicate that care providers are ill-equipped to offer adequate prevention services to HIV positive persons.[21,22,23] Some providers feel uncomfortable or unable to offer these services. Others do not see prevention as part of their clinical duties. Some feel tension between their role as patient advocates and their broad public health role. In addition, prevention may be given low priority by providers relative to the more pressing health needs of an HIV-positive client. In an environment of increasing demands on providers, lack of time is also a critical concern. Solutions to these barriers include innovative configurations of personnel; linkage of preventive services with specific treatment settings, such as drug treatment and mental health treatment clinics; and increased funding from all sources, both public and private. Provider training that addresses these issues, however, is probably the single most important way to improve access to prevention with positives in the clinical care setting.

Finding Solutions

Agencies throughout the Government are implementing programs designed to increase prevention with positives efforts.

HRSA Activities

HRSA is currently implementing several initiatives with the goal of making prevention with positives a routine part of HIV management.

Research Questions for the SPNS Initiative
Prevention With HIV-Infected Persons Seen in Primary Care Settings

- Are provider-driven interventions in clinical settings effective?
- What specific models are most effective with different target populations (e.g., men of color who have sex with other men, heterosexual women, rural drug users)?
- How can clinicians effectively assess risk and produce behavior change, given time constraints?
- Do clinicians have the skills needed to effectively conduct prevention interventions?
- What can be done to strengthen clinician skills?
- What tools are effective as providers conduct risk assessments and prevention interventions?
- What are the obstacles to conducting HIV prevention activities with HIV-infected individuals in a clinical setting and how can they be overcome?
- Can an integrated approach that includes physician assessment and referral improve behavioral outcomes?
- What roles can multidisciplinary teams play in risk assessment and producing behavior change?

Prevention With HIV-Infected Persons Seen in Primary Care Settings is a 5-year initiative of the CARE Act SPNS program. During Year 1, a grant was awarded to the University of San Francisco for establishment of an Evaluation and Support Center for the initiative. The center is currently developing a multisite evaluation design for behavioral interventions with HIV-infected persons. In Years 2 through 5 of the initiative, four or five demonstration projects will be funded as part of the SPNS program's effort to identify more effective prevention for positives interventions in the care setting (see box).

The Prevention for HIV-Positive Persons Project is a HRSA/CDC initiative comprising six demonstration projects. The interventions target HIV-positive individuals in care as well as those who are not in care. This initiative also has a component that links HIV-positive people to care.

HIV Prevention for Persons Living With HIV/AIDS: Intervention in the Clinical Setting is a video/CD-ROM presentation that includes potential solutions to providing prevention messages in clinical settings, such as development of prevention protocols specific to the care delivery site. It also provides suggestions on effective communication with clients regarding prevention.

The AIDS Education and Training Centers have made HIV prevention among HIV-infected patients a priority topic area in their clinical care education curricula.

National Institutes of Health Consensus Statement

Several national organizations and Federal agencies have issued recommendations regarding prevention, but recommendations specific to providing prevention with positives in clinical care are rare. In 1997 the National Institutes of Health (NIH) developed a consensus statement on HIV risk behavior prevention that included the following six conclusions and recommendations:

1. Preventive interventions are effective for reducing behavioral risks for HIV/AIDS.
2. The epidemic is shifting toward the young, particularly gay members of ethnic minority groups, and it is increasing among women.
3. Programs to help HIV-positive individuals avoid risky behavior over long periods of time are needed.
4. Legislative restrictions on needle exchange and on programs aimed at youth need to be lifted.
5. Funding for drug and alcohol treatment needs to be increased.
6. The breach between HIV/AIDS prevention science and legislation needs to be removed.[24]

Institute of Medicine Report

In 2001, the Institute of Medicine (IOM) issued the report *No Time to Lose: Getting More From HIV Prevention*, which examined the state of HIV prevention efforts primarily within the CDC. However, the report also reviewed prevention with positives activities within HRSA.[25] The authors called for enhanced HIV prevention efforts in the clinical setting as part of the standard of care for HIV-infected persons. The report pointed out that although the goal of the CARE Act is to ensure a continuum of services for HIV-positive persons, the focus has been on treatment and support services related to primary care. The IOM stated that health care providers should have adequate time, training, and resources to conduct effective HIV prevention counseling and acknowledged that enabling this activity may require adjustments in health care provider time allocations, specific financial incentives from public and private sources of health coverage, or both.

Guidelines for Incorporating HIV Prevention and Care

Guidelines using an evidence-based approach are being developed through a collaboration of HRSA, CDC, NIH, and the HIV Medical Association of the Infectious Disease Society of America. The guidelines, which are not yet available to the public, have three major components:

1. Recommendations for risk screening to identify patients at highest risk of transmission. The guidelines include specific recommendations for sexual behavior assessment at the initial and each subsequent visit.
2. Recommendations for behavioral risk-reduction interventions and referrals for major underlying psychosocial barriers to behavior change.
3. Recommendations for facilitating notification and counseling of sexual and needle-sharing partners of infected individuals.

These guidelines are based on the idea that clinicians caring for HIV-infected persons can play a key role in helping their patients reduce risk behaviors, even in constrained practice settings. The recommendations address sexual and drug injection behaviors, because

Bringing People Into Care

A new report on the HIV/AIDS Bureau (HAB) Web site describes CARE Act efforts to enhance outreach to bring people with HIV into care. The summary of a 2002 National CARE Act Technical Assistance call includes a review of HAB's outreach policy (which applies to all grantees), some examples of how grantees are implementing outreach, a consumer perspective, and resources. For further information, review the report at: *http://hab.hrsa.gov/tools/TACR2002jun.htm*.

those behaviors lead to nearly all new HIV infections in the United States. The document will provide information on the strength of each recommendation, the quality of evidence supporting the recommendation, and the outcome for which the recommendation is related. Few accounts of validated prevention with positives interventions have been published in the literature, so many of the recommendations will be based on interventions among high-risk HIV-negative persons.

New Multimedia HIV/AIDS Awareness Campaign Launched

Viacom and the Kaiser Family Foundation have launched KNOW HIV/AIDS, a campaign to educate the general population about the global impact of AIDS and to promote prevention and testing among higher-risk populations, including young people, African Americans, Latinos, women, and men who have sex with men. The campaign will raise awareness about HIV/AIDS through public service announcements, television and radio programming, and free print and online content. For more information, go to *http://www.knowhivaids.org/* or call toll-free (866) 344-KNOW (5669).

Complimentary to the emergence of these guidelines is an ongoing study at George Washington University in Washington, D.C. Authors are currently evaluating the financial, regulatory, and legal barriers related to the reimbursement of prevention activities through Medicaid. Findings are currently being drafted and should be available to the CARE Act community by mid-spring.

Conclusions

Several overarching goals must be achieved if prevention efforts for HIV-positive persons in clinical care are to be improved.

From a provider perspective, a common understanding of the services needed for prevention with positives must be developed in collaboration with all stakeholders; those services should be made part of the standard of care. For example, integration of services addressing substance abuse, mental illness, and other factors that hinder safe behavior is of paramount importance. Also, young people and other emerging populations at high risk for HIV need comprehensive, sustained health information and support so that they may develop the lifelong skills necessary for avoiding risky behaviors. Providers need tools for addressing phenomena like treatment optimism and epidemic fatigue in an open and frank manner.

From a funding perspective, prevention with positives needs to become a concrete, billable, fundable activity if patients are going to receive prevention services. Moreover, the confusion as to whether prevention services are reimbursable through certain programs is not always well understood and must be addressed.

From a structural perspective, barriers separating care and prevention should be minimized, and the idea that prevention is treatment should be advocated. Providers must be made aware that prevention with positives is considered part of primary care and is currently reimbursable under the CARE Act. Risk assessment should be ongoing, not just at intake, and should be modified to reflect the needs of each segment of the target audience. Provider training that targets every aspect of prevention, including assessment, intervention delivery, and outcome measurement, needs to be a high priority. This training should be ongoing, and it should be available to all those involved in care and service delivery.

Finally, a protocol for establishing successful prevention with positives programs for all risk groups needs to be established, and HIV-positive persons need to be included and involved in the process of developing and evaluating models. Community epidemiological data need to be used to develop tailored clinical interventions, which should be targeted toward emerging high-risk groups, particularly youth.

Although significant breakthroughs have been made in managing HIV disease, the need for prevention in clinical care has never been greater. In the context of growing HIV prevalence in the United States, prevention among HIV-positive people represents the best opportunity for stopping the epidemic.

—Madhavi Reddy Patt, M.D., M.P.H.

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