Psychosocial HIV Interventions in the Second Decade: A Note on Social Support and Social Networks

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In "Counseling the HIV-Infected Client," Hoffman attempts to transform the enormous task faced by counseling psychologists, and others, struggling with psychosocial aspects of the HIV epidemic by presenting a simplified, individually focused, and universal model of AIDS-related psychological care. Unfortunately, this is not a parsimonious model articulating relationships among constructs, but rather a catalog, and incomplete at that, of factors that may influence the HIV-related experience. The importance of social support and social networks, health care and institutional systems, demographic characteristics, and individual psychological resources in coping with catastrophic illness have long been recognized in the field of health psychology (Rodin, & Salovey, 1989). Indeed, even the issues of stigma (Scrambler, 1984) and time (Cohen & Lazarus, 1979) as critical, relevant variables in the illness experience have been addressed elsewhere, although their peculiarities in AIDS have a somewhat different quality. Others (Becker & Joseph, 1988; Coates, 1990; Herek & Glunt, 1988) have sought to apply these fundamental factors to conceptualizing the psychosocial impact of AIDS.

After a decade of this epidemic, researchers and practitioners have learned the importance of imparting information accurately and using caution when developing interventions appropriate to the particular subgroups targeted.

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This is so because the epidemic is linked to private, intimate behaviors that are difficult to influence and vary between genders, across those of different sexual orientation and ethnicity, and among drug-using cultures (Bayer, 1989; Mays & Cochran, 1990; Mays & Jackson, 1991). These same differences also invite socially constructed discriminations and bias. In this environment, one would hope that "Counseling the HIV-Infected Client" would offer state-of-the-art guidance to counseling psychologists. Unfortunately, it does not. Still, Hoffman is correct in realizing that this epidemic does represent something new for counseling psychology, a discipline that came of age (Kagan, 1979) when catastrophic infectious diseases, such as HIV, were far from the concerns of most Americans, even in health care settings.

What is it that makes this epidemic so unique when psychologists seek to practice their art of psychological healing? First, there is not one monolithic AIDS epidemic, but rather several overlapping, evolving epidemics that have dwelled in the experiences of many Americans now for 10 years or more. Its effects on communities differ radically depending on the nature of the community itself. A second aspect of the HIV epidemic is that, as with any social disaster, its effects are felt at a multitude of overlapping individual and social levels. AIDS does not just kill individuals; HIV reaches out across social networks both to infect and to destroy. HIV assaults our social interconnectedness and destabilizes the world as we know it. However, many Americans have had little contact with HIV-impacted communities and may be oblivious to these peculiarities of the epidemic. For them, AIDS, like cancer or heart disease, is simply a distant, catastrophic illness whose effects are limited to an individual's mortality. The reality that HIV can erase two generations of a family leaving grandparents or orphaned children to fend for themselves or cause a friendship network's extinction has yet to be fully comprehended by many. But these truths about HIV profoundly influence individuals' responses to the epidemic, whether they are personally infected or not, and the issues with which they must seek resolution during counseling.

This view of the HIV epidemic argues strongly against either the viability of a static, universal model of psychosocial reactions to HIV infection or an individual focus to treatment as adopted by Hoffman. Instead, one might expect reactions to HIV to reflect diversity and an ever-shifting focus on the different troubling aspects of HIV-related distress. This calls, too, for greater complexity, specificity, and flexibility in the response by counseling psychology. An approach encompassing diversity and conceptualizing the individual's unique experiences within social context is consistent with the basic philosophy of counseling psychology and its focus on growth and positive living in nonpsychiatrically disturbed populations (Gelso & Fassinger, 1990).
Although we cannot address this issue in its full complement here, we would like to offer some examples of how a focus on diversity, social networks, and social context might influence an understanding of the psychological needs of HIV-affected individuals.

Many people think of AIDS as a disease of gay men. This perception probably arises from the fact that approximately 83% of reported AIDS cases in White Americans have occurred among men who have had sex with other men (Centers for Disease Control, 1991). The effect on the visible gay male social community has been profound (Helquist, 1989). HIV has also shaped the attitudes and expectations of many of these gay men in ways that may seem incomprehensible to those who are not closely tied to these communities. Many HIV-infected gay men who identify with the gay community face their own personal experience with the disease in 1991 with information, models, support networks, community norms, behavioral proscriptions, and expectations that have evolved over the last decade. They are probably not the first in their social networks to struggle with HIV disease. In fact, newly infected or recently symptomatic men may know the disease intimately in all its gruesome physical, social, and psychological aspects. They may have already functioned as a caretaker for a lover, ex-lover, or as a “buddy” for someone incapacitated by the disease. Their reactions to their own health threat may be quite different from someone without this previous history.

Whether HIV seropositive or seronegative, gay men may be experiencing unmet needs for emotional support and practical assistance to continue positive living in a community so devastated by HIV disease (Raveis & Siegel, 1990). As the AIDS epidemic continues to cut a swath through their ranks, repetitive grief reactions will become more prominent in psychotherapy settings, both on the part of clients and the counselors who serve them. The psychological sequelae of repetitive grief and its most effective treatment are not fully known. Much of what has been written on bereavement focuses on the single loss event in which an individual has time to regain equilibrium before another loss event occurs (Parkes, 1985; Seplowin & Servalli, 1985). HIV changes all that, pushing psychologists to rethink what is “normal” bereavement in the context of multiple and chronic loss.

In a different vein, most of what we know about the psychological experience of AIDS is drawn from work with White gay men. Ethnic minority gay men, many of whom may be more tied to their ethnic identity and ethnic community rather than to the primarily White gay community, may cope with HIV infection in sometimes obviously and sometimes subtly different ways. There may be differences in perceptions of risk of HIV infection, relationships to the health care systems, socioeconomic resources, and experiences
of racism that influence the effects of behavior change interventions (Cochran & Mays, 1991; Mays & Cochran, 1988a, 1988b). At a public policy level, the concerns of ethnic gay men have not been prominent in shaping the nation’s response to HIV, in spite of the impact of the disease among these men, their families, and their various communities (Cochran & Mays, 1988).

Indeed, in the African-American and Hispanic communities, AIDS has and will have a broader impact on the lives of all individuals, regardless of sexual orientation, than is true in White America. More than half of all reported AIDS cases in Blacks (58%) and Hispanics (54%) over the age of 13 years are not among men who have had sex with other men but rather among men and women infected through intravenous drug use (40%), heterosexual sexual contact (10%), and other modes of transmission (7%) (Centers for Disease Control, 1991). Although for Whites only 5% of all reported cases of AIDS are in women, for Blacks (18%), American Indians or Alaskan Natives (14%), and Hispanics (13%), women are more likely to be among those diagnosed with AIDS. Among reported cases involving Asian Americans or Pacific Islanders, 8% are women. The greater incidence of AIDS cases in Black, Hispanic, and Native American women has important implications for the future course of this epidemic, as well as for its social effects.

In ethnic minority communities, reliance is, and will be, primarily on formal systems in the health care sector rather than on informal community-based systems. This presents its own set of problems very different from those faced by gay White men who have developed extensive informal “community-based” networks of support, both emotional and tangible. Even something as fundamental as the definition of “community” for understanding ethnic minority women’s psychosocial needs is problematic because much of the community-based resources are geared for male intravenous drug users or gay men of color. For many ethnic minority women, HIV disease is framed within a social system of family that differs in its psychosocial roles and boundaries from “community” or “family” networks as constituted by White gay men and lesbians (Levine, 1990).

Finally, as we enter the second decade of HIV disease, many of those struggling with this disease are among the economically disadvantaged (Fullilove, 1989; Mays, 1989) or suffer considerable financial loss secondary to HIV-related medical treatment making it unlikely that they would seek psychotherapeutic care in the private sector. However, when issues associated with HIV do enter the psychotherapist’s office, the issues can range from worries expressed by uninfected, low-risk individuals struggling with the nuances of dating (Cochran & Mays, 1989) to the concerns of those directly
impacted by HIV. It is the latter on whom Hoffman focused. We agree with Hoffman that service provision to HIV-infected individuals introduces a multitude of complicated issues for psychologists.

One aspect we have highlighted is the recognition that HIV wreaks its havoc within social structures. This has direct implications for traditional methods of practice. As an example, we can take the notion of “safe conduct” (Graham, 1982; discussed as “safe passage” by Hoffman). This model of care, in which the health care professional acts as a psychologically stabilizing force for patients with terminal illness as they traverse the downward illness trajectory, was first developed in the field of cancer. The model provides a clear role for the psychotherapist in helping an individual to die with a minimum of psychological discomfort. However, AIDS casts its own permutations on the offering of “safe conduct” by a therapist. Counseling psychologists who begin therapy with one HIV-infected individual may find themselves enmeshed in whole social networks being decimated by the virus. If the client is a gay man, the counselor may originally offer “safe conduct” to him, but ultimately also to his surviving “AIDS widower,” the bereaved partner’s new partner, and a handful of close friends. If the client is a woman with children, some of whom themselves may be HIV infected, therapy focused on her individual psychological needs will not be enough without addressing the issues of who will care for her children, or for her aging parents, when she is too ill to do so or after she has died. In other words, the unwritten social contract between therapist and client may be quite different in AIDS, as opposed to other terminal diseases that are not of infectious origin. Unlike other terminal illnesses, with AIDS the therapist must sometimes offer “safe conduct” to whole social networks that cease to exist. This, we can presume, may be intensely stressful for the psychologist.

What we have tried to articulate, here, is that the competent treatment of psychosocial issues in HIV-related disease involves more than just adapting existing models of individual functioning under health threats and applying them within a traditional psychotherapeutic context. The social, ethical, and medical issues surrounding the AIDS epidemic have led to alterations in the way in which medical science conducts its business, changing the traditional acceptance of placebo-based designs and speeding the release of new drugs for dying patients. The psychosocial impact of HIV disease calls, too, for changes in the way that we as psychologists practice our craft with HIV-affected populations. Developing state-of-the-art psychological interventions will call for the best creativity that we have to offer as a profession.
REFERENCES


