Over the course of two decades of HIV prevention and treatment, we have witnessed tumultuous change: new and evolving epidemics, changing clinical presentations, new treatment opportunities, and empowerment of and disclosure by people with HIV in the light of continuing discrimination. However, the presentations at the 6th International AIDS Impact Conference, which took place in July in Milan, Italy, amply demonstrated the central role of an enduring component that determines the human experience of HIV: mental health. This component has evolved over 22 years stretching from anxieties relating to fear, loss, and bereavement to those regarding drug toxicity and adherence, from stresses around prolonged life and chronic disease to the psychological pressures experienced by uninfected people in communities disproportionately affected by the epidemic.

Conference sessions and presentations, representing the full breadth of the pandemic, were united by the common evidence for the role of psychological issues in determining behavior, quality of life, service needs, adherence, substance use, and disclosure issues. This article reviews some of the most compelling presentations.

Treatment Adherence and Side Effects

HIV antiviral treatment-related presentations covered topics related to adherence and to side effects. A French study of adherence found that psychological morbidity, specifically depression, was associated with discontinuation of efavirenz (Sustiva). Further, multivariate analysis demonstrated the increasing likelihood of discontinuation in the presence of unemployment, lack of a steady partner, and multiple episodes of depression [Tue 6.1, Spire, Marseilles].

An Italian study of personality profile and treatment adherence found that those who were more likely to adhere were older, and had lower \"state\" anger (anger related to life situations), lower \"trait\" anger (anger that is part of an individual\’s personality), and lower angry temperament than those who were less likely to adhere. Higher levels of adherence were also associated with higher cooperation as measured by a personality profile subscale, a finding that researchers interpreted as underlining the importance of establishing strong and trusting relationships with clinical staff [Wed 9.2, Leombruni, University of Turin].

Two New York studies demonstrated that peer support was effective at sustaining treatment adherence. Further, both studies offer alternatives to clinic-based adherence services. The first study found that a peer support intervention for HIV-positive people with severe mental disorders was able to reach out to the intended client group and provide a feasible method for support. A particular strength was the involvement of HIV-positive peer workers who both were using antiviral medications themselves and were from the same geographical neighborhood as subjects. Of the total sample, 27 percent of subjects had severe mental disorders, and peer workers were able to talk about adherence in 67 percent of all contacts [Tue 12.4, Colson, Harlem Hospital].

The second study demonstrated feasibility and high contact rates for a peer intervention for two separate intervention groups: HIV medication adherence and latent tuberculosis medication adherence. Randomized control trial evaluation data showed that of the patient contacts for the two groups, 40 percent and 33 percent respectively were currently using street drugs, and 12 percent and 25 percent respectively were recently homeless. The evaluation demonstrated a significant increase in the tuberculosis treatment...
Editorial: Reclaiming History
Robert Marks, Editor

Welcome to the first FOCUS update issue, combining conference coverage with book reviews. This year, the update also includes a description of the Centers for Disease Control and Prevention’s new HIV prevention initiative, which appeared, seemingly as a mandate and with great fanfare, in April 2003. Since April, the CDC has backpedaled, apparently in response to the uproar the proposal has caused.

While the new initiative does emphasize two important prevention strategies—increasing access to HIV antibody testing, including the use of the new rapid antibody test, and targeting people with HIV for prevention interventions—it also undermines the historical ethos of the epidemic. From medical research and pharmaceutical development to patient care and disease prevention, the response to HIV has been about invention: in many areas, the resulting innovations have raised the standard of care for all other diseases. But the CDC initiative, in whatever way it gets implemented, signals an end to this vision, suggesting instead that we lower the standard of care for HIV to bring it in line with approaches to other conditions.

The initiative has been criticized most for its apparent abandonment of those HIV-negative people who may be at highest risk for acquiring infection. While the CDC has relented a little on this point, stating that it is important for HIV-negative people to have access to testing, the failure to mention interventions for the group of people most likely to contract HIV is significant.

Even more significant is the fact that the success of even the best proposals in the initiative depends on the development and adherence to client-centered counseling principles. Yet the initiative seems to deal a blow to the idea that HIV prevention, and indeed disease prevention in general, is a psychological process.

For instance, while the initiative appropriately proposes that HIV testing be better integrated into medical settings, it also endorses “simplified HIV-testing procedures . . . that do not require prevention counseling before testing.” This may merely correspondingly, it found that the perceived lack of improvement in symptoms or the worsening of medication side effects was associated with negative views of HIV and antiviral treatment, poorer psychological profile, and lower adherence [Wed 9.6, Cooper, University of Brighton].

Finally, an innovative multidisciplinary team reported improved diagnosis, medical intervention, and HIV-related surgical treatment after offering a psychological intervention that focused on modifying the self-perception and clinical experience of patients [Tue 6.4, Bianconi, Modena, Italy].

Family and Children

While in many richer countries, antiviral treatment has reduced the number of infants born with HIV disease, parents with HIV-positive children continue to face adherence rates [Wed 9.5, Colson, Columbia University].

Researchers reported that psychological intervention was crucial for helping people affected by treatment-related body fat redistribution (lipodystrophy) adjust to anxiety, depression, erosion of body image, and reduced self-esteem. A French study presented data on the negative effects of lipodystrophy on sexual satisfaction [Tue 6.6, Gaigi]. A Portuguese investigation found a relationship between presence of lipodystrophy and helplessness and perceived loss of control, poor coping, low self-esteem, anxiety, depression, and sexual and social difficulties [Tue 6.5, Nabais, Hospital Santa Maria, Lisbon]. A third study found a relationship between improvement in HIV-related symptoms and higher levels of adherence;
psychosocial challenges. A study of Belgian parents who were caretakers of their own HIV-positive children found that the primary psychological concern for these parents was fear of disclosure and stigma [Tue 7.1, Noestlinger, Institute of Tropical Medicine, Antwerp]. A British study found that about 20 percent of parents surveyed had serious concerns about high levels of emotional and behavioral difficulties among their HIV-positive children [Tue 7.4, Divac, St. Mary’s Hospital, London].

Researchers presented two interventions for families with HIV-positive members. One model of care for family members integrated psychological and medical management with psychosocial and developmental care for children. The multidisciplinary service offered expertise in psychosocial and developmental needs, growth and diet, adult sexual health, and HIV medical management [Tue 7.3, Dodge, St. Mary’s Hospital, London]. The second program detailed family caregiver interventions ranging from basic HIV information through self-help support groups and medical updates [Tue 7.6, Bartoli, University of Padua, Italy]. The study highlighted a range of interventions to meet differently staged needs and culturally acceptable formats.

Drug and Alcohol Use

Alcohol use among HIV-positive gay men with alcohol use disorders was significantly associated with detectable viral load and poor self-reported health [Tue 9.8, Kutnick, City University of New York]. However, although HIV-positive gay subjects with alcohol use disorders reported unprotected anal intercourse with HIV-negative partners (19 percent of sample) or status-unknown partners (41 percent), the study uncovered no association between alcohol use and unsafe sex [Tue 9.2, Kutnick, City University of New York]. Two further studies found no link between substance use and unprotected anal sex among men who have sex with men [Tue 9.6, Myers, University of Toronto; Wed 6.6, Bolding, City University of London].

According to a U.S. study, social network analysis of injection drug users found that HIV-positive users had larger support networks and emotional support—including more women in their networks, more relatives, and more sources of formal assistance—than HIV-negative injection drug users. This finding suggests the potential for developing powerful and sustainable approaches to prevention and care that build on natural support structures among people with HIV [Tue 9.4, Knowlton, Johns Hopkins University].

Further, a study using ethnographic field data and sexual network surveying demonstrated the positive influence of friends, family, and peers on reducing HIV risks related to drug use, sexual activity, and condom use. For both injection drug users and non-users, friend and peer norms influenced personal choices, and users actively encouraged each other in making healthier choices [Tue 9.1, Friedman, National Development and Research Institutes, New York].

Sexual Impact and Dysfunction

Longer and healthier survival among people living with HIV has led to increased sexual activity, and with it, sexual dysfunction. For example, among gay men with HIV using antiviral treatments, 52 percent reported reduced interest in sex and 49 percent reported erectile problems, compared to 40 percent and 36 percent respectively among heterosexual men using HIV antiviral drugs. Older age, depression, anxiety, fat distribution changes, and the use of protease inhibitors and non-nucleoside reverse transcriptase inhibitors were associated with sexual dysfunction [Wed 2.7, Catalan, Chelsea and Westminster Hospital, London]. An Australian study found that HIV-negative gay men in mixed-HIV status relationships experienced more sexual problems—for example, erectile dysfunction, premature ejaculation, and loss of libido—than did HIV-negative men in seroconcordant relationships [Wed 2.1, Kippax, University of New South Wales, Australia]. A Belgian study found that sexual dysfunction was also common in women with HIV; however, it was associated with depression and anxiety and not with the use of HIV antiviral drugs [Wed 2.6, Colebunders, University of Antwerp]. Conversely, a British study found that sexual dysfunction was associated with the heavy use of protease inhibitors—that is, a history of using three or more—in addition to other organic and psychological factors [Wed 2.5, Mandalia, Chelsea and Westminster Hospital, London].

Counseling and Disclosure

Stigma and discrimination have remained huge challenges to the well-being and safety of people with HIV. The presence of HIV antiviral medications may “out” an individual as HIV-positive. A New York study found that this dynamic contributes to poor adherence as patients attempt to hide or modify their regimens, and that side effects were also a threat to keeping HIV status private. However, respondents also noted that disclosure often led to greater support [Tue 10.1, Klitzman, Columbia University].
Disclosure among pre-adolescents and adolescents poses problems for both adherence and psychological development, with loneliness, fear, and isolation rising as significant concerns [Tue 10.3, Bartoli, University of Padua, Italy]. Australian researchers reported that 14 percent of HIV-infected people are hepatitis C co-infected, and these individuals are significantly more likely to have negative experiences of disclosure and discrimination. This may be due in part to a higher health (identified in other studies as a factor in unintentional disclosure), having been HIV-positive longer, and having injected drugs [Tue 6.3, O'Brien, La Trobe University, Melbourne]. Italian researchers developed a program, using both individual and group sessions, to support parents in disclosing to their children that the child is HIV-positive [Tue 10.2, Mundo, University of Padua, Italy].

**Mental Health Services**

Presenters reported data on referral and access to mental health services. British researchers analyzed matched cases of HIV-positive heterosexual and gay men, and found that heterosexual men were less likely to be referred to a psychological medicine unit, to be referred for sexual problems, or to have depression, adjustment disorders, or a co-morbid personality disorder. However, the heterosexual men were more likely to have substance abuse, social network, and housing problems [Tue 12.1, Orr, Chelsea and Westminster Hospital, London]. An Australian study analyzed mental health needs and referral of people to a team that offers assistance to providers who experience management difficulties with clients with AIDS dementia complex or HIV-related mental illness. Over time, they found a decrease in AIDS dementia complex referrals but an increase in mild cognitive problems that were described as complex and not easily treated. This complexity arose from multiple diagnoses—including hepatitis C co-infection, mental illness, drug and alcohol issues, and other disabilities—in conjunction with psychosocial problems such as housing, lack of social support, and financial and behavioral difficulties [Tue 12.2, Attwood, ADAHPT, Sydney].

**Conclusion**

The models presented in Milan offer good examples of important steps to take in program development. But it remains a challenge to plan and to ascertain through evaluation studies which service models are most feasible, acceptable, and effective. Once effective services are in place, it is crucial to ensure equitable and open access. Mental health problems may present in settings without trained staff, they may be temporal or ongoing, they may vary culturally, and they may be mild enough to hinder detection. In response, we must promote awareness among the full range of HIV practitioners of the central role and high prevalence of mental health difficulties, and we must ensure that practitioners can recognize when these difficulties interfere with HIV prevention, care, or quality of life.

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**Clearinghouse: AIDS Conferences**

December 11–14, 2003, Phoenix: 2003 North American AIDS Treatment Action Forum. To contact organizers, phone or write: Paul Woods, Conference Registrar; 202-483-6622 ext. 343 (phone); pwoods@nmac.org (e-mail); www.nmac.org (web site).

February 8–11, 2004, San Francisco: The 11th Conference on Retroviruses and Opportunistic Infections. To contact organizers, phone or write: Retrovirus Conference Secretariat, 115 South Saint Asaph Street, Alexandria, VA 22314; 703-535-6862 (phone); 703-535-6899 (fax); info@retroconference.org (e-mail); www.retroconference.org (web site).

March 8–11, 2004, Philadelphia: 2004 National STD Prevention Conference. To contact organizers, phone or write: Microbicides 2004. To contact organizers, phone or write: Microbicides 2004 Event Office, Unit 22, 88 Clapham Park Road, London SW4 7BX, United Kingdom; 44-20-7720-4411 (phone); 44-20-7720-7719 (fax); info@microbicides2004.org.uk (e-mail); www.microbicides2004.org.uk (web site).

April 20–24, 2004, Melbourne, Australia: 15th International Conference on the Reduction of Drug Related Harm. To contact organizers, phone or write: Conference Secretariat, Australian Drug Foundation, P.O. Box 818, North Melbourne 3051, Melbourne Victoria, Australia; 61-3-9278-8137 (phone); 61-3-9278-8101 (phone); 61-3-9238-3008 (fax); ihrc2004conference@adf.org.au (e-mail); www.ihr.net (web site).

July 11–16, 2004, Bangkok: The XV International AIDS Conference. To contact organizers, phone or write: IAS Conference Secretariat, Berzeliusväg 8, SE-171 77, Stockholm, Sweden; 46-8-508-846-40 (phone); 46-8-508-846-64 (fax); info@aids2004.org (e-mail).
The CDC’s New Prevention Initiative

In April 2003, the Centers for Disease Control and Prevention released new guidelines that represent perhaps the broadest reform of HIV prevention policy since the beginning of the epidemic. Based on increasingly accurate data and HIV epidemiological tracking, it elevates two approaches above all others: improving access to HIV antibody testing and more effectively targeting people with HIV for prevention interventions.

The CDC bases these conclusions on data that identify: recent outbreaks of syphilis among men who have sex with men; increases in newly diagnosed HIV infections; and the end of declines in HIV illness and deaths that had resulted from improved antiviral treatment in the late 1990s. The CDC estimates that 25 percent of HIV-positive people are unaware of their serostatus, and that in 2000, 31 percent of people who were tested for HIV did not return for results.

Finally, the CDC bases its recommendations on the recent approval by the U.S. Food and Drug Administration of the OraQuick “rapid” HIV antibody test, which “provides HIV results in 20 minutes, can be stored at room temperature, requires no special equipment, and can be performed outside clinical settings.” (Preliminary HIV-positive results detected by the rapid test still need to be confirmed, at this point, by non-rapid laboratory tests.)

The following text, quoted verbatim from the new initiative, provides an overview of the CDC’s interpretation of these data and their implications for prevention policy:

“The new initiative . . . is aimed at reducing barriers to early diagnosis of HIV infection and increasing access to quality medical care, treatment, and ongoing prevention services. [It] emphasizes the use of proven public health approaches to reducing the incidence and spread of disease. As with other sexually transmitted diseases (STDs) or any other public health problem, principles commonly applied to prevent disease and its spread will be used, including appropriate routine screening, identification of new cases, partner notification, and increased availability of sustained treatment and prevention services for those infected. . . .

“The initiative consists of four key strategies:

- “Make HIV testing a routine part of medical care. CDC will work with professional medical associations and other partners to ensure that all health-care providers include HIV testing, when indicated, as part of routine medical care on the same voluntary basis as other diagnostic and screening tests. Previously, CDC has recommended that patients be offered HIV testing in high HIV-prevalence acute care hospitals and in clinical settings serving populations at increased risk (e.g., clinics that treat persons with STDs). This initiative adds to those recommendations to include offering HIV testing to all patients in high HIV-prevalence clinical settings and to those with risks for HIV in low HIV-prevalence clinical settings. Because prevention counseling, although recommended for all persons at risk for HIV, should not be a barrier to testing, CDC will promote adoption of simplified HIV-testing procedures in medical settings that do not require prevention counseling before testing.

- “Implement new models for diagnosing HIV infections outside medical settings. In 2003, CDC will fund new demonstration projects using OraQuick to increase access to early diagnosis and referral for treatment and prevention services in high-HIV prevalence settings, including correctional facilities. In addition, CBOs [community-based organizations] will pilot new models, particularly in non-medical settings, for diagnosis and referring persons for treatment and prevention services. Also . . . CDC will increase emphasis on PCRS [partner counseling and referral services]. In 2004, CDC will implement these new models through health departments and CBOs.

- “Prevent new infections by working with persons diagnosed with HIV and their partners. [CDC will achieve this by developing and disseminating guidelines, reaching people with HIV both in and outside of medical care settings, and conducting demonstration projects for prevention case management]. Finally, CDC will increase emphasis on partner notification and also will support new models of partner notification, including offering rapid HIV testing to partners and using peers to conduct partner prevention counseling and referral.

- “Further decrease perinatal HIV transmission. CDC will promote recommendations for routine HIV testing of all pregnant women, and, as a safety net, for the routine screening of any infant whose mother was not screened.”

References


For those of us providing direct service, it is a given that culturally appropriate and specific interventions can help those individuals most at risk for acquiring HIV change sexual and drug-using behaviors. Such interventions have also been successful in improving treatment adherence and overall quality of life for people living with HIV.

With the current dismal economic and fiscal climate facing HIV prevention and treatment, however, there is a pressing need for quantitative data and evidence to support ongoing efforts in the field of HIV prevention and psychosocial treatment. For this reason, *Innovative Approaches to Health Psychology*, an anthology that illustrates the development and implementation of successful prevention and treatment interventions, is an important and timely book.

**A Survey of Interventions**

Each of 13 chapters focuses on a different set of interventions, and describes how practitioners and researchers identified target populations and behaviors, designed and implemented interventions, and evaluated the results of their work. The populations covered in the book include adolescents, pregnant women, African American women, gay and bisexual men, and injection drug users. The interventions fall into three main categories: risk reduction interventions that focus on changing behaviors and community norms; interventions for optimal disease management, for example, treatment adherence; and biomedical interventions to prevent infection, for example, post-exposure prophylaxis.

The chapters are well written and succinct, reflecting the knowledge and expertise both of the writers and the editors. Not only do these explorations provide detailed illustration of the development and implementation of the interventions, but also they offer sufficient guidance and positive outcome data to help readers implement similar programs.

**Stories from the Front Lines**

One of the most compelling chapters of the book “Group Interventions for Serious Medical Illness” discusses treatment for clients along the spectrum of HIV infection, ranging from those awaiting test results to those who are seriously ill. Groups have been a key element in the psychosocial treatment of HIV disease since the epidemic’s onset. Unfortunately, as we have seen recently in San Francisco, funders are increasingly scrutinizing the continued relevance of HIV-related group approaches.

This chapter provides concrete quantitative data demonstrating the effectiveness of groups in decreasing psychological distress, increasing coping skills and support, and decreasing sexual risk and treatment-interfering behaviors for people with HIV. Additionally, for people with asymptomatic HIV, group participation has improved levels of key markers of immune functioning. Finally, the chapter goes into great detail about a group intervention for people with advanced, symptomatic HIV disease, perhaps the most psychologically vulnerable clients, who are nonetheless increasingly overlooked by a society that believes “AIDS is over.”

The third section, addressing biomedical interventions, offers the book’s most future-oriented perspectives. Shaping the course of both HIV prevention and treatment, these innovations have implications that extend far beyond HIV. Chapters 11

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**No FOCUS Next Month**

As of this past January, the *FOCUS* publication schedule changed: *FOCUS* is now published 10 times a year, with no issues in December or June. This will sustain *FOCUS* over time in an era of rising costs and decreasing HIV funding. If you have any questions, please contact Jennifer Jones at jejones@itsa.ucsf.edu or 415-502-4930.
and 12 explore the potential impact of HIV vaccine development and post-exposure prophylaxis (PEP) on HIV prevention counseling. These chapters underscore the importance of remaining abreast of new technologies including benefits and limits in assisting clients to establish habits and behaviors that promote health and quality of life. For example, there is a widespread fear among prevention counselors that complacency has been fueled by the belief that HIV treatments can prevent HIV infection in the absence of behavior change. Both chapters highlight the importance of providing individualized yet structured counseling to help clients develop and maintain safe behaviors in conjunction with biomedical interventions that may prevent HIV infection.

Chapter 13, which focuses on adherence, offers clinicians concrete strategies for tackling one of the hardest challenges faced by people with HIV: adhering to complex medication regimens, which are often accompanied by physical side effects. The authors suggest that the problem of non-adherence is best addressed through programs that include a combination of cognitive-behavioral and social learning models of behavior change. For example, the Partnership in AIDS Clinical Trials (PACT), developed and implemented by the Center for AIDS Prevention Studies, applies interventions that range from individualized needs assessments—to identify factors that might impact adherence—to long-term maintenance strategies emphasizing adherence techniques that a client can administer him or herself.

Conclusions
Perhaps the book’s only shortcoming is its failure to address the complex issue of intervening around multiple risk behaviors. For example, the chapter “Innovations in the Application of Social Cognitive Principles to Develop Prevention Interventions among Gay and Bisexual Men” overlooks the tremendous impact of recreational drug use, in particular methamphetamine use, on the sexual behavior of gay and bisexual men.

Having said this, Innovative Approaches to Health Psychology is a crucial tool for practitioners providing prevention and treatment to a wide range of clients living with HIV. It is also a testament to the efforts of those who, often with few resources and little experience, have changed the landscape of health psychology and public health far beyond the realm of HIV.
Portrait of an Epidemic
Jennifer Jones


Less a book of photography than a revealing portrait of the lives of HIV-positive men and women, Roslyn Banish’s book Focus on Living accomplishes mightily what it sets out to do: reempower the icon of the individual in the face of an epidemic too often symbolized by the anonymity and sterility of statistics. The format of the book—photographs of individuals paired with their personal narratives—invites the reader to enter into each story. This privileged access to the intimate details of personal history and daily life creates a space in which the reader’s own concept of “the face of AIDS” can grow and change.

Starting from dramatically different points—from a Native American reservation in Utah to rural Texas to cities like New York and Oakland—the common realities of life after diagnosis affirm the conviction that while treatments are sustaining lives and transforming the nature of what it means to be HIV-positive, the disease still has very real and far-reaching implications. The narratives cross lines of sexual orientation, race, class, and background, capturing a wide spectrum of sexual orientation, race, class, and background, capturing a wide spectrum not only of lifestyles and attitudes, but also of perspectives on life, its dreams and disappointments, and ways of reconciling the future with the complications wrought by a disease. The narratives also tackle the extended dimensions of HIV: addiction, homophobia, stigma, enculturated silence, sexual activity, dating, childhood abuse, and disclosure. Each subject shares the ways in which his or her life has been transformed by HIV. Two incarcerated women talk about what it means to be HIV-positive, the disease still has very real and far-reaching implications for a life threatening” disease who nonetheless seem unafraid to live.

Author
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Next Issue
Despite the pervasiveness of “harm reduction” interventions, many people perceive of harm reduction in terms of particular strategies, such as needle exchange, and in opposition to others, for example, abstinence-based drug treatment. Yet, at its foundation, harm reduction is an approach that excludes nothing from its menu of client-centered options. In the January issue of Focus, Edith Springer, ACSW, a pioneer in the field of harm reduction and the Director of Clinical Services at New York Harm Reduction Educators, discusses the key tenets of harm reduction and their broad application. Harm reduction for methamphetamine users may be particularly complex and is crucial to battle the growing epidemic of use among men who have sex with men. Also in the January issue, Susan Kingston of the Seattle and King County Department of Public Health and Miles Conrad of Seattle Counseling Services review harm reduction approaches for methamphetamine users.
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