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—and function more as a theoretical framework than as a rigid chronological guide.

**The History of HIV: The First Three Phases**

**Disbelief/Terror.** In the early years of the epidemic, disbelief was understandable: AIDS seemed more paranoid fantasy or science fiction scenario than conceivable reality. The concept of such an illness was too discrepant with our Western assumptions about medicine, life, and the world; in Piagetian terms, this was information that, given its immensity and horror, could neither be assimilated nor accommodated. To accept the reality of AIDS required a fundamental retooling of cognitive and emotional capacities to comprehend life and the world, and this could happen only gradually.

The central underlying belief of this time could be characterized as, “This cannot be.” Prominent defense mechanisms, individually and collectively, included projection and denial, with many gay men rationalizing that the illness could or would not affect them: “I’m safe because . . . I live in a small town . . . I don’t go to the baths . . . I’ve never had an STD.” For men who did not engage in these defensive strategies, including those men whose lives had already been undeniably touched by AIDS, this was a period of anxiety, fear, and terror borne from the shocking severity of what was unfolding.

**Action/Belonging.** As disbelief faded, these brittle defenses evolved into more adaptive coping strategies, the most prominent being action. With impressive determination, gay men effected an enormous cultural shift in response to the epidemic, adopting safer sex practices and constructing an elaborate network of AIDS-related services. Communal grief was funneled into projects such as the AIDS Quilt; communal rage ignited the birth of ACT-UP and other activist groups. By the mid-1980s, the core unspoken belief had shifted from “This cannot be,” to “Do something!”

From a coping perspective, the response of action was as important as the content of specific actions themselves. Action fueled hope. It reinvigorated a belief in personal control, countered feelings of helplessness, and imbued the suffering of many with meaning. It became a conduit for, and escape from, grief. Most profoundly, action represented an urgent attempt to deny death, as if “doing something” could stop the dying. ACT-UP’s slogan, “Action equals life, silence equals death,” was as much a fervent wish as political rallying cry.

Action also enabled many gay men to forge deeper connections with other people. It fostered a newfound sense of belonging to the gay community and a concomitant healing of internalized homophobic shame. It strengthened bonds with friends, family, or lovers, and offered an opportunity to connect with others, including lesbians, outside the insular gay male world. For some, it evoked a transcendent sense of
Editorial: The End of Community?

Robert Marks, Editor

For every wound that time heals, another one opens. Year after year, the struggle with grief, illness, death, and unending risk has taken a huge toll on the psyche and cohesion of communities of gay men and the people who share community with them.

The modern gay movement was reshaped by HIV in the early 1980s. Some believe that the epidemic forced what had been a community bound together only by the politics and sexual freedom of gay liberation to add another dimension: emotional intimacy. This change, while forged by the horror of AIDS, ultimately strengthened a sense of community, reducing the isolation and fragmentation that gay people naturally feel in a straight world. If, in fact, the gay community was in a more fragmented state when the epidemic began, then Steven Schwartzberg’s assertion that we have again become fragmented makes even more sense; we may really recede, or has the community bound together only by the politics and sexual freedom of gay liberation to add another dimension: emotional intimacy. This change, while forged by the horror of AIDS, ultimately strengthened a sense of community, reducing the isolation and fragmentation that gay people naturally feel in a straight world. 

Burnout/Despair. Beginning roughly in the early 1990s, burnout, despair, and grief overload became the defining emotional features of gay male communities. Having so much cumulative illness and death, and too many disappointing false starts regarding medical progress, gay men could no longer sustain the previous levels of emotional and practical involvement. Activism and community participation continued, but with neither the same fervor nor the same magnitude. Even the grief of those years took on the tone of despair, expressed more through withdrawal and fatigue than engagement or rage.

Today: Early Recuperation/Fragmentation

Beginning in 1996, the unprecedented success of combination treatment fundamentally altered the landscape of AIDS, psychologically as well as medically. Many men who were near death have regained health and vitality; many more men with HIV have never developed serious symptoms. Because of two interrelated processes—early recuperation and fragmentation—
AIDS has become less prominent in gay life, at least overtly. This is evident in many ways: the reduced coverage of AIDS in the gay (and mainstream) media, the decline in new AIDS-related gay social initiatives, and even, anecdotally, the decreasing amount of time gay men discuss AIDS in individual psychotherapy. HIV is also less visible in a more literal sense: most seropositive gay men now look robustly healthy.

*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 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. This can lead to harmful consequences, including heightened sexual risk and increased HIV transmission. 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.

Had the major treatment breakthroughs occurred five years earlier than they did, gay men’s early recuperative processes might have evolved differently, with more vociferous communal expressions of grief, relief, and activism (to address, for example, the class, race, and gender inequities in access to the costly new drugs). However, given that the medical advances arrived only after years of ever-deepening emotional depletion, the numbing exhaustion that had taken hold set the tone. Viktor Frankl, the psychiatrist and concentration camp survivor, captures a similar phenomenon in *Man’s Search for Meaning* as he describes liberation after years of Nazi imprisonment:

> We walked slowly along the road leading from the camp... We came to a meadow full of flowers. We saw and realized that they were there, but we had no feelings about them... we did not yet belong to this world.

In the evening when we all met again in our hut, one said secretly to the other, “Tell me, were you pleased today?”

And the other replied, feeling ashamed as he did not know that we all felt similarly, “Truthfully, no!” We had literally lost the ability to feel pleased and had to relearn it slowly.

*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.

Many people have experienced near-miraculous results through combination treatment, but others have not. This variability in outcomes has profound ramifications, individually and communally. It is a new phenomenon in the epidemic that strains the “we’re-all-in-this-together” ethos of earlier years. (Prior treatments, including zidovudine [ZDV; AZT] monotherapy, eventually failed most people.)

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 affecting 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.

Communal Reactions, Individual Lives

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 of 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 guilt and shame can be exacerbated and inadvertently reinforced by the tacit social prohibition against expressing too much public joy or relief about renewed health. In addition, men who had been seriously ill may experience what has been called the "Lazarus syndrome," with attendant reactions of anxiety, depression, uncertainty, and practical, financial, and relational challenges stemming from their unexpected revitalization.6

Men not responding well to the newer treatments may now encounter less communal trends affecting their lives and those for whom it does not. For many years, seropositive individuals, even while facing stigmatization, also had a respected, at times honored, status within the gay community. This seems far less true today. 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 hearkening back to the earliest years of the epidemic.

Conclusion

The shift in the past few years toward a less communal AIDS focus affects all gay men, regardless of HIV status. After the initial years of disbelief, the epidemic brought people together and provided many with a rich sense of purpose; this is the paradox inherent in any tragedy. When AIDS was something to be fought, and fought together, it was a means by which many gay men not only coped successfully with HIV, but also shed layers of internalized homophobia. But fighting for something can provide a greater sense of purpose than achieving it, and the lack of a shared, externally-imposed goal or "enemy" can rekindle loneliness and anxiety, resurrecting as it does the core human challenge to create, for oneself, meaning and direction in life.

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 some time, gay men will again need to come together to mourn the innumerable losses that defined our lives for so many years. To echo the words of Viktor Frankl, when it comes to recovering from AIDS, gay men still do "not yet belong to this world."

Clearinghouse: Adaptation to HIV

References


Reeves PM, Merriam SB, Courtenay BC. Adaptation to HIV infection: The development of coping strategies over time.
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.”

Chronic risk has prevention implications for both seropositive and seronegative people, suggesting a lifetime not only of vigilance, but also of sustained behavior change. It requires every sexual encounter to include the possibility of a dialogue about HIV risk and, for people with HIV infection, to include the possibility of disclosure of their HIV status. People with HIV may already suffer from a sense of being plague-stricken, unattractive, flawed as sexual individuals, and denied their sexuality by society. Many gay HIV-positive men express the heavy burden of never being permitted to lose control or to make any mistakes as: “I am simply not allowed to be human.” At the core of chronic risk is its potential threat to the individual’s sexual well-being. This article defines some of the effects of chronic risk and proposes a psychosexual and existential context within which these effects may be understood.

HIV Saturation

Anecdotal evidence suggests that one of the effects of living within the context of chronic risk may be “HIV saturation,” an exhaustion brought on by an ongoing vigilance and attention to prevention messages, particularly among HIV-negative men. HIV saturation may have a detrimental impact on an individual’s sexual well-being, and this may lead to a rejection of HIV-related behavior change either as an occasional lapse or as conscious choice. A factor that may reinforce this indifference is the belief, demonstrated in several studies, that HIV is less dangerous and contagious in the age of new HIV antiviral treatments.

Social psychology recognizes that uncontrollable or unpredictable events are more stressful than predictable ones, and that coping can involve either avoidance or confrontation of the stressor. Living perpetually on the boundary between being infected and being uninfected falls into the category of the unpredictable. Even though this situation appears controllable through standard safer sex practices, constant vigilance may lead some toward avoidance coping. Where there is avoidance, denial of risk or lack of preparation is likely to impede the implementation of safer behaviors.

Sexual and Emotional Distress

Chronic risk and its potential sexual boundaries—symbolized by condom use or limits on sexual practices—may also lead to a sense of sexual and emotional distress. Sexual distress may manifest as the fear of being sexually spontaneous, as sexual isolation, as concerns about infecting someone or being infected, as worries about sexual performance, and as sexual symptoms (including reduced sexual interest or desire, and sexual dysfunction). People living with HIV may find that any sexual distress they experience may be reinforced by HIV disease progression and physical deterioration. Distress can easily turn into unsafe sex: there is evidence to suggest that for
gay men, depression, anxiety, and associated negative mood states are closely related to the failure to maintain safer sex.\(^2\)

There appear to be no studies of HIV-negative people that have investigated the impact on sexual well-being of the stress of chronic risk, limited sexual activity, and the association of sex with risk and death. There have been a few studies of HIV-positive gay men that investigated perceived sexual distress and its impact on psychological well-being and quality of life.

In one study of seropositive gay men and heterosexual women, the vast majority reported dissatisfaction with their current sexual lives. However, sexual satisfaction was higher among those men who had unprotected sex than those who had protected sex. More than one-third of subjects experienced a lack of sexual interest and more than one-half reported sexual symptoms (in particular, declined sexual desire and erectile dysfunction) in the prior year. Sexual symptoms did not correlate with HIV-related physical symptoms. Sexual symptoms and sexual dissatisfaction were associated with psychological distress (including helplessness, hopelessness, and depressed mood) as well as with diminished quality of life. Psychological distress also correlated with lower levels of quality of life. In other words, there seemed to be a close interplay between sexual and psychological distress and diminished quality of life.

For gay men whose identification is strongly vested in sexual performance, sexual behavior change may further be construed as an "identity death," resulting not only in the loss of sexual pleasure and meaning, but also in the loss of self.\(^3\) This may exacerbate already existing low self-esteem among many gay and bisexual men, a situation that arises in the context of the internalization of the anti-gay attitudes endemic in society. Such identity and esteem problems have also been associated with unsafe behavior.\(^4\)

**A Psychosexual and Existential Context**

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.\(^1\) 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 counter-weight 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.

**Conclusion**

Individual sexuality and sexual well-being are central to psychological well-being, quality of life, and HIV prevention. Without an ongoing dialogue about chronic risk and its related concerns, care may be undermined by a vicious circle of sexual distress, psychological suffering, reduced quality of life, and ultimately failed prevention efforts.

---

**References**


**Authors**

Lena Nilsson Schönnesson, PhD is Associate Professor of Social Work, University of Göteborg, Sweden and licensed psychologist at the Gay Men’s Health Clinic, Southern Hospital/Karolinska Institute in Stockholm. She is the co-author with Michael W. Ross of Coping with HIV Infection: Psychological and Existential Responses in Gay Men (Kluwer Academic/Plenum Publishers, 1999). Michael W. Ross, PhD, MPH, MHPEd is Professor of Public Health, University of Texas, Houston. He has published widely in the areas of sexually transmitted diseases, HIV, and gay men, and is the American Editor of the journal AIDS Care.

---

**New Book on Depression**

The UCSF AIDS Health Project announces *HIV and Depression: Context and Care*, the fifth title in its monograph series. Offering practical advice on assessment and treatment, the book emphasizes the contexts in which depression occurs, including cultural, clinical, and HIV-related contexts.

The book costs $11.95 plus $2.00 shipping and handling and 8.5 percent sales tax for California purchasers. Send payment and address to UCSF AIDS Health Project, Box 0884, San Francisco, CA 94143-0884. For multiple, rush, or international orders, call 415-502-4930.
Conceptions of HIV
Bartos M, McDonald K. HIV as identity, experience or career. AIDS Care. 2000; 12(3): 299–306. (La Trobe University, Melbourne, Australia.)

An Australian interview study identified three ways seropositive individuals conceive of their relationship to their HIV infection: HIV as identity, HIV as experience, and HIV as career. This conception affects the ways a person responds to HIV treatment adherence and failure, HIV prevention, and HIV community.

Researchers interviewed 76 people with HIV; 63 were men and 13 were women, and 60 identified as gay or bisexual. Respondents had been living with HIV for periods ranging from one year to 13 years. Eighty-one percent of gay men and 88 percent of heterosexual women and lesbians reported having contact with AIDS organizations, compared with only 67 percent of heterosexual men. Similarly, 61 percent of gay men spent at least some time with other HIV-positive people, compared with only 38 percent of women and 20 percent of heterosexual men. Finally, 46 percent of all the women and 61 percent of all the men said they believed in “HIV community.”

The conception “HIV as identity” was most characteristic of gay men. From this perspective, HIV treatment becomes a marker of self-health and treatment failure or poor adherence may be internalized as personal failure. Changes in HIV treatment regimen can be difficult, because they may require changes in ways of living. Those who considered HIV to be central to their identity or sense of self also found sexual negotiation to be difficult for two reasons: they viewed the failure to disclose HIV status as a failure to be true to themselves, and they believed that condom use could be interpreted by sexual partners as disclosing “pariah status.”

The conception “HIV as an experience” was particularly characteristic of women and heterosexual men. This conception draws a clear distinction between the “accident” of infection—as “something to be dealt with, not dwelt within”—and the sense of self as an integrated whole. Participants who regarded HIV as an experience were less likely to be on medications, and were more likely to distance themselves from HIV by missing or altering doses as a mark of self-control. These individuals saw HIV community in “narrowly instrumental terms”: it occurred at specific times, such as during support group meetings. In addition, managing relationships took priority over managing HIV transmission.

Finally, some participants, regardless of gender or sexual orientation, maintained strong ties to the HIV community, whether they actually held jobs in the AIDS field or volunteered as subjects for medical studies. But unlike those who experienced HIV as identity, those who conceived of HIV as a career acknowledged a crucial separation between self per se and involvement with HIV as something you do. “HIV careerists” were the most likely to describe themselves as adherent to treatment regimens. Their condom use depended on the context of the situation, and they had a strong tendency to believe that safer sex is a mutual responsibility.

Perceptions of Safe and Unsafe Behaviors
Vince J, Bolot R, De Vleeschouwer P. The cognitive structure of the domain of safe and unsafe gay sexual behaviour in Belgium. AIDS Care. 2001; 13(1): 57–70. (University of Ghent, Belgium; and Pomona College, Claremont, California.)

Gay men who engaged in protected anal sex were gratified by more types of sexual behavior than were men who engaged in unprotected anal sex, according to a Belgian study that asked subjects to rate sexual techniques. In addition, “unsafe” men perceived pleasure and danger as two independent “cognitive dimensions” that they used to structure sexual behavior. For “safe” men, these two dimensions mangled to form one dimension: what was safe was gratifying and vice versa.

Researchers surveyed 331 gay men over the age of 30. They defined risky or unsafe
sex as unprotected receptive or insertive anal sex with non-steady partners. Only 6 percent of the men in the study fell into the unsafe category; 94 percent were categorized as safe. Participants rated their perceived gratification and perceived risk for 25 sexual techniques ranging from French kissing, mutual masturbation, and spanking to sadomasochism and insertive and receptive oral and anal sex. Overall, safe men rated as safer and more gratifying sexual techniques that did not involve penile penetration or transmission of bodily fluids, including mutual masturbation, massage, and deep kissing.

Safe men attributed more equal levels of gratification to both insertive and receptive anal sex, whether with a condom or without a condom, than did unsafe men. For example, unsafe men and safe men did not differ in their perceptions of gratification and risk related to unprotected receptive anal sex; however, unsafe men assigned 40 percent more gratification than did safe men to unprotected insertive anal sex. This relationship was also true for oral sex. Further, unlike unsafe men, safe men attributed equal levels of risk to unprotected insertive and receptive anal sex. Finally, unsafe men made a sharper distinction than safe men between what is gratifying and what is risky for them and what is gratifying and what is risky for their partners.

Renewed Health and Disease Perspective

In a small study of HIV-positive adults, participants who had undergone perspective transformations after initial diagnosis with HIV did not revert—in light of renewed health—to the self-oriented and materialistic views of the world they had prior to HIV infection. Also, due to improved prognosis, participants adopted a future-oriented perspective, greater attention to self-care, and greater integration of the HIV-positive status into their self-definition. After their initial reactions to diagnosis, participants developed new perspectives that included a desire to make meaningful contributions to their communities, heightened sensitivity to life and other people, and service to others.

Two years later, a follow-up assessed how the improved prognosis brought on by combination antiviral treatment affected participants’ perspectives regarding HIV and their selves. The final sample consisted of 14 of the original 18 participants (eight White, five African American, and one Hispanic). Ten of the participants reported being on protease inhibitor therapy.

Participants continued to make meaningful contributions to the community and demonstrated great appreciation for their lives and the lives of others. They reported that they were making more plans for the future due to improved prognosis, and many continued to volunteer to do AIDS outreach, speak publicly about HIV, or work in AIDS research. Also, they were able to find a healthy balance between attending to their own needs and caring for the needs of others. Finally, there was a notable difference in the centrality of HIV in the lives of participants in the second interview. Two years earlier, most participants had defined themselves primarily in terms of their HIV status. At the time of the second interview, HIV ceased to occupy a dominant role in terms of self-definition, being integrated with other concerns such as job, home life, and personal relationships.

Next Month
Over the past decade, there has been compelling evidence that many people with HIV have experienced physical and sexual victimization prior to infection. Today, new studies show not only that violence may directly increase the risk of HIV infection, but also that HIV infection may increase risk of violence. In the May issue of FOCUS, Sally Zierler, DrPH, MEd, Professor of Community Health and Associate Director of the AIDS Program at Brown University, reviews the relationship between violence and HIV and discusses the implications of this relationship for the health care setting.

Also in the May issue, Stanford University researchers Cheryl Gore-Felton, PhD, Lisa D. Butler, PhD, and Cheryl Koopman, PhD look at the relationship between HIV-related violence and post-traumatic stress disorder.
DID YOU KNOW?

You can access a FREE searchable archive of back issues of this publication online! Visit http://www.ucsf-ahp.org/HTML2/archivesearch.html.

You can also receive this and other AHP journals FREE, at the moment of publication, by becoming an e-subscriber. Visit http://ucsf-ahp.org/epubs_registration.php for more information and to register!

ABOUT UCSF AIDS HEALTH PROJECT PUBLICATIONS

The AIDS Health Project produces periodicals and books that blend research and practice to help front-line mental health and health care providers deliver the highest quality HIV-related counseling and mental health care. For more information about this program, visit http://ucsf-ahp.org/HTML2/services_providers_publications.html.