Being HIV-positive does not mean a person stops being sexual. Today, with the success of HIV treatments, more people are living with HIV longer than ever before, and studies indicate that as many as 70 percent of people living with HIV are sexually active at some point after diagnosis. Prevention strategies that facilitate risk reduction among people with HIV are of vital importance.

But understanding what prevention with people living with HIV means and how it can be incorporated into existing prevention approaches is still evolving. This article reviews some of the basic concepts of prevention with people with HIV, explores how and why this strategy should differ from traditional HIV prevention, and offers providers suggestions on how they might integrate prevention into their work with people with HIV by using a “positive sexual health” approach.

Prevention with People Living with HIV

Most people living with HIV are conscientious and careful in their sexual behavior. A meta-analysis of more than 60 studies found that two-thirds of these studies demonstrated that HIV-positive men who have sex with men do “as much if not more” as HIV-negative men to assure that HIV is not transmitted.1 While rising HIV rates confirm that some HIV-positive people continue to have sex that transmits HIV, it is only recently that prevention providers have come to truly recognize the burden HIV places on sexual activity of people with HIV as they struggle to manage the possibility of transmitting HIV to others.

It was only last year that the U.S. Centers for Disease Control and Prevention prioritized prevention with people with HIV. The CDC’s policy statement, “Advancing HIV Prevention,” recommends expanding testing for those unaware of their HIV-positive status, improving access to medical care, increasing partner notification assistance, and providing prevention services to enhance risk reduction for people with HIV.2

Although the initiative highlights the importance of HIV prevention services for people with HIV, it prescribes no particular approach for these services. Many providers are relying on traditional prevention models and messages to achieve new goals. These traditional messages focus primarily on persuading HIV-negative people to avoid behaviors that may lead them to contract HIV. Obviously, except in terms of “reinfection,” the goal of avoiding HIV will not motivate people who already have HIV.

In fact, mental health professionals such as Berkeley, California psychotherapist Walt Odets believe that such messages may actually discourage prevention among some HIV-positive people.3 While well intended, HIV prevention messages such as “wear a condom every time” or “reduce your harm” may increase the stigmatization of HIV, isolate people living with the disease, and diminish an HIV-positive person’s sense of self-efficacy and self-worth, two psychological factors that are key to risk reduction.4,5

Even when prevention with people with HIV approaches have gone beyond these traditional messages—for example, seeking to persuade individuals to embrace activities to avoid further harm to themselves and others—they too often apply the negative motivators for behavior change that are the bedrock of traditional prevention. For example, many interventions encourage people with HIV to recognize their responsibility to avoid infecting HIV-negative partners; others focus on the real risk of contracting other sexually transmitted diseases that might complicate living with HIV. In each case, these messages can communicate that sex may be too dangerous for people with HIV.

“This article uses the term “prevention with people with HIV” rather than “prevention for people with HIV,” the term used by many in the field, to acknowledge the key role that HIV-positive people play in developing and informing prevention work.
Editorial: Revolutionary Prevention?

Robert Marks, Editor

Since 2003, when the CDC announced a new initiative emphasizing "prevention for positives," HIV prevention providers have criticized the plan as sacrificing uninfected people in its zeal to target people with HIV. While the agency has since backtracked—also articulating the importance of prevention for HIV-negative people—there is no doubt that prevention with and for people with HIV is now a national priority.

The CDC's shift is not without merit. HIV transmission, of course, always involves a person with HIV—whether, or not, that person knows he or she is infected. And for many years and for many reasons, prevention intervention was disproportionately focused on people without HIV. As Kim Gilgenberg-Castillo states in this issue of FOCUS, the revolution in HIV treatment, which has so changed the lives of people with HIV, also requires a revolution in HIV prevention and, specifically, in prevention with people with HIV.

But, while prevention should help people with HIV reduce the risk of transmitting HIV, such efforts will never be enough to fully respond to the epidemic, because many people with HIV do not know they are infected. For all intents and purposes, these individuals do not perceive themselves as people with HIV—and how they see themselves is all that matters.

For this reason, the CDC initiative also prioritizes an increase in access to HIV testing. This is a noble and reasonable public health goal—an attempt to ensure that individuals know their HIV status—but the initiative's biggest flaw seems to be its failure to acknowledge human nature. That is, the language of the initiative seems to underplay the fact that the sexual activity that leads to HIV seroconversion always involves an HIV-negative person, and that risk and risk reduction always unfolds in the context of the dynamic between two partners, one HIV-negative, the other HIV-positive, and each with his or her own prevention needs.

On the other hand, it is fortunate that the CDC's actions have provoked more than just criticism. At least in the area of prevention with positives, they have sparked the sort of creative thinking that goes beyond the black-and-white language of the initiative. A good example of this is Gilgenberg-Castillo's discussion of positive sexual health, which like Douglas Hudson's reflections on counseling challenges, is applicable to both HIV-positive and HIV-negative individuals. While we are in the early stages of a "prevention revolution," reading about positive sexual health confirms for me that there are innovators on the front-lines of this insurgency.

References


HIV treatment success has meant that a much higher percentage of people with HIV are able to lead longer and more fulfilling lives, which extends beyond mere survival and includes being sexually active. This treatment revolution can be matched with a similar prevention revolution. Prevention with people living with HIV can be described beyond negative motivators by acknowledging sexual activity as healthy and supporting the sexual needs and behaviors of people living with HIV. In contrast to the deficit-based models of traditional HIV prevention, which depend on emphasizing the danger of sex, positive sexual health is a strengths-based approach. It views sexual expression as a natural, restorative activity that can mediate the oppressive aspects of living with HIV, foster self-esteem, and increase a person's ability to control sexual situations and implement HIV prevention steps.

Does Prevention Teach That Sex is Wrong?

A case example demonstrates the drawbacks of "safer sex" counseling that does not support positive sexual health. Jason, a 23-year-old, Native American gay man, came into a residential housing and medical center for young people living with HIV. Normally gregarious, Jason sat down and proceeded to break down into tears. After a year-long stint of abstinence due to his HIV-positive diagnosis and the subsequent break-up with his boyfriend, he had engaged in a recent sexual encounter that left him devastated.

After a sleepless night marked by the pangs of intense loneliness, Jason went to an adult bookstore and performed oral sex on a man he did not know. Although this encounter relieved his sense of isolation temporarily, his loneliness returned shortly, this time complicated by guilt and shame. Jason was angry at himself for not disclosing his HIV-positive status, upset that he might have infected another person, and worried about the legal implications of transmitting HIV; would he go to jail?

Most people have consensual sex without having to worry about spreading disease or being incarcerated. Yet, for Jason and others with HIV, sex is different. It can feel both punitive and pleasurable. How does anyone—a client or counselor—respond appropriately to a sexual situation that is so
Unlike models that emphasize the danger of sex, positive sexual health frames sex as a restorative act that can foster self-esteem and increase the ability to control sexual situations.

therapy. Providers should remember to approach these issues slowly, taking cues from the individual client about his or her willingness to discuss them, at the same time keeping the door open to further conversation when, or as, the client is ready to engage in this conversation. Sexuality, like HIV, is a constant that cannot be addressed in a single session. Spending 10 to 20 minutes with the client talking about sex can be effective, if done routinely, to reduce client discomfort and facilitate critical thinking. The goal is empowerment rather than restraints.

The key to meaningful and sustainable risk reduction lies in acknowledging that participation in risk behavior is not a result of personal deficiencies in knowledge or intention but is mediated by contextual influences. Providers cannot be expected to change the world, but any of us can make an effort to build a supportive counseling environment that strengthens a client's ability to resist negative external forces.

One way to do this is to redefine sex so it is not seen as a linear continuum ranging from “safe” to “unsafe,” but as a much more complex matrix that includes, among other things, passion, love, lust, hope, comfort, joy, fidelity, and reproduction. It is the role of the provider and the client to strive to appreciate the existence and power of these conscious and unconscious desires and their effects on sexual decision making. This can be achieved by asking clients about their lives, their role models, and the values and beliefs they rely on to guide decision making. What are the origins of these beliefs? Do they validate or diminish a client's sense of self? Through this deep process of self-reflection, clients and providers can come to understand how cultural “scripts” about “right” or “wrong” become internalized, undermine self-acceptance, and distort the sense of control needed to adhere to self-protective behaviors.

Exploring with clients how HIV has changed their lives, particularly in terms of comfort with sexuality, is also crucial. Unprotected anal intercourse with an anonymous partner, for example, may not be about intentionally disregarding the safety of self or others; it may represent a means to fight against the anxiety and isolation that can accompany the stress of being diagnosed with a terminal illness. It is not meant to be destructive; rather, it may represent a person's lack of consciousness about how sex serves an unmet psychological or physical need. In fact, clients who recognize the role sex plays in providing them with physical satisfaction, as well as social connection, appear to take greater steps to protect these valuable sexual relationships.

Since sex can be as loaded a topic for providers as it is for clients, particularly when a client has HIV, it is important for providers who participate in these conversations to be attuned to their personal values and beliefs about sex, illness, and loss. Overlooking one's own attitudes and beliefs can interfere with a provider's ability to incorporate a sexual health approach into his or her practice. Finally, it may be useful for providers to seek consultation to address feelings of impatience or judgment that might interfere with the ability to remain neutral.

Conclusion

The revolution in prevention requires providers working with people with HIV to offer these clients an affirmative conception of sexual activity. Providers using a positive sexual health approach seek to eliminate barriers to sexual health, such as HIV-related stigma, by offering risk reduction counseling from a perspective of strength building. A positive sexual health strategy pays particular attention to the unique issues that arise in the context of living with HIV such as loss, uncertainty, isolation and hope. It offers clients an opportunity to live with HIV without sacrificing quality of life.

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References

Many people with HIV lead what many of us would call “normal” lives. They have jobs, homes, and health insurance, and work at staying healthy by taking care of themselves: exercising, eating right, and avoiding recreational drugs or alcohol to excess. It is not uncommon, however, to see people with HIV who are homeless, have psychiatric and substance abuse issues, and continue to engage in risky sexual behavior. These clients can be inconsistent about keeping appointments, have difficulty participating in prevention education conversations, or be unwilling to practice prevention methods.

Under these circumstances, prevention counseling with people with HIV can challenge a practitioner’s capacity to provide client-centered care, for example, to avoid labeling a client as “non-compliant” or to respect a client’s difference while maintaining clinical beliefs and personal values. This article looks at some of these issues through the lens of two case studies and offers insights into not only working with “difficult” clients, but also raising the topic of HIV prevention with any HIV-positive client.

Melanie: Confronting Discrepancies

Melanie is a 21-year-old HIV-positive transgender client who came in to discuss her difficulty finding a job. It was a busy day, and I felt rushed while listening to her. She showed me a rash and said that it was “just anxiety.” I recommended that she check in with her doctor.

A few days later, Melanie came by to let me know that she had contracted syphilis, for which she had been treated. Melanie had said she had been abstinent over the past few weeks from both methamphetamine and sexual activity. I recognized the discrepancy in her stories, but felt hesitant to confront her. Melanie, who is homeless and often trades sex for money, is fragile and frightens easily, and she is often out of touch for weeks at a time. But, her dream is to get her life in order, and to find a career and a strong intimate relationship.

How might I assist Melanie in meeting her dreams? What were my priorities for her? Did my intentions for her match what she perceives as her desired future? How should I deal with my fear of confronting her about the discrepancy in her story?

Through the process of discussing my reactions to Melanie with my supervisor, I realized that Melanie might feel as uncomfortable about our interaction as I felt.
suspected Melanie knew that I had a different agenda for her, but that she was unsure what to do about it. I knew I needed to be willing to put my own process aside in order to feel comfortable seeing and hearing Melanie for who she is, what she deals with in her life, and how she and I can work together to assist her in reaching her goals.

I also noticed that, despite my best intentions to feel otherwise, I was blaming Melanie for using methamphetamine and having unsafe sex. I seemed to be avoiding conversations of risky behavior in order to not overwhelm or “scare away” Melanie. Through the process of peer support, self-reflection, and my belief that compassionate prevention education works, I was able to develop a “next step” plan for my interaction with Melanie. I resolved to talk with her, this time paying closer attention to her wishes.

Nicolas: Remorse and Anger

Nicolas, a 19-year-old bisexual client with HIV, described having unsafe sex with a guy—he called him John—that he had just met. John was from out of town, and because John had not raised the issue of HIV or sexually transmitted disease status, Nicolas had decided that it was okay to have unprotected anal sex. Nicolas said, “I'll probably never see the guy again anyway.”

This response was not unusual for Nicolas, but he had never been so “matter of fact” about it before. As we talked, I realized that he seemed disassociated from the act. At first, his feelings appeared to be remorseful. He spoke as if asking me for approval or forgiveness. But, after a few minutes, he began to rationalize his actions and he became angry, saying, “That's the way it is.”

I did not know what to say. How could I show him that it was okay to discuss his actions and work through anything that confused him? How could I help him reconcile having HIV with feeling normal human emotions and needs? How could I assist him in understanding the value of his own safety and health?

After the interaction, I realized that I had listened to Nicholas in a way that was different from the way that I had listened before. I recognized that I had been able to let go of my pre-conceived judgments about what Nicolas should have done simply by focusing on what Nicolas was saying and what he wanted from our meeting.

Nicholas confirmed concerns he’d raised in the past about being afraid of rejection. No matter how uncomfortable it had been for him to not disclose his HIV status, it felt better than the possibility of rejection that might come from admitting to be HIV-positive.

By paying attention to my thoughts and reactions to Nicolas, and by allowing myself to show concern as well as be direct with him, I gained his trust, which enabled him to feel more willing to be open and vulnerable without the fear that I would reject him. By taking responsibility for my own judgments and agendas, I removed the possibility that I would “attack” Nicolas, and this created room for discussion that led to explorations of truth both for Nicolas and for myself. As a result, I was able to encourage him to focus on the relationship between his self-esteem and his fear of rejection. I was also able to talk to him about the remorse he felt and whether it truly balanced the avoidance of rejection.

Conclusion

One of the most important aspects of client-centered prevention counseling is to help clients gain confidence in addressing issues of self-esteem and personal desire (including sex and drug use). A client’s lack of confidence creates not only obstacles to deeper explorations, but also an atmosphere of tension between client and counselor, which a client may take personally or perceive as shameful or as a sign of failure.

Providing prevention counseling to HIV-positive people whose lives are very different from my own can be challenging. I have found it helpful to step back from myself and to try to avoid making premature conclusions about the nature of the client's life or his or her wishes. I have also had to accept that sometimes clients make decisions with which I do not agree and sometimes I have to struggle with my feelings about them. I have to remind myself that everyone’s path to health is different and that my job as a counselor is to help a client find his or her path and move along it in the best way possible.
Recent Reports

Risk Reduction for HIV-Positive Individuals

A study that compared affirmative HIV prevention messages with negative ones among sexually active people with HIV found fewer instances of unprotected sex following interventions that emphasized the negative consequences of sexual risk behaviors. The study contrasted “gain-frame” messages, which focused on the benefits of protective behavior with “loss-frame” messages, which focused on the serious consequences of high-risk behavior.

During a 10-month period in 1999–2000, researchers recruited 886 HIV-positive participants, who had been sexually active within the prior three months, from six large California HIV clinics. Interviewers administered demographic and behavioral questionnaires in private rooms, allowing participants the option of recording sexual behavior responses on paper rather than answering aloud. They reassessed participants up to seven months following the end of the intervention.

Researchers randomly assigned each clinic to one of three interventions: gain-frame, loss-frame, and control group. Two clinics implemented gain-frame counseling, emphasizing the benefits of practicing safer sex; two clinics implemented loss-frame counseling, emphasizing negative consequences of unsafe sex; and two clinics implemented the control condition, an intervention to enhance adherence to HIV antiviral therapy.

Of the 585 participants who completed follow-up interviews, 175 were in the gain-frame group, 214 were in the loss-frame group, and 196 were in the control group. The groups did not differ significantly in terms of age, gender, viral load level, CD4+ cell count, whether they were on HIV antiviral treatment, or years since testing HIV-positive. Collectively, 63 percent of all participants were male; their mean age was 38 years.

The three groups did differ significantly by sexual orientation and race. Men who have sex with men made up 65 percent of the gain-frame sample, 80 percent of the loss-frame sample, and 75 percent of the control sample. African-American men comprised 21 percent of the gain-frame sample, 18 percent of the loss-frame sample, and 8 percent of the control sample.

In all three groups, among participants with one partner at baseline, there was no significant change in instances of unprotected sexual encounters. Among those with two or more partners at baseline, however, instances of unprotected sex did change: it decreased four percent in the control group and increased 10 percent in the gain-frame group, although these changes were statistically insignificant. In the loss-frame cohort, however, unprotected sex decreased by 38 percent, which was statistically significant.

Having HIV may predispose patients to think in terms of potential losses, thus accounting for the greater effectiveness of loss-frame messages. Alternatively, focusing on positive consequences of safer behavior may not have a strong influence on individuals who already have HIV. However, the findings may be compromised by the smaller sample size in the gain-frame group, as well as lower baseline prevalence of unprotected sex in this group compared with the loss-frame group.

Behavioral Risk among People with HIV
Crepaz N, Marks G. Towards an understanding of sexual risk behavior in people living with HIV: A review of social, psychological, and medical findings. AIDS. 2002; 16(2): 135–149. (U.S. Centers for Disease Control and Prevention.)

A comprehensive review of the literature on risk among people with HIV highlighted, among the variety of variables associated with risk, the roles of knowledge about HIV and perceived behavioral control over condom use in leading to an increased likelihood of unprotected sex.

Researchers located 61 articles published between 1980 and 2001 through keyword searches in AIDSLINE, MedLINE, and PsychINFO. All studies contained a measure of sexual risk behavior in HIV-positive men or women, as well as a measure of at least one social, psychological,
Researchers divided participants into three groups according to risk level of unprotected anal sex with partners at risk for contracting HIV: almost 60 percent of participants reported no unprotected anal sex with HIV-negative or status-unknown partners; 14 percent reported unprotected receptive—but not insertive—anal sex with these partners; and 23 percent reported unprotected insertive anal sex with these partners.

Overall, unprotected anal insertive sex was significantly more common with HIV-positive partners than with HIV-negative partners. Further, only 6 percent of participants had unprotected anal insertive sex with partners who they knew were HIV-negative.

Participants in both groups that engaged in any unprotected anal sex—insertive or receptive—with at-risk partners were significantly more likely than those in the third group to use nitrate inhalants (poppers). Compared to men in the other two groups, men who engaged in unprotected anal insertive sex with partners at risk for contracting HIV also reported more temptation for unsafe sex and less perceived responsibility to protect their partners from HIV.

Men reporting only unprotected anal receptive sex with partners at risk for HIV reported lower levels of anxiety compared to men in the two other groups. However, men engaging in unprotected anal receptive sex experienced slightly higher levels of loneliness than men engaging in anal insertive sex.

**Next Issue**

Depression remains a constant challenge for both HIV-positive and HIV-negative people. In the October issue of *FOCUS*, Judith Rabkin, PhD, MPH, Professor of Clinical Psychology in Psychiatry at Columbia University, reviews the literature on the diagnosis and prevalence of depression among people with HIV. She also discusses treatment options and outcomes, and barriers to treatment including health insurance coverage.

Also in the October issue, Thomas Coates, PhD, Professor of Medicine at the University of California, Los Angeles, discusses recent findings on the relationship between depression and HIV-related risk and risk reduction, particularly among gay men.
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