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FOCUS

A Guide to AIDS Research and Counseling

Adapting to Hope and Uncertainty: Two Decades of FOCUS

In 1985, the California Department of Health Services contracted with the UCSF AIDS Health Project, then less than a year old, to produce a newsletter for mental health providers on AIDS research and counseling. In December 1985, AHP published the first issue of what was then called *FOCUS: A Review of AIDS Research*. You are reading the 234th issue of *FOCUS*, which remains one of the longest running AIDS publications in the world.

From the beginning, *FOCUS* took on the challenge of narrating the psychological and social conditions of a biological state. This narrative describes a 20-year journey from uncertainty and fear, to hope and clarity, back and forth, again and again. The trip has required navigating confusion and integrating knowledge; in the end, it has been a story of adaptation.

To mark the 20th anniversary of *FOCUS*, we have put together a retrospective that looks at these key themes through excerpts of more than a dozen articles. These articles represent only a fraction of the almost 1,600 pages that make up the history of *FOCUS* and only a few of the hundreds of authors whose work deserves attention.

We have divided these articles into three areas: HIV prevention, care for people with HIV, and community responses. To supplement these articles, we have included, in sidebars, excerpts of first-person narratives that we have occasionally published.

The First Year

In its first year, more than 50 percent of *FOCUS* articles broadly described the psychosocial challenge of living in the shadow of a previously unknown and deadly disease, including psychological distress and adjustment, bereavement, suicide, and the role of psychiatry. Another 25 percent sought to outline the epidemiology of the disease. The final 25 percent covered medical and

technical issues such as disease progression, treatment, and HIV testing technologies.

In the early 1980s, many had imagined AIDS would be cured by 1985. By the first issue of *FOCUS*, however, editor Michael Helquist wrote, "Perhaps the most basic fact about the AIDS epidemic in this country is that it will not go away. In addition, all researchers warn that Americans can expect AIDS to get much worse before it gets better." In the second issue, Jeffrey Mandel, then Director of the UCSF Biopsychosocial AIDS Project, named the emotional challenge for people living in the epidemic: "Perhaps the most striking and recurring theme . . . is the struggle to maintain hope."

Three Variations on Uncertainty

By the first year of *FOCUS*, three groups had emerged within the gay-identified community: those with AIDS, those with AIDS-related conditions (ARC), and those who were uninfected or who did not know they were infected. For each of these groups, uncertainty manifested in different ways.

The most significant manifestation of uncertainty was ARC. Later known as symptomatic HIV disease, ARC was that large gray area of effects that did not fit into the very specific AIDS definition cobbled together by the Centers for Disease Control and Prevention. The CDC definition was based on the idea that certain diseases and physical conditions could arise in humans only when there was a breakdown of the immune system, and that these conditions could be attributed to AIDS only when this immune breakdown could not be explained by any other cause. But there were many other AIDS-related conditions, some extremely serious, that did not fit neatly within these parameters. During the first six months of *FOCUS*, several articles highlighted the difficulty of living with ARC. Mandel reported, "We found people with ARC more distressed than persons with AIDS."

Seven months later, Judy Macks, then AHP's Coordinator of Mental Health Training, echoed these findings in an article on the Second International Conference on AIDS in

20
YEARS OF
FOCUS

If you are drawn to read more of the articles excerpted in this retrospective issue, FOCUS is offering free, complete electronic versions of the full-length original articles. Write to Jennifer Regan with the name and author of the article at jennifer.regan@ucsf.edu to receive a PDF of the original issue. Paper copies, where they still exist, cost \$5.00.

Paris, reporting on data from several studies that documented the seemingly disproportionate distress of people with ARC. She also discussed the third major group of people dealing with the epidemic: uninfected people who, because they were in one of the “risk” groups, lived under the cloud that they too had been infected or would become infected. She described the phenomenon of “AIDS anxiety,” a more severe form of what plagued the large number of gay men who were known as the “worried well.” These men, believing they were at high risk, became obsessed with fears of having AIDS and dying and repeatedly visited their physicians.

By 1985, the key routes of HIV transmission and HIV prevention were clear. The HIV antibody test, which had been available since March 1985, was a highly accurate and accessible method of determining whether a person was infected. The April 1986 issue was devoted to HIV counseling and testing, and one year later, the lead article by Peter Goldblum and Neil Seymour provided counseling guidelines to help people decide whether or not to take the test. The December 1986 issue defined the approaches to prevention that had already worked to protect the majority of people at highest risk for infection.

But the apparently long “incubation” period of HIV, confusion about the length of the “window period,” controversy about testing and confidentiality, the lack of treatment, and the omnipresence of illness, dying, and death, all diluted the capacity of these two areas of knowledge to calm widespread fear, despair, and uncertainty in communities hardest hit by the epidemic. Woven through the articles in the first years of *FOCUS* are references to the litany of debilitating, disfiguring, cognitively impairing, and deadly conditions that comprised the CDC’s definition of AIDS.

The 20-Year Evolution

For years after 1985, researchers fell short of initial predictions to develop a vaccine, a cure, or even effective treatment, but time offers the distance to observe a steady improvement in HIV-related care. As New York therapist and author Michael Shernoff would observe in 1997: the 15 years between 1982 and 1997 unfolded with a string of important discoveries about the virology of HIV, new drugs to fight opportunistic infections, and a dizzying array of new antiviral treatments. All of this would be, and continues to be, balanced by the immense adaptability of HIV, enabling it to resist, and a string of false hopes like the “wonder drug” Compound Q. Shernoff was not the first to compare the journey to a roller-coaster.

In the mid-1990s, viral load testing and triple combination treatment, first with at

least one protease inhibitor and now with newer drugs and a variety of combinations, made living long an achievable goal. Yet, since that time, *FOCUS* has emphasized the challenges: access to treatment; adjusting to treatment success; the reality of treatment failure; the difficulties of side effects, continued disease effects, and adherence; and the continued life-threatening nature of HIV. *FOCUS* has explored other conditions, such as substance use and mental illness, which complicate living with HIV and providing HIV-related care, and the challenge of introducing prevention into HIV-related care.

HIV prevention is also, at its core, a success story—despite the huge toll that AIDS took in the early years. In the midst of this holocaust, most gay-identified men adopted risk reduction and have successfully mediated rigid guidelines with creative strategies, such as negotiated safety, that seek to make these guidelines sustainable over time. Injection drug users, particularly in U.S. cities and European countries that have implemented needle exchange, have experienced dramatic reductions in HIV transmission. In richer countries, antiviral drug prophylaxis has reduced mother-to-child transmission to a shadow of what it had been. Antibody screening of blood and blood products eliminated new infections among transfusion recipients and people with hemophilia.

Yet, again, *FOCUS* has accentuated the negative: the conditions that sustain HIV transmission, conditions that have not changed much over 20 years. They include: psychological factors such as substance use, a history of childhood sexual abuse, and depression; marginalizing social forces such as poverty, racism, and homophobia; and the challenges related to behavior change such as the fatigue of sustaining risk reduction for 10 or 15 or 20 years.

For most people in richer countries, living in the epidemic is dramatically easier in 2005 than it was in 1985. This retrospective issue tracks this success, but the history of *FOCUS* is necessarily the story of a killjoy. For every improvement, *FOCUS* has sought the failure, the defect, the difficult adjustment, the subpopulation whose conditions—whether economic, geographic, or psychological—limited the benefit it might have experienced.

This perspective is not the result of stubborn negativity. The nature of mental health care is to identify emotional distress, and every development—good or bad—has had fallout that has required interpretation and intervention, all in the service of helping clients recognize meaning and foster resilience. Were a vaccine and a cure to appear tomorrow, distress would not automatically disappear, and neither would *FOCUS*.

HIV Prevention

The moment researchers understood that AIDS was a transmittable disease—and how it was transmitted—is the big bang of prevention. Unfolding from that point were the dramatic behavior changes that saved millions of lives. The five articles excerpted here challenged readers to grapple with the situations of the people who benefitted least from prevention interventions. These articles draw on clinical observations, psychological theory, ethnographic study, and cross-cultural counseling. While each article deals ostensibly with a single population of people affected by HIV—gay men, youth, people of color—their wisdom easily translates into universal principles for prevention.

The Homosexualization of AIDS

Walt Odets, PhD

The “homosexualization of AIDS” describes the psychological and social processes through which the personal and social identities of gay men have become unrealistically and destructively tangled with the identities of those who are infected with HIV. . . .

For those gay men accustomed to life on the fringes of a rejecting heterosexual society, the acceptance gained by having AIDS can feel irresistible. Many are finding it easier to be threatened by AIDS, to die of AIDS, or to be guilty for not dying of it, than they have ever found it to be gay. It is this that is often at the heart of the homosexualization of AIDS: AIDS has given many gay men a disease which, in all of its horror, offers a more comfortable identity than that of being homosexual. . . .

The cost of such acceptance for the man who becomes infected is his life; but for the uninfected survivor, the entanglement of gay identity with AIDS exacts serious costs of a different, more subtle kind. Survival may be experienced as a betrayal and abandonment of those who are infected. A gay man may feel that by surviving he is betraying his personal identity as a gay person, and he may feel that he is no longer part of the community—as it now often seems, many of its members sick or already dead—a community which is the only human community in which he has ever been able to be who he truly is. . . .

If gay men cannot clarify their confusion of identity between being gay and having AIDS, cannot reestablish individual and social identities free of this extreme entanglement, and if they cannot discuss the bewildering and painful feelings that everyone, infected

and uninfected, is experiencing in response to the epidemic, it will almost surely cost the gay community decades of psychological, social, and political growth. Because of the social and psychological gains made by the gay liberation movement of the 1970's, it is easy to overlook the fact that 25 years ago, depression, anxiety, isolation, and loneliness were seen routinely in the lives of a majority of homosexual men. The HIV epidemic, with its dead, its ill, and its survivors, has returned depression, anxiety, isolation, and loneliness to the lives of too many in this community.

Moral Development and HIV Prevention among Adolescents

Mark Hochhauser, PhD

Moral development theories frame the challenge for HIV risk reduction in terms of the different approaches required for adults and adolescents. But the challenge goes deeper: successful moral and psychological growth may in fact require risk.

Risk-taking is a part of normal psychological development. Although sexual and drug-use abstinence may provide the greatest safety from HIV infection, total elimination of risk-taking behaviors during adolescence may compromise psychological health. In a study of 101 16-year-olds, who had been followed since preschool, Jonathan Shedler and Jack Block reported that those adolescents who had engaged in some drug experimentation, primarily with marijuana, were the best adjusted, while frequent drug users were characterized by interpersonal alienation, poor impulse control, and emotional distress. Surprisingly, the study found that adolescents who had never experimented with any drug were relatively anxious, emotionally constricted, and lacking in social skills. While chemically healthy, they were not psychologically healthy. The authors concluded that drug experimentation, in and of itself, does not seem to be psychologically destructive. This conclusion may be extended to sexual experimentation, and it challenges the wisdom of defining abstinence as the only goal of prevention programs.

The goal of prevention should not be to eliminate all risky behaviors from life; instead it should be to help adolescents and young adults learn about inappropriate and appropriate risks. There is a life after adolescence, and individuals who have grown up in a riskless environment may not be able to cope with the challenges of adulthood, for example, the workplace or parenthood, without having had some risk-taking experiences. . . .

The Homosexualization of AIDS. 1990; 5(11): 1–2.

Moral Development and HIV Prevention among Adolescents. 1991; 6(12): 1–4.

Psychoanalyst Erik Erikson observed that adolescence is a time for resolving the crisis between role identity and role confusion. The basic question that the adolescent tries to answer is “Who am I?” A typical adolescent works at developing a sense of self by testing a variety of roles—including sexual roles—and integrating these different roles to form a single identity. If prevention programs seek to discourage role testing, will adolescents be able to develop coherent identities?

Reaching the Hip-Hop Generation

Patrick McLaurin and Ivan Juzang

The mainstream’s well-intentioned messages aimed at African American youth are reaching the wrong audience with the wrong information. . . .

The failure of educational efforts up to now lies in the assumptions upon which communications strategists have based most of the messages to this audience: that there is a homogeneous “street culture”; that inner-city youngsters are making decisions in their mid- to upper teens about whether to engage in self-destructive or antisocial acts; that the dominant culture’s linear style of communication is effective for an audience that comes from an oral tradition; and that mainstream society has enough credibility with this audience to dispense super-parental injunctions like “Just say no!” and “Stay in school.” It is not that simple.

“Street culture” dissolves upon close observation into a series of overlapping sub-cultures—drug cultures, hip-hop cultures, gang cultures, sex cultures, age defined cultures—whose common traits and needs are very different from those assumed by outsiders. On the streets, where childhood can be very brief, decisions about drug use and other behaviors are made much earlier than mainstream culture imagines.

And the mainstream assumption that the streets harbor rudderless, leaderless young people, yearning for a catch phrase upon which to focus their lives, is treated with the derision it probably merits. This culture has its leaders. It has a social structure. But, like the White counterculture movement of the 1960s, African-American, inner-city teenagers are far more certain of who they are *not* than who they are, and their efforts at self-definition, even when this includes behaviors they know to be antisocial and self destructive, are defended on grounds that they are, at least, authentic. . . .

The task of imbuing a message with “street life” is two-fold. First, it must be shareable, that is, entertaining, engaging, and couched in terms that conceal any origins in mainstream value systems. Second, it must have sufficient longevity for the sharing to take place and for the message to gain street acceptance. . . . This is not easy in a culture characterized by constant change. . . . The study’s focus groups uncovered two important findings related to content: teens want skills not directives—“Don’t tell us what to do, tell us how to do it, step by step, without losing the approval of our peers”—and many teens endorse mainstream values in this culture, but have problems expressing these positions so that they are socially acceptable. One “How To” is creating a “language of rejection,” that is, expressing the rejection of a particular behavior without rejecting the culture or group.

Another focus group finding was the significant desire among adolescents to see their culture portrayed in a more positive and multifaceted fashion . . . Finally, messages were more likely to be accepted if they dealt with central “thematic” areas . . . for example, group cohesiveness and the conception of African Americans as victims.

HIV and Culture: Working Downhill

Amanda Houston-Hamilton, DMH and Noel Day

Culture is the force that shapes a person’s core, that tells each of us how *to be*, how to survive. It is a group’s design for living, which defines the perception and interpretation of *the group’s* experience of being human. A successful culture evolves over time to meet needs specific to particular environments and circumstances, new conditions, or the assimilation of other groups and their precepts. Shared meanings and values develop not only within ethnic groups, but also within affinity groups—based, for example, on social class, gender, and sexual orientation. Behavior is culture made manifest, giving visible form and expression to beliefs, values, and attitudes of both client and counselor.

Herb Shepherd, a pioneer in the field of organizational change, used to say he had the choice of “working uphill or downhill” when he was trying to modify an organization . . . To work downhill, he would . . . analyz[e] an organization’s culture and [identify] consistent strategic interventions based on its inherent values. . . .

The most influential behavior change models in the HIV counseling arena reflect

Reaching the Hip-Hop Generation. 1993; 8(3): 1–4.

HIV and Culture: Working Downhill. 1998; 13(12): 5–6.

"My boyfriend . . . is HIV-positive, and I'm not. He's just told me . . . that he's been fucking and getting fucked by another guy with HIV, and they're not using condoms. . . . We have a good relationship and good sex, and we always use condoms. . . . He's [not] had much sex in his life, and he wants to explore a bit. . . . I've been having sex with others occasionally, too. But I just assumed we would both be having safe sex. . . . I don't know what it's like to have HIV, and I don't want to tell him how to live his life. But we are partners and I feel scared for his health, angry that he would put himself at risk like that, and hurt and pissed off that he made this decision without taking me or our relationship into account."

—Name Withheld, 1998; 13(10): 4–5

Anglocentric, pedagogical notions, and the idea of changing cultural attitudes—a central HIV education method—is the epitome of working uphill. Anglocentric principles value individual responsibility and control, assume that the medical system is trustworthy, and propose that client-based issues like low self-efficacy or denial are the primary obstacles to behavior change. They suggest that single interventions are appropriate and that information—the more the better—should be presented in a didactic form with knowledge passing in one direction, from presenter to audience.

Any of these assumptions may contradict a

client's world view. Working downhill means working within the context of a client's perspective and taking time to define meanings within this world view that will suggest authentic motivations for risk reduction. But HIV education typically negates alternative theories and alienates a significant part of its intended audience. For example, as a legacy of the Tuskegee Institute's syphilis experiments, in which Black subjects went untreated for 40 years, many African Americans distrust the medical system, question the role of HIV as the cause of AIDS, and view the epidemic and even standard prevention measures such as condom use as part of a larger genocidal plot against African Americans. Counselors can choose either to dismiss such responses as dysfunctional or to explore the meaning of such beliefs, acknowledging the credibility of such suspicions and joining with clients to discover what each sees as the HIV prevention implications of such a history. . . .

In the scant qualitative work published, ethnic minorities have been considered inherently "hard to reach," a term that serves simply to distance populations with whom professionals are unfamiliar. Appropriate interventions to many groups have been hindered more by this marginalization than by the cultural attributes that researchers ascribe to them.

Many clinicians avoid interventions with clients whose cultures seem at face value different from their own and, in this way, avoid interactions that might risk failure. But one of the best models for working

downhill with cultural values lies in the fundamental premise of client focused work: the client is at the center of the interaction, and the therapist, as facilitator of change, collaborates with the client, listening for the meanings and metaphors that can establish and promote the intervention plan the therapist and client have developed together.

Chronic Risk and Sexual Distress

Lena Nilsson Schönnesson, PhD, and
Michael W. Ross, PhD, MPH, MHPed

HIV infection is still a significant reality in industrialized countries. As a result of the success of HIV antiviral treatments, there are far more people alive with HIV than ever before, and for a variety of reasons, HIV transmission continues to plague men who have sex with men. Living in communities with high HIV seroprevalence forces every sexually active person to consider HIV risk during every sexual act, creating a context of "chronic risk."

In order to better understand the potential negative impact of chronic risk on sexual well-being and prevention efforts, the psychological and existential aspects of sexuality have to be acknowledged. First, there is the hedonistic aspect: some sexual activities are perceived as more pleasurable than others and some are more important than others to sexual satisfaction and identity. Second, there is a boundless dimension to sexuality, that is, the desire to give in physically and psychologically to another person without any constraints. Third, sexual behavior incorporates strong symbolism, for example, unprotected intercourse may represent intimacy. For many—both gay and heterosexual—protected sex implies relinquishing the hedonistic, boundless, and symbolic meanings of sexuality. In this context, it is understandable that behavior change becomes linked with feelings of loss, grief, and rage. For people who respond in this way, the phenomenon of chronic risk prolongs this suffering.

Sexuality also has a symbolic existential meaning relating to the value of life and its continuity. In this way, it is a counterweight to death. The condom may represent a barrier to intimacy that negates the boundless dimension of healthy sexuality. In the context of chronic risk, the protected sexual act—bounded and constrained—can come to symbolize death. Since individual sexuality is based as much on emotional as on rational aspects of sexual expression, neglecting the impact of these psychological and existential components may ignore a possible source of unsafe behavior.

Care for People with HIV

The journey back and forth between hope and uncertainty mirrors the journey of 20 years of *FOCUS*. It is almost impossible to talk about the emotional reality of living with HIV without talking, at any given moment, about what was known, what was not known, and what was imagined. The articles excerpted here cover this ground from a variety of perspectives: the spiritual dimension of care for people who are facing death, the opportunities and dangers of psychological denial, the empowerment of women struggling with HIV and addiction, and the promise of the transformation of HIV into a “chronic illness.”

A Framework for Hope

John Fortunato, MA

Hope is a loaded word among HIV caregivers. We sincerely want to encourage hope in people with HIV disease and yet we often feel ambivalent about proffering it. Why the hesitancy? One source of our discomfort is the fear of encouraging false hope. . . .

Imparting false hope to people with HIV disease constitutes an unwholesome intrusion into their lives, and comes from outside the client and the disease. But some of the difficulties encountered in supporting hope in infected clients stem from HIV disease itself.

Most notably, the domain over which hope can operate does not remain constant during the course of HIV disease. That is, the locus of hope changes as HIV disease progresses. When clients first find out they are seropositive, caregivers often feel pressured to give false hope—hope of a cure or of indefinite management of the infection and avoidance of death. Wanting to help, but not wanting to lie, we often give mixed messages of hope. On the one hand, we tend to avoid the issue of *ultimate* hope and talk instead about *now* and about protocols and procedures. On the other hand, in trying to respond to clients’ despair, we tend to allude to clinical data about survival rates and people’s ability to have “lots of good years” after infection.

As the health of people with HIV disease begins to deteriorate, we tend to focus more and more on the present and the near-term future. Clients at this stage often stop alluding to the distant future, and so do we. During the terminal stages of the disease, clients often focus on dying and talk little, if at all, about hope. In response, practitioners concentrate on pain management, life

review, and helping clients achieve as good a death as possible.

There is something very right about this progression. But something about hope in AIDS care is missing here. What is right is the tacit acknowledgment that, as patients with progressive illnesses approach death, their worlds become smaller. In self-psychological terms, their pool of external supportive selfobject functions dries up. These selfobjects might include one’s job, hobbies, recreational activities, the sense of having wholeness of body, or the ability to relate meaningfully with others, whether sexually, politically, affectionally, or intellectually. Inevitably, people with HIV disease—like other people with progressive illnesses—must incrementally give up hope of deriving self-affirmation through some and eventually most of these life functions. As their worlds shrink, it seems absolutely appropriate that caregivers help them shift their focus and concentrate on the smaller worlds that have now become their reality. . . .

What lacks in this progression is any cogent method of dealing with eschatological hope and the discomfort it raises for AIDS caregivers. However, this uneasiness can be overcome. Moreover, in good conscience, we really must help HIV-infected people work through the question of what happens to them when they die. . . .

It is the shift from a “this-worldly” locus of hope to an “other-worldly” locus of hope that seems to cause the most disconcerting caregiving bump. To smooth that transition, caregivers need two things: a conceptual model that follows the development of hope over the course of HIV disease, and a way of understanding eschatological hope that minimizes their own discomfort. The conceptual model would help assess clients’ current levels and loci of hope, describe their belief systems, evaluate their abilities to be introspective, appraise the solidity of their senses of self, and describe their most-used self objects. Such a framework would help caregivers provide appropriate and supportive care at each stage of a client’s hope.

Recognizing Denial among HIV-Infected Clients

Jody Oppen Reiss, LCSW

Denial has been variously defined as a healthy psychological defense, an avoidance of active coping, a stage in the dying process, a primitive defense mechanism, a potentially dangerous avoidance of reality,

A Framework for Hope. 1993; 8(7): 1–4.

Recognizing Denial among HIV-Infected Clients. 1994; 8(8): 1–4.

"The trial has ended, and I have elected to receive maintenance doses of Compound Q [the experimental antiviral derived from the Chinese cucumber]. I have free, monitored access to a drug that would otherwise be unavailable to me. The side-effects [like being in a car wreck] have begun to diminish. . . . Was it all worth it? . . . It's not so much that I anticipate something definitive like a cure or boundless energy or the tripling of my T-cells. Rather, [it's about] being part of a process, a process that brings me hope and may solve the riddle of this disease. To do something is to cede control to the virus. I can see surely now that the uncertainty of an experimental drug is better than the unchallenged course of this capricious disease."

—Chris Adams. 1991; 6(8): 4–5.

a component of depression, and an essential ingredient of hope. Denial can be seen as an unconscious process or as a conscious cognitive strategy. Whichever definition is adopted, the challenge for clinicians working with people with HIV disease is to differentiate between adaptive and maladaptive aspects of denial.

There is no question that a certain level of denial is healthy when coping with a life-threatening illness. When death is in full focus, there is little room for life. Denial is a mechanism that allows a person with HIV disease to make plans for the future, to get beyond day-to-day cares, to remain a participant in the world, and to be motivated to fight back. Likewise denial may

help the clinician to distance from the inevitable loss and focus on the here and now.

On the other hand, denial can put others at the risk of HIV infection, keep an infected person from seeking medical care, contribute to substance abuse, or inhibit a client from reaching out to friends and family. Although denial may be essential at certain stages of illness, it appears that healthy adjustment and acceptance of the dying process includes a shedding of this defense. . . .

Denial has traditionally been thought of as an unconscious process whereby painful feelings are repressed to the point they are no longer consciously experienced. . . . When it comes to HIV disease, denial is rarely capable of submerging the reality of infection entirely. . . . While the unconscious process of denial may not be effective in eradicating an awareness of HIV disease, many people will consciously attempt avoidance.

HIV-related denial arouses countertransference in a unique way. The client who continues to have unsafe sex, the young man who keeps riding his motorcycle although blind in one eye from CMV retinitis, the mother who puts off making plans for her child's guardianship, the client who chooses not to take medication: all these situations have the potential for disaster. They demand that the therapist consider abandoning neutrality in favor of direct influence. . . .

Working with denial requires that the clinician be attuned to its presence and able to continually assess and reassess how denial

serves the client. The clinician must contain his or her bias but not be afraid to use gentle confrontation when bias is rooted in the knowledge that the client may endanger him or herself or others. And the clinician must be able to walk with the client the fine line between denial and hope. There are times when supporting denial is the most healthy and appropriate course, times when the clinician's grounding in reality allows the client to look into the future with less fear, and times when the best stance for the clinician is simply to support and witness as a client, accepting illness and the possibility of death, finds that denial falls away.

Supportive Counseling for HIV-Infected Drug Using Women

Gillian Walker, ACSW

Until recently, most drug users have been men, and their non-drug-using female partners have functioned as the glue that kept their families together, sheltering as best they could the next generation, often suffering abuse in the process. Today, 60 percent of crack users are women, the majority of whom are mothers of small children and the heads of single-parent households. . . . It is estimated that more than half of all drug-using women in the major epicenters of the eastern United States are HIV-infected, and drug use among women is correlated to unprotected sex, injection drug use, and needle sharing. . . .

Feminist psychologists like Carol Gilligan assert the importance of relationships in the psychology of women. They believe that girls form a sense of self, self-worth, and feminine identity through the ability to build and maintain relationships with others. By contrast, boys are occupied by issues of differentiation and action in the external world, repressing their relational capacities in order to become male. These theorists suggest that the mother-daughter relationship is critical to the psychological well-being of women of all races, a relationship that is replicated in the mothering of the next generation. It is this relationship that is most vulnerable to fracturing by the male psychological approaches that inform most drug treatment programs.

Gilligan goes on to propose that these differences are so basic as to affect moral decision-making. Men make moral judgments on the basis of "justice" as defined by rules, while women make judgments based on the obligations of interpersonal connection. From this "care" perspective, rules may be violated to honor the demands of relation-

"My experience may illustrate both the silver lining . . . and the cloud [of what appears to be a manageable illness]. . . . Ironically, even though I have gained weight, I mainly experience feelings of loss. I am in limbo, my life a compromise between side effects and an HIV regimen that seems to be keeping me alive; a process of sustaining a body that will never be well, but may very well continue to be. While so many of my friends have died, I have not; I am still here. I feel as if the world is passing me by, a dinosaur who has survived the ice age. But, I also feel that I am here for a reason. I still have some creative spark in me, and some ability to give back to the community that has helped me so much."

—Richard Goldman. 2001; 16(3): 5–6.

ships. To maintain order and achieve the goal of abstinence, drug treatment programs usually emphasize justice over care. The drug user is perceived as a potential manipulator who, if not watched closely, will subvert treatment goals by playing on feelings of care and compassion. Treatment often involves coercive and shaming corrective interventions—including rejection, sign-wearing, prescribed haircuts, group confrontations of attitude and behavior—to identify and eradicate negative behaviors thought to be associated with immaturity and continuing susceptibility to drug use. These interventions are particularly destructive for women drug users in treatment. . . .

Children may be the strongest and most loving attachment for drug-using women, an attachment that is filled with hope for a better future. Although there has been an increase in the number of treatment programs for women with children, there remains a critical shortage, and few programs take advantage of the powerful motivating factor inherent in the mother-child bond. As a result, there are few treatment options appropriate for women who are pregnant or have young children. . . .

Drug treatment for women should seek to be empowering: family-centered; caregiving, that is, helping women feel genuinely cared for; and liberating, that is, providing opportunities for self-development, employment, and education to balance traditional caretaking roles. By nurturing the bonds between clients and their families, therapy centers on supporting behaviors that develop the "self-in-connection" rather than working to achieve insight or to confront problematic behaviors. . . .

Back to the Future: Survival, Uncertainty, and Hope

Avi Rose, LCSW

I know that the epidemic is not yet over, and maybe it is premature to think in terms of post-traumatic stress at a time not yet "post." I also know well that many people living with HIV do not have adequate access to quality health care and expensive medica-

tions. But to the degree that the epidemic is shifting, we are faced with the challenge of envisioning a future beyond AIDS. . . .

None of us came to AIDS as a blank slate. Each of us already had his or her own history, circumstances, and character. For people living with HIV, the nature of going back to the future depends in part on what the future looked like before their lives were changed by the epidemic. If you were feeling good about yourself, doing fulfilling work, had loving relationships with friends and family, felt connected to the community, felt that you had control over your own destiny, and had a sense of purpose and direction in your life, going back to the future probably looks wonderful.

But if you were doing work you hated, felt isolated, anxious, or depressed, were struggling with major addictions, or were barely able to make ends meet, going back to the future may be daunting. On the one hand, anything is possible; on the other, obstacles are frightening and demoralizing. For many people living with HIV disease, dealing with the loss of government benefits or the impact of new immigration policies may make it difficult to feel hopeful about the future, no matter how promising the new HIV treatments are.

Facing the future is sometimes complicated by people having felt left behind by their uninfected friends in the past. Understandably, people with HIV disease measure themselves against their uninfected peers. For those with middle-class opportunities and expectations, this means looking at those who have settled down to careers, families, financial security, and retirement planning. This is especially difficult for the large number of people whose lives were interrupted by HIV during a stage of life when they ordinarily would have been building the foundation for a seemingly secure future. It is important, though sometimes difficult, to face feelings of envy, anger, and resentment, mourning lost opportunities in a way that makes it possible to move forward.

A sense of abandonment is even more evident among people for whom combination therapy is not working. There have always been disparities in antiviral success among people with HIV disease, but these differences have never been so sharply delineated. . . . Shared adversity often fosters camaraderie, and for those who have not yet been doing well with new treatments, the treatment success of others can engender a feeling of being left behind by their treasured comrades. For those who are doing well, it can be difficult to not succumb to survivor guilt, even if survival still feels precarious.

As mental health and medical providers, it is especially important for us to ensure that

Back to the Future: Survival, Uncertainty, and Hope. 1997; 12(7): 1–4.

community and emotional support embrace everyone. We must be particularly careful not to abandon those who might make us feel impotent and uncomfortable when they do not do as well as they are “supposed to.” We need to somehow ensure that there is ample room for the despair of some of our clients, the excitement of others, and the community and solidarity which is still crucial to everyone. . . .

The success of triple combination therapy and protease inhibitors has indeed been exhilarating. But while exhilaration is hopeful and exciting, it can also leave people feeling dizzy and disoriented. There is still so much uncertainty—not a new challenge in the epidemic or, for that matter, in life, but a challenge nonetheless. It is hard for people to tolerate, let alone embrace, uncertainty. Over the years, I have seen people get into trouble pursuing certainty and the “either/or” thinking that comes with it: either I’m going to die immediately, or I’m going to live forever; either I need to give up right now, or I need to pretend I have no limitations. I have found that people do best when they can hold many possibilities at the same time and live with uncertainty—to affirm life, and to move forward, “to live like they’re going to live”—while facing the full range of possibilities.

While certainty is an illusion, it is a powerful and appealing one. Some people are feeling disoriented by the new surge of hope. Not that they wanted their lives to be shortened by HIV, but they thought they knew what to expect. As someone told me, “I had it all planned out,” referring to his expectations to eventually fade and die. He had a plan, and now he needs help in coming up with a new, less “certain” one.

The Changing Picture of HIV: A Chronic Illness, Again?

José Catalan, FRCPsych, Lucinda Green, MRC-Psych, and Flick Thorley, RMN

It is not surprising that some optimists in 1997 were heard to predict that HIV was about to enter a new phase, becoming manageable “like any other chronic disease, such as diabetes.” . . . Chronic illnesses can be regarded as the diseases of affluence. In the days when life was harder than it is now and when working and living conditions, malnutrition, infectious diseases and the perils of childbirth meant that only a minority reached old age, there was limited opportunity and little time for people to develop chronic disorders. Improvements in stan-

dards of living and working conditions, better diet, cleaner water, and adequate sewage facilities have all contributed, together with advances in medical treatments, to increases in survival and longevity. These improvements have, in turn, allowed the burgeoning of new problems, for example, heart disease, diabetes, obesity, arthritis, cancer, and degenerative neurological disorders.

The umbrella term *chronic* is a label used in opposition to “acute,” a time limited, self-contained disease. It hides a wide range of diseases with few things in common: they do not go away easily, they last for a long time, and on the whole, they are never successfully eradicated. It is useful to realize that HIV infection has always been a chronic illness, in the sense that it develops over a number of years. In the early days of the epidemic, it was calculated that only about 50 percent of HIV-infected individuals would develop HIV-related opportunistic conditions within 10 years of infection, although once these problems appeared, decline tended to be rapid, survival after an AIDS diagnosis sometimes lasting less than two years. HIV infection is still a chronic disease, but one where the time span has extended beyond these original expectations.

What is the relationship between chronicity and other features of a disease? The time scale of an illness (chronic or acute) tells us little about its severity: diseases can be chronic and severe as well as chronic and mild, or acute and severe as well as acute and mild. Many chronic diseases such as multiple sclerosis, are indeed severe, even if they have periods of remission when the disease is quiescent; others, such as diabetes or hypertension, require close monitoring of treatment effects. Unfortunately, this distinction between chronicity and severity is sometimes lost when discussing diseases, particularly in the context of HIV infection: describing HIV as a chronic illness implies that it is a less severe condition, a manageable if not altogether curable condition. . . .

Is HIV a chronic disease? To the extent that it lasts years and, to date, cannot be cured, it is a chronic illness and has always been one. It has appeared to be an acute illness sometimes, because of the difference in manifestation and severity between early illness and later acute illness. Today, however, the term chronic has acquired new meanings in the context of advances in HIV management. Describing HIV as chronic illness implies a less severe manifestation throughout its course; it suggests not only that survival is extended, possibly considerably, but also that people with HIV can [as Armistead Maupin states,] start “thinking about living . . . without having to call it denial.”

Community Responses to HIV

It is difficult—and often unnecessary—to separate the actions of individuals from the actions of communities and societies. Some *FOCUS* articles, such as three excerpted here, are particularly notable for what they have said about the role of these groupings of people and the interactions between communities and individuals. This perspective has become particularly important in the past decade, as HIV providers and planners have sought to attend more closely to community well-being as a route toward both prevention and care goals.

What's Housing Got to Do with It?

Mindy Thompson Fullilove, MD and
Robert E. Fullilove, EdD

Two parallel realities—neighborhoods dying and neighborhoods being reborn—have characterized the AIDS epidemic in the United States. The devastating spread of HIV infection has been felt with equal force in the bleakest areas of some of America's urban centers and in the most sparkling havens of gay culture. AIDS and urban destitution have spun together over the past 20 years, during a period when civil rights, women's rights, and gay rights movements have simultaneously experienced invigorating successes and crushing defeats. . . .

Coalition is an important political strategy for minority groups because coalition can influence political will. Coalition politics, particularly between gay activist organizations, and the public health and AIDS research communities, have been important to the advances in the fight against AIDS. This coalition is fundamentally challenged by what many have called "the changing face of AIDS," that is, the growing number of minorities, intravenous drug users, children and women who are ill with HIV disease. Staggering inequalities in education, power, and resources, and differences in language exist to separate the groups. Gay men appear to be organized and to have personal resources. Scientists and public health officials appear to have access to the resources of the research community. People of color appear to have nothing. Yet all of this is, perhaps, illusion.

In major urban areas, the gay community—with as many as half its members infected with AIDS—faces biological destruction unless added resources can help it survive the crisis. Scientists and public health officials fight a constant battle against AIDS discrimination within the health establish-

ment. Communities of color are weakened, but have resources of patience, nurturance and rage that have ensured centuries of survival under oppressive conditions.

What do these disparate groups have in common? They share the urgent commitment to control the spread of HIV, to limit the effects of illness among the infected, to save those who are dying. Despite a history of marked differences that have continued into the present, the potential future of these communities is all too similar. For the gay community, a biological bulldozer could wreak devastating havoc equal to forces of destruction that have demolished the inner city. For the health of the community, it is clear that AIDS is but a symptom of the vulnerability of the human organism. If we cannot unite to limit the spread of disease, then disease—if not this one, then the next one—may eventually engulf the planet. . . .

Houses are fundamental representations of civilization. Houses hold the family, link families together, form communities, and are, therefore, the physical structures of survival. The house-by-house destruction of a community is enfeebling; it breeds disease. More importantly, house-by-house destruction can be caused by a bulldozer or a microorganism.

Limiting the spread of AIDS is a house-to-house project. In some neighborhoods, we must rebuild houses and give the homeless shelter. In other neighborhoods, we must visit the sick and make sure the grass is cut. . . . Perhaps it is this house-to-house preservation of our communities that can unite us in the future.

The New Health Care Paradigm

Jonathan Mann, MD, PhD

Over the past decade, the effects of AIDS on the health care paradigm has been revolutionary. First, since neither drug nor vaccine was available to fight HIV infection, behavior was immediately accorded central importance in the fight against AIDS. Each society rapidly discovered that it had neglected to consider the concept of "behavior" in its prevailing health philosophies and practices and that it was profoundly ignorant about sexual activity, the major behavior of concern.

Then, AIDS, much more than any other previous health issue, stripped away the veils that had covered the deficiencies and inequities in the ways health care and social services were organized and delivered, and highlighted the neglect of groups within society and the low priority accorded to health. People with HIV disease also articulated human needs with a clarity and passion not formerly

What's Housing Got to Do with It? 1990; 5(12): 1-2.

The New Health Care Paradigm. 1991; 6(3): 1-2.

"Why did I feel so uneasy about being out as a person living with HIV disease at an AIDS Conference? . . . It was the feeling of being "other than," of being a Patient in a sea of Doctors. I felt like everyone was talking about me and I was the only one who knew it. . . .

On the other hand, I was moved by [the] immense compassion and dedication toward people living with AIDS. I felt a sense of community with other participants, whether or not they were infected. I felt my grief lift as I . . . saw the international effort of activism, research, and creative prevention programs. [T]he voices of camaraderie . . . revive[d] my spirit."

—Diane K. Haas. 1993; 10(8): 5–6.

encountered and for which the existing structures and services were often fundamentally unprepared.

Next, people infected with HIV and those labeled as members of "high-risk groups" declared their intent to participate in, rather than simply submit to, the processes of prevention, care, and research. The shock waves from this courageous determination to participate have not subsided; they have challenged, for every disease, methods of research and shaken deeply held assumptions about the roles of infected and ill people in their treatment.

Participation broadened

even further as thousands of grassroots organizations responded to often desperate needs for prevention and care services, frequently reacting to the inadequate response of government. As a result, the prevailing view of government as the major actor in protecting health was challenged by the realities of community action and activism.

Finally, somewhat unexpectedly, those involved in the pandemic found themselves speaking the language of human rights and dignity. In what other health area, at what other time, has there been such widespread and worldwide talk of "rights" and "social justice"? Invoking the concepts of human rights—nondiscrimination, equity, and justice—it is not only the *content* of policy and institutional action that has been challenged, but also the *process* through which policies and decisions have been reached.

These acts and many others—the understanding of AIDS as a global problem, the convening of international conferences, and the response of community organizations—have altered the way we think about health, individuals, and society. Towards what new vision, with what insight and power to promote health and prevent disease, is AIDS leading us today?

The key to the new paradigm is the recognition that behavior, both individual and collective, is the major public health challenge of the future. In shifting the major emphasis to behavior, the new paradigm will replace coercion with support, and discrimination with tolerance for diversity. The concepts of incorporation, adaptation, and symbiosis may be more relevant and useful in thinking about social interactions than old dichotomies of external versus internal, or individ-

ual versus collective. Just as AIDS blurs distinctions between the role of pathogens and the role of immunity in personal health, the next paradigm of health must embody a new understanding of the meaning of "internal" and "external," and a new definition of what is the "self" and what is the "other." . . .

Using our current vocabulary—for new words may be required—"solidarity" describes a central concept in this emerging perspective on health, individuals, and society. The AIDS pandemic has taught us a great deal about solidarity. The basis of solidarity is tolerance and non-discrimination: a refusal to separate the condition of the few from the fate of the many. Charity is individual; solidarity is inherently social, that is, concerned with social justice, and therefore also economic and political.

Gay Men Adapting to AIDS: Twenty Years of Coping

Steven Schwartzberg, PhD

Communal influences play a significant role in individual mental health, both in terms of the specific emotional themes that predominate at a given time, and the extent to which a person's own life journey mirrors or deviates from these larger psychocultural trends. This article identifies several overarching AIDS-related communal themes that have evolved for gay men over the past 20 years, and proposes four major phases of adaptation to the epidemic: disbelief/terror, action/belonging, burnout/despair, and early recuperation/fragmentation. Of course, such "communal" phases are, by necessity, imperfect abstractions—as is the very notion that gay men constitute a solitary, identifiable community . . .

Beginning in 1996, the unprecedented success of combination treatment fundamentally altered the landscape of AIDS . . . Because of two interrelated processes—early recuperation and fragmentation—AIDS has become less prominent in gay life, at least overtly. . . .

Early Recuperation. HIV-related illness, death, and new infections have by no means ceased, but as combination treatment has curtailed the lethality of AIDS, gay men have begun recuperating. After what Robert Lifton terms "massive death experiences," recuperation begins not with sharp emotional catharsis, but with a yearning to find respite from the years of intense bereavement and overwhelming emotion. The current relative quiescence of gay men regarding AIDS is rooted in this wish to regain

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psychological equilibrium. Communal energy has moved away from the saturating pain of the previous years, because in light of improved treatment, it is now possible to do so more credibly than before.

Yet any communal recuperative processes can be only tentative, since HIV continues to have a significant impact on gay men. Thus, the diminution of AIDS in gay communal awareness, even if in the service of emotional healing, poses significant risks. It colludes with a magical fantasy that the epidemic is over and can be encapsulated in the past. . . . It also reinforces the defensive denial of present or future grief, as if there will be no further emotional consequences of having lived through an epoch of so much loss. . . .

Fragmentation: Overlapping with early recuperation, gay men are no longer adapting to the epidemic primarily as a community. Although this fragmentation relates to issues such as the changing demographics of HIV, generational factors, and the desire to funnel energy into other causes, community fragmentation is intensified because combination treatment does not yet work for all people. . . . This variability in outcomes . . . strains the “we’re-all-in-this-together” ethos of earlier years.

Given these factors, many gay men no longer have a communal base that mirrors or supports their own particular process of HIV-related healing, grieving, or coping. Men who are faring well, be they seronegative or responding well to treatment, may feel implicitly silenced because of their good fortune; men who are not faring well may feel implicitly silenced because their presence violates a communal fantasy that the epidemic is over and AIDS no longer matters. HIV has become “privatized” among gay men: it is less and less an epidemic afflicting a community, and increasingly a serious illness affecting individuals.

A few years back, gay men faced a schism between the seropositive and the seronegative. Although echoes of this polarization still reverberate, a more apt demarcation today is between men for whom HIV remains a pressing emotional issue in their lives and those for whom it does not. In the first group are seropositive men who are not responding to treatment, those who experience intolerable side effects or difficult regimens, and their loved ones, regardless of HIV status. In the second group are most seronegative men and seropositive men for whom treatment is effective and bearable. . . .

How do these larger communal trends affect individual lives? Some phases of reaction—particularly the epoch of communal action at its height in the late 1980s—lend themselves easily to a sense of belonging,

community support, and finding a larger purpose in personal suffering. At that time, men who sought to express their rage, grief, or despair found, or created, community structures to do so. Now, many of those structures are no longer as available, and far fewer new ones are being created. As a result, feelings of isolation, invalidation, and anomie are apt to be more common.

Currently, men responding well to treatment may experience relief, gratitude, a deepening life appreciation, and cautious optimism. But they may also be prone to feeling guilt or shame, not only for surviving when so many have died, but also for regaining or maintaining current health when others are still ill. This . . . can be exacerbated . . . by the tacit social prohibition against expressing too much public joy or relief about renewed health. . . .

Men not responding well to the newer treatments may now encounter less communal support than they would have earlier . . . [when] seropositive individuals . . . had a respected, at times honored, status. . . . The emotional struggles of men with failing health may now be compounded by a sense of invisibility. The current community ethos may be most detrimental to such men, creating for them feelings of disenfranchisement, disempowerment, and community rejection . . .

The current phase in gay men’s communal adaptation to AIDS is by no means the last one. Whatever follows next, it remains the case that AIDS-related grief is far from resolved. At the same time, gay men will again need to come together to mourn the innumerable losses that defined our lives for so many years.

Next Issue

AIDS Impact, the 7th International Biopsychosocial Conference on AIDS, took place in April in Capetown. In the November Annual Update Issue of *FOCUS*, **Seth C. Kalichman, PhD**, Professor of Psychology at the University of Connecticut, and **Andrea Fuhrel**, a graduate student in social psychology, report on the proceedings.

Also in the November issue, **Les Pappas**, a pioneer in HIV prevention, reviews *Community Interventions and AIDS*, edited by Edison Trickett and Willo Pequegnat. **Mario Sandoval, MA**, the Coordinator of the Considering Work Program at the AIDS Health Project, reviews *HIV+ Sex: The Psychological and Interpersonal Dynamics of HIV-Seropositive Gay and Bisexual Men’s Relationships*, edited by Perry Halkitis, Cynthia Gómez, and Richard Wolitski.

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