Coping with Loneliness and HIV

Ami Rokach, PhD

Dean Ornish states, "Our survival depends on the healing power of love, intimacy, and relationships. Physically. Emotionally. Spiritually." In North America, the need for high-quality human contact is also fueled by a societal preoccupation with strength and success. Lack of success in business or personal life is taken to indicate a terrible individual flaw, which further isolates people from one another. Susan Gordon describes this chain of events: "To be alone is to be different, to be different is to be alone, and to be in the interior of this fatal circle is to be lonely. To be lonely is to have failed." 1

Illness—HIV disease in particular—is a fertile environment for this dynamic: HIV-related stigma and fear distance others from people with HIV, and a sense of failure and shame causes people with HIV to isolate themselves. This article defines the causes and effects of loneliness, the ways in which HIV enters this equation, and how people with HIV tend to cope with loneliness.

Being Alone versus Being Lonely

Being alone does not necessarily mean being lonely. Aloneness, if it is planned or welcomed can result in a solitude that may enhance self-knowledge or life meaning. 2 In contrast, loneliness, while it may entail geographical aloneness or social isolation, reflects the aversive and painful experience of not belonging, not feeling connected, or not feeling valued by others. It has consequences that are detrimental to emotional, physical, and spiritual well-being.

Clark Moustakas was the first contemporary writer to develop the concept of loneliness anxiety. 3 He distinguishes loneliness anxiety from existential loneliness, which he characterizes as the reality of being human, of realizing and facing experiences of tragedy and upheaval, of being born and dying as a separate entity—all alone.

Moustakas defines loneliness anxiety as the fear of being lonely. This fear inspires the denial of pain and fuels the hectic social activity of modern life, responses that are aimed at one goal: relieving the fear of loneliness and blurring the realization of alienation. This strategy may be dysfunctional: taken to its extreme, it may result in a lonely person running, as if on a treadmill, to escape his or her loneliness.

Most people desperately fear loneliness and the feelings of helplessness and hopelessness that are often part of its vicious cycle. People with loneliness anxiety may structure their lives in ways to avoid the agony of loneliness and thereby maintain a denial of these feelings, grasping for any activity or relationship to assuage the suffering. For example, someone may engage in superficial social involvement or a clinging attachment to anyone who will tolerate it.

Loneliness anxiety and the need to belong, be valued, and loved often motivate people to engage in intimate relationships that may be superficial, unsatisfying, and unstable. Any relationship inspired by loneliness and the fear of its pain involves alienation and pain and, ending in eventual separation, provokes more loneliness. Antiseptic sex—having sex with someone only as a means of warding off loneliness—may be a prime example of the extent to which a person may go to escape the terror of loneliness. People want and need love. When they cannot get it, they settle for sex, even when it increases HIV-related and other risks.

The Effects of Loneliness on Health

No one has walked this earth without experiencing loneliness at some point in his or her life. Recent studies suggest that a large proportion of the population frequently feels lonely. 4 These studies have found that as many as 40 percent of their samples answered affirmatively the question: "Have you felt lonely in the past week?"
The great paradox of being human is that we are both among the most social of animals and the most individual. Our psychology provides us with the tools to make emotional connections and the understanding that these connections will never be enough to bridge the gap between one person and another.

But as Ami Rokach describes in this issue of FOCUS, not all of us feel the weight of this existential dilemma. Deep down inside, however, many of us fear loneliness, putting us at risk of what Rokach identifies as “loneliness anxiety.”

Other factors in our lives—ranging from the marginalization experienced by stigmatized groups, for example, some African Americans, gay men, or people with HIV, to the self-imposed isolation of loneliness—can undermine the carefully constructed emotional balance that protects us from the detrimental effects of loneliness.

Relieving loneliness anxiety and isolation is central to supporting the HIV healing process and reducing risk among people who are uninfected. Rokach reviews the coping mechanisms that HIV-positive people tend to use. Ben-David Barr discusses the role of three types of social support models in relieving loneliness and furthering HIV prevention goals.

While the mechanisms that Rokach describes are widely accepted, the strategy of HIV-related social support, and particularly social support groups, has come under fire. In a climate of scarce HIV funding, many social support programs are considered extravagant; those that include dating workshops or recreational activities are further condemned as frivolous.

Full disclosure: the AIDS Health Project offers social support groups to augment a full range of mental health services. By incorporating clear HIV-related strategies that are effective, these activities are neither wasteful nor trivial. Beyond the headlines lampooning “bowling nights” for people with HIV as a truth that does not fit in the 48-point type: social support decreases the use of more expensive medical and psychiatric services by reducing risk among uninfected people and improving health-seeking behaviors among HIV-positive individuals. The great paradox of being human—at least in the United States—is that while we are hard-wired to seek community, when it comes to building society, we cling to an ideal, a myth, that self-reliance is more valuable than social support.

Loneliness has been linked to depression, anxiety, and interpersonal hostility, an increased vulnerability to health problems, and suicide. Although a cause-and-effect relationship has not been established, research has also repeatedly demonstrated that lonely people are plagued by other physical, emotional, and social problems.

Andrew Weil has observed that the widespread isolation experienced in Western society is unhealthy physically, emotionally, and spiritually. “I do know for sure that connectedness is necessary to well-being. You can eat as much salmon and broccoli as you can, take antioxidants for the rest of your life, breathe terrifically, and walk all over the earth, but if you are disconnected [from others], you will not achieve optimum health.”

This connectedness to others is so important that its nature affects the biopsychosocial process that influences behavior and promotes or impairs health.

HIV disease remains a highly stigmatized condition, fraught with fears of contagion and moral judgments that marginalize people with HIV as a group and distance individuals with HIV from their friends and families. Even in friendship systems and families where a person with HIV is accepted and embraced, the disease process of debilitation and pain and its psychological counterpart of shame may alienate individuals from their natural support systems. Battling a serious illness, being shunned by others, and ending up lonely may result in heightened feelings of anger, further social withdrawal, intensified depression, and diminished treatment adherence.

Coping with Loneliness

Over the past two decades, research has highlighted both cognitive and behavioral changes for coping with loneliness. Not only do we need to truly connect with others, we may also need to learn how to initiate, maintain, and even terminate relationships in ways that do not result in further loneliness, anxiety, and depression. A Toronto study grouped strategies for coping with loneliness into the following six factors, examining their use among people with HIV:

- Acceptance and reflection: the ability to be by oneself in order to become acquainted with one’s fears, wishes, and needs, and consequently, to accept loneliness and its resulting pain;
- Self-development and understanding: the increased self-intimacy and growth that arise from participation in groups...
Antiseptic sex—having sex only to ward off loneliness—is an example of the extent to which a person may go to flee the terror of loneliness.

The study examined 125 people: 38 outpatient cancer patients, 34 people recruited from HIV support groups, and 53 people who did not report any serious health problems. The average age of participants was 39 years; the average educational level was grade 12. There were roughly the same number of men and women.

People with HIV engaged significantly more than people in both of the other groups in organized support or social groups and in medical help. They also relied more on their support systems, and on the active pursuit of daily responsibilities and gratifying activities. Finally, they engaged more than others in alcohol and drug consumption.

Of the six factors, acceptance and reflection was so fundamental to successful coping that all three groups used it to a similar extent. Acceptance and reflection requires a willingness to experience fear, anger, agony, and disillusionment, but this factor enables individuals to confront loneliness and accept it rather than to attempt to escape it. This is the first step to coping with loneliness.

Religion and faith also seemed to be fundamental to coping with loneliness. Rae Andre suggests that a person might successfully deal with loneliness by finding solace, that “emotional experience of a soothing presence.” He observes that ritual is an important source of solace, providing a connection to the past and the future and thereby anchoring an individual in time and space. In this way, religion and faith may not only connect a person to other worshippers; it may also generate the solace that comes from feeling related to a protective supreme being and from participating in rituals that anchor people to the certainty and stability of this being.

As noted above, people with HIV were most likely of all three groups to find active participation in support or social groups to be helpful in coping with loneliness. Self-development and understanding increases the self-intimacy, renewal, and growth that often result from active participation in organized groups—ranging from Alcoholics Anonymous to HIV support groups to social clubs—and from medical or psychological support and guidance from the clergy.

According to Dean Ornish, “When you can share your darkest secrets and mistakes with another person who listens without judgment, it is like shining a light in the darkness . . . A support group helps heal isolation, alienation, and loneliness.” Accumulating evidence suggests a strong link between social bonds and both physical and emotional well being. Ornish maintains that social support helps people navigate life, but his quotation of Rachel Naomi Remen suggests an even more fundamental role for support networks: “Intimacy heals suffering. We suffer not because we’re in pain. The real suffering is that we feel we are alone.”

People with HIV use distancing and denial to cope with loneliness more frequently than people with cancer or those in the general population. It is natural for people with life-threatening illnesses—afraid not only of losing their lives, but also family, friends, and employment—to distance themselves from that situation through denial. It is conceivable that for those who “favor” the defense mechanism of denial, denying HIV will be accompanied by denial of other uncomfortable aspects of illness, including loneliness. Although this approach may successfully block pain in the short term, it cannot diminish loneliness on an ongoing basis. Substance use may facilitate denial, modulating a person’s perception of loneliness.

Conclusion

HIV disease may increase the likelihood and severity of loneliness, and loneliness may impede the ability of people with HIV to cope. It appears that people with HIV—to a greater extent than others—seek to “re-enter society” by continuing to pursue daily activities, thus creating new opportunities for social contact. As James Billings observes, “We have a world full of people who have a genetic predisposition to affiliation, the need to belong.” That predisposition is felt most acutely in light of social alienation, often felt by people with HIV. By helping people with HIV identify any loneliness they experience, accept it, and cope with it, counselors can enable clients to balance this predisposition with the reality of their lives.
A large body of research documents the deleterious effects of social isolation on health. While research also identifies social support as a protective factor that promotes positive health outcomes—including improved HIV treatment adherence, reduced HIV disease progression, and increased HIV risk reduction—social support programs have been criticized as frivolous in the highly politicized world of HIV funding.

This article provides a brief overview of socially focused interventions followed by a discussion of the challenges and benefits of incorporating these interventions within HIV prevention programs. In this context, social interventions are those that promote the development of social support and a sense of community affiliation among participants in order to achieve HIV-related behavior change. The article discusses the three types of social intervention that are most likely to produce an immediate effect on loneliness and risk reduction: skills building and support group models; social network models; and social capital models. It does not review other types of social interventions such as social marketing.

Skills-Building and Support Group Models

Skills-building and support group interventions have been central to HIV prevention since the beginning of the epidemic. Many of these interventions evolved from already existing psychological and health promotion concepts. The Health Belief Model, the Theory of Reasoned Action, later Social Cognitive Theory, and the Transtheoretical Model of Behavior Change helped explain how people develop new behaviors.

Most urban communities in the United States have emotional support programs for people with HIV and their caregivers. These groups are designed to help address loneliness, isolation, and HIV-related anxiety. Other programs address skills building among at-risk but uninfected people such as HIV-negative gay and bisexual men, substance using women, and sexual partners of HIV-positive individuals. These programs typically consist of time-limited—for example, twelve-week—support groups designed to increase confidence and skills in making and maintaining behavior changes.

Research has shown that these groups nurture abilities related to communication, sexual negotiation, and planning, for example, the ability to anticipate the need for safer sex supplies such as condoms.

A frequently cited limitation of social support and skills-building programs is that they are most effective at providing assistance to small numbers of at-risk individuals and that they are too complex or too expensive to use with large populations. An additional criticism is that HIV prevention has over-emphasized interventions that modify individual health factors and overlooked the effects of social norms and group affiliation on risk behavior.1,2

Social Network Models

In response to criticisms about this over-reliance on individually focused interventions, HIV researchers investigated the effectiveness of social network models. Based on the work of Jeffrey Kelly and his colleagues, social network interventions train key opin-

While social interventions entail risks, they promote community affiliation, self-determination, and risk reduction.

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References


Miller M, Paone D. Social network...
ion leaders to disseminate information and promote new community norms. Diffusion theory details how individuals adopt new information and offers guidelines on how to identify the most effective opinion leaders. Existing networks serve as information channels that can be tapped to deliver prevention messages. In a sense, these programs rely on a person’s desire to conform to peer group values, illustrating the protection that can be achieved when an individual feels connected to a social group and that group promotes healthy behaviors.

Several research projects have demonstrated the effectiveness of social network models to reduce HIV risk behaviors, for example, among gay and bisexual men in mid-sized southern U.S. cities and low-income women living in community housing. Social support has typically been included in social network interventions as an incentive to increase participation. Social network interventions focus on influencing social norms in existing groups. But what happens when there are no established opinion leaders in a network or when networks are nonexistent or weak? In such situations, program developers must create interventions that promote social support, social interaction, and peer group affiliation.

**Social Capital Models**

“Social capital” is a term popularized in sociological discussions of the role of citizen participation in civic and social life; in the context of HIV prevention, it describes projects that attempt to encourage community participation and develop socially focused assets such as social norms, cohesive social networks, and civic institutions. According to Ichiro Kawachi, “Social capital consists of features of social organization—such as trust between citizens, norms of reciprocity, and group membership—that facilitate collective action.”

Social capital and social network models share the belief that promotion of appropriate social norms will reinforce HIV risk reduction behaviors, but social capital approaches also develop community leadership and social networks where they are weak or nonexistent. Although social capital perspectives have typically looked at geographic communities, these methods also hold potential for population groups that lack cohesion, for instance, substance users, low-income women, gay men of color, and families of people living with HIV.

Early volunteer-based responses to providing HIV care—the Buddy system of the Shanti Project, for example—easily fit within a social capital model as did several other HIV prevention projects. For instance, the Stop AIDS program, which began in San Francisco in the late 1980s, focused on promoting community dialogue and encouraging project participants to identify actions they could take to personally address HIV risk reduction.

Another, more recent, influential model was the M’powerment Project, which evaluated the effect that participation in community-building activities that included HIV prevention messages had on the risk behavior of young gay and bisexual men. Young men in control cities demonstrated reduced risk behavior. A key recommendation from the M’powerment Project study is that “HIV prevention programs must be embedded into the satisfaction of needs for social and community belonging.” Among the activities that the project used were ongoing outreach efforts, development of a community center, establishment of ongoing community meetings, and implementation of participant-developed social events.

Influenced by the outcomes of social network interventions and the M’powerment project, some community-based groups began to increase the social

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**References**


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See also references cited in articles in this issue.

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support components of their HIV prevention programs. For instance, in 1994, the Gay City Health Project in Seattle began a series of community-building interventions by promoting dialogue among gay and bisexual men and encouraging community members to identify their own HIV prevention needs. The project held a series of community forums, some with as many as 300 participants. In the weeks after a forum, participants met and developed HIV interventions and social projects. Many of the projects focused on the participant’s desire to create a stronger sense of community affiliation. For instance, one group of participants organized a weekend retreat with a series of workshops that addressed topics such as aging, survivor guilt, spirituality, and the impact of stigma and shame on gay identity. Participants also developed skills-building projects such as dating workshops, and book clubs.

Empowerment theory, as well as traditional community organizing methods, influenced the development of social capital interventions. These perspectives promote the importance of community participation in the identification and amelioration of community problems, and have inspired interventions such as needle exchange programs, safer injection practices trainings, and activities such as those developed by Gay City.

When interventions incorporate entertainment, community control, or harm reduction perspectives, they often provoke heated public debate. Significant segments of society still favor programs that proscribe behaviors, maintain professional control of interventions, and do not mix recreation with risk reduction. While often controversial, social capital interventions have significant potential to create stronger connections among project participants, thereby enhancing group members’ sense of belonging and their ability to collectively address community problems—what social psychologist Albert Bandura refers to as “collective efficacy.”

Challenges to Implementing Social Models

Socially focused interventions have great potential to reduce HIV-related risk, loneliness, and isolation. Two significant challenges impede the implementation of these methods.

First, if poorly articulated, their HIV prevention goals may lead to projects that fulfill only recreation and socialization goals, and these goals alone are not without risks. Social networks can influence individuals to engage in unhealthy behaviors, while social capital activities can gather large numbers of individuals in ways that may amplify risk. The circuit parties that have developed in gay communities are a clear example of how such a project can promote risk. Initially organized as HIV fundraisers, these events have evolved into large-scale raves where social norms include acceptance of pervasive substance use and unsafe sexual behavior.

Some might argue that it would be more effective HIV prevention to isolate those who engage in risky behavior. This might be an acceptable practice if the goal were to change the behavior of a specific individual, for example, to encourage a recovering drug user to avoid interaction with other drug users. But this is not a strategy that will create increased health and well-being for groups and communities; instead, it will exacerbate loneliness and isolation.

Second, there is only limited evidence to prove the efficacy of social capital interventions. The best methods to evaluate community-level behavior change require complicated and expensive controlled trials beyond the budgets and expertise of most community-based organizations. In order to strengthen social interventions, it is necessary to find more opportunities to support and strengthen cooperative evaluation between universities, public health programs, and community agencies.

Conclusion

Socially focused interventions illustrate both our desire for belonging and our fear of exclusion. Within HIV prevention programs, we have begun to recognize how these responses influence behavior. While these complicated interventions entail risks, they also offer opportunities to promote community affiliation and self-determination, fostering the connections that can lead to healthier individuals and communities.

Change in FOCUS Schedule

To sustain FOCUS over time—in an era of rising costs and decreasing HIV funding—we have decided to heed the advice of readers and reduce the number of times FOCUS comes out each year. As of January 2003, FOCUS will be published 10 times a year, with no issues in December or June. If you have any questions about this change, please contact Jennifer Jones at jejones@itsa.ucsf.edu or 415-502-4930.
Recent Reports

**Family More Powerful Than Friends**
Kimberly JA, Serovich JM. The role of family and friend social support in reducing risk-behaviors among HIV-positive gay men. *AIDS Education and Prevention*. 1999; 11(6): 465–475. (Ohio Department of Mental Health; and Ohio State University.)

Although friends are often thought to be more supportive than family members, a Midwestern U.S. study reports that familial support has a greater effect than friend support on reducing intentions of risky behavior among people with HIV. Social support has been found to reduce depression, physical distress, and hopelessness, increase psychological well-being, and diminish HIV-related risk-taking behaviors.

Of the 142 HIV-positive men surveyed in the study, 84 percent were White; the mean age of the sample was 37 years. Thirty-six percent were partnered, 38 percent single, and 21 percent dating. Sixty-four percent of participants were infected with HIV from unsafe sexual practices. Participants filled out questionnaires and underwent interviews about perceived and actual support from friends and family, behavioral intentions, and actual sexual risk behaviors.

Perception of greater family support was correlated with behavioral intentions such as intending to limit sexual partners in the future, but not with current risk-taking behaviors. Perceived support from friends did not appear to affect either intentions or actions.

Participants who talked to family members about personal feelings were more likely than those who did not to intend to limit their number of sexual partners, to ask about their partners’ sexual history, and to be monogamous, but not to actually change their risk-taking behaviors. Participants who shared private feelings with friends were less likely than those who did not to limit their number of sexual partners. Participants with greater numbers of friends to socialize with—or with more friends offering positive feedback—were less likely to intend to abstain from sex. However, sharing private feelings with friends did predict an intention to remain monogamous and to ask about a partner’s sexual history.

Friend support was not correlated with either an increase or decrease in actual sexual behaviors. These findings suggest that people with large numbers of friends may be more needy than others and, therefore, more likely to engage in risky behaviors. The negative influence of positive feedback from friends may also implicate the element of peer pressure.

**Family Support Reduces Loneliness**
Serovich JM, Kimberly JA, Mosack KE, et al. The role of family and friend social support in reducing emotional distress among HIV-positive women. *AIDS Care*. 2001; 13(3): 335–341. (Ohio Department of Mental Health; and Ohio State University.)

Perceived family support plays a significant role in the improvement of mental health among women with HIV, according to a small Midwestern U.S. study. Participants who reported feeling supported by family experienced lower levels of loneliness, depressive symptoms, and stress than those who did not.

Researchers interviewed 24 HIV-positive women about levels of perceived and actual social support and mental health. The sample was predominantly African American (54 percent), with a mean age of 39.5 years. Fifty percent of participants had received an AIDS diagnosis, and more than 25 percent had at least one opportunistic infection.

Perceived family support was more highly correlated to lower levels of depression, stress and loneliness than actual, or utilized, support from family and from friends. The perception of family support accounted for a large percentage of the variance in rates of psychological dysfunction: 56 percent for depression, 56 percent for loneliness, and 53 percent for stress. One interpretation for this result is that the belief in the potential of family and friend support can be more comforting than the reality of seeking out and getting support.

While participants rated their friends as generally more supportive than family,
family support was correlated with improved mental health, while friend support was not. This may be due to the different meaning family support carries; support from family can be harder to maintain but once achieved, may feel more unconditional and lasting than support found in friendships. The longevity of familial support may alone account for its affect upon mental health.

**Hopelessness, Depression, and Social Support**


Feelings of hopelessness among people with HIV increase with a lack of social support and can create or worsen depressive symptoms, according to a longitudinal study of 103 seropositive gay men.

Clinicians assessed participants at the beginning of the study (baseline) and six months later for levels of hopelessness, depressive symptoms, and five types of social support: emotional support, material support, affirmation, subjective social integration, and objective social integration. Researchers defined hopelessness as having negative expectations about future events and assessed depressive symptoms through a structured clinical interview.

Participants who reported low social support during baseline interviews had higher levels of hopelessness at the six-month follow-up. Increased hopelessness during this period was in turn associated with a higher risk for depressive disorders. Having feelings of hopelessness during baseline assessment did not predict a decrease in social support, nor did depression have an effect on future levels of hopelessness, regardless of the level of the person’s social support. These findings suggest that hopelessness mediates between social support and depression, and support the “hopelessness theory of depression”: for people who lack social support, hopelessness can increase and potentially lead to depression in light of negative life events.

**Negative Effects of Social Interaction**


While the positive effects of social support on people with HIV have been established, a San Diego study suggests that the adverse effects of certain social interactions—that is, conflictual interactions—can increase distress, leading to worsening physical health, and that these effects are stronger than the positive effects of social support.

Researchers recruited 140 HIV-positive individuals, who completed questionnaires that measured coping behaviors, perceived and actual social support, conflictual social interactions and mood, as well as physical limitations and current symptoms of HIV. Seventy percent of participants were male, and their ages ranged from 23 years to 61 years. The sample was 71 percent White, 18 percent African American, 8 percent Hispanic, and 3 percent of other ethnicities.

There were strong associations between conflictual social interactions and the “coping strategies” of wishful thinking (imagining a better time), anger (criticizing oneself or others), and isolation. Elevated levels of HIV-related symptoms were related to wishful thinking, more conflictual social interactions, an increase in social isolation, and feelings of fatalism.

Because psychological distress has detrimental effects on physical health, conflict with others can initiate a vicious cycle: conflict induces poorer health, which in turn creates a more negative mood and withdrawal, leading to greater conflict within one’s social network.

**Next Month**

Improved antiviral treatment has transformed HIV care, but providers still face a tangle of challenges, including rising infection rates, HIV treatment failure, barriers to medication adherence, insufficient reimbursement or funding for their services, and a shrinking pool of colleagues. In the March issue of *FOCUS,* Wayne Sotile, PhD, Co-Director of Sotile Psychological Associates in Winston-Salem, North Carolina and the Managing Editor of *The Resilient Physician Newsletter,* discusses HIV provider burnout, particularly among medical providers.

Also in the March issue, Lawrence Goldyn, MD, a San Francisco physician who has worked with HIV for more than a decade, describes how burnout manifests in HIV-focused primary care practice.
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