



# An Eye to the Future of HIV/AIDS and Social Relationships

## An Epilogue

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The social consequences of the HIV/AIDS epidemic have gone unrecognized for too long. Researchers of HIV/AIDS have for years examined drug regimens, treatments, and transmission of HIV, but far less work has examined the relationships of people with HIV/AIDS and how people with HIV/AIDS live with the disease. Our hope is that the chapters in this book help to fill this gap by presenting a range of research regarding social interaction and HIV/AIDS. This book has addressed how an HIV-positive person interacts with others and the effect of HIV on how others respond to an HIV-positive person.

With new treatments, people with HIV/AIDS are living longer, even further reinforcing the need to study social aspects of HIV/AIDS. It may be that, with increased awareness, more people are also aware of diagnoses earlier in the course of the disease and are receiving health care earlier (HIV testing has increased, even giving rise to a new home-based

test). Very little research is presently available that explores the relationships of those who are HIV positive. Much investigation of health problems has occurred previously, but less attention has been given to increasing the psychological, emotional, and relational quality of the lives of people with HIV/AIDS.

### *Effect of New Treatments*

At the XI International Conference on AIDS (Vancouver, Canada, 1996), physicians and researchers from around the world began to speak about a possible eradication of the deadly disease. Scientists met to discuss new treatment strategies and medical regimens for HIV-positive persons. This created, for the first time in 15 years, cautious optimism in a community battling a disease that has debilitated and killed millions around the world. This unprecedented optimism has come from the work of researchers experimenting with new drug combinations often referred to as antiretroviral therapies, more commonly known as cocktail therapies (which include protease inhibitors). The most beneficial aspect of this treatment is that, for some patients, viral load (the amount of virus in the body) can be reduced to extraordinarily low levels or become virtually undetectable in the bloodstream. Many HIV-positive individuals have experienced a rebound in immune functioning with these therapies. If the virus can be caught early enough and the individual is receptive to treatment, HIV-positive people may be expected to live much longer, experience fewer associated illnesses, and maintain a higher quality of life.

These new therapies do, however, have associated difficulties (see Greene & Cassidy, in press). First, the availability of treatment is limited and very expensive. Typically, at present, only those individuals employed by private companies, enrolled in federally funded clinical trials, or with access to subsidies for medications receive treatment. Second, some researchers have found antiretroviral treatment does not work for certain strains of the disease. Third, because of the toxicity of the drug combinations, side effects for some persons are near intolerable levels (e.g., nausea). Finally, being treated with antiretroviral therapies requires individuals to adhere to very strict and sometimes cumbersome treatment protocols. Because noncompliance can quickly result in the virus becoming drug resistant, patients are forced to carefully monitor and maintain demanding dosage schedules. Despite the drawbacks of the

new antiretroviral drug therapies, it is possible with these medical advances that HIV/AIDS may become a chronic condition rather than a fatal illness. At first glance, then, the news appears to be very positive: HIV-positive people may live longer, fuller, and healthier lives. If it is true that HIV/AIDS will become a chronic, manageable disease, what issues will infected persons confront?

A number of the social issues facing HIV-positive persons have been addressed in this book. For example, disclosure of an HIV-positive diagnosis continues to be an important issue for HIV-positive persons. If HIV/AIDS becomes chronic, disclosure may become even more consequential. How will helping professionals persuade HIV-positive persons to disclose to a sexual partner when the threat of imminent death is no longer attached to the disease? If rates of disclosure to family members and friends decrease, how will the infected person be able to access social support? If the stigma associated with HIV/AIDS is dependent on perceived control of infection, then stigma is unlikely to change for quite some time.

This epilogue will first discuss research in the book by summarizing findings presented for stigma, self disclosure, coping, social support, and identity; the social interaction model of coping with HIV infection presented by Derlega and Barbee (Chapter 1) provides a way to understand how these variables are interrelated. Next, we will cover implications for groups such as therapists, health care practitioners, community organizations, message designers, and policy makers. Finally, we will look at conclusions and directions for future research on social consequences of HIV infection.

### ■ Summary of Social Interaction Themes for HIV-Infected Persons

Taking the chapters together, there were five main themes that emerged as important social issues surrounding HIV/AIDS. People who are HIV infected struggle with stigma, self-disclosure, coping, social support, and identity issues, and these are crucial in their relationships and in the model of coping with HIV infection developed by Derlega and Barbee (Chapter 1). This section focuses only on social or relational vari-

ables and includes other factors (e.g., depression) only in relation to their effect on social relationships. The variables discussed include stigma, self-disclosure, coping, social support, and identity.

### Stigma

AIDS has been labeled the most controversial disease in modern history (Powell-Cope & Brown, 1992), and HIV-infected persons report that facing stigma is one of their greatest challenges and sources of stress (see Chapter 2). Reactions to HIV-infected persons are influenced by who is infected as well as how they are infected. There is a misperception that HIV/AIDS can only be contracted through stigmatized behaviors (see Chapter 1), initially male-to-male sex and intravenous drug use. There has also been slippage where the categories of gay, promiscuous, and AIDS have collapsed or become nearly synonymous (see McAllister, 1992; Watney, 1987). The news coverage of AIDS has clearly contributed to this stigma. As Watney (1986) noted, "A disease of chimpanzees or gerbils would have attracted more sympathetic coverage" (p. 47). HIV-infected persons must deal not only with the disease and their feelings but the reactions of others.

Deviance is often labeled as illness, and certain illnesses carry meanings other than biomedical, such that the illness becomes a metaphor for characteristics attributed to the person (McAllister, 1992; Sontag, 1979). One central component separating HIV/AIDS stigma (except, for example, leprosy) is potential threat to the health of another. Fear of contagion (sometimes based on lack of knowledge about transmission) remains despite extensive public awareness campaigns. The public association of AIDS with risk *groups* rather than risk *behaviors* remains, as has been the case since early in the epidemic.

Stigma includes a group focus in which the differences of a group are emphasized rather than its similarities to other groups. This tendency to emphasize the differences between groups and similarities within groups (especially in the outgroup) is known as the outgroup homogeneity effect (see Mullen & Hu, 1989; Ostrom & Sedikides, 1992). Understanding this process is crucial in explaining stereotyping and stigma: "Some cultural groups sustain themselves by assigning positive traits and rewards to their group (ingroup), while assigning unfavorable traits and potential punishments to outside groups" (Michal-Johnson &

Bowen, 1992, p. 161). People typically judge the group to which they belong (the ingroup) as being more variable and positive than the group to which they do not belong (the outgroup). The result of this outgroup homogeneity bias is that members of the outgroup are all perceived as being alike. This lack of perceived group variability leads to stereotyping, and this is a good way to understand how the concepts "gay man" and "HIV positive" have become equated.

AIDS stigma has also led to labeling and blame, focusing on responsibility for the disease (see Chapter 2). Attributions about stigma are often based on perception of control over infection. Stigma seen as uncontrollable evokes more favorable responses, but stigma perceived as controllable evokes very negative responses. This kind of control stigma can be seen in popular terminology labeling children as "innocent victims," and this has created a victim continuum (innocent versus deserving) in some perceptions. It may be that stigma is a way to disassociate or create distance for some through assignment of responsibility to those infected. If people do not participate in the blaming behaviors, they may be able to convince themselves they are not at risk.

Another interesting concept not well explored in the literature but addressed in this book is "courtesy stigma." People who are closely associated with HIV-infected persons also get stigmatized, mostly in negative ways (see Chapter 2). In Chapter 6, this is identified as stigma by association, affecting volunteers who work with HIV-infected persons. This can hold true not just for family members and friends but also for health care providers and workers, social workers, and therapists who treat or work with HIV-infected persons. HIV-serodiscordant couples are yet another example of those dealing with the association effects of stigma (Chapter 9). Merely associating with HIV-infected persons can bring about the same kinds of stigma that targets HIV-infected persons. Courtesy stigma may be the basis for some people avoiding HIV-infected persons (fear association), possibly leading to distance from friends, family, and others. This courtesy association is not unique to AIDS (though it is probably more intense); for example, families with incarcerated members or an alcoholic member often go to great lengths to conceal these facts.

HIV/AIDS-related stigma runs through many chapters in this book, and stigma is central to Derlega and Barbee's (Chapter 1) model of coping with HIV infection. Perhaps one of most insidious effects of AIDS-related stigma, apart from lack of opportunity to gain social support for

those infected, has been hesitancy to disclose. Failure to disclose serostatus is one of the causes of the continuation of the epidemic because it means failure to notify others (e.g., sexual or needle-sharing partners) of their risk for infection and, simultaneously, self-denial of opportunity to gain social support. Next, we will turn to how HIV-positive people deal with issues of disclosure.

### Self-Disclosure

The initial response of many is to keep an HIV-positive diagnosis a secret. One of the consequences of AIDS-related stigma can be nondisclosure and potentially decreased social support, with possible negative physical and psychological health effects (Chapter 2). Kimberly, Serovich, and Greene (1995) reported that HIV-positive women experienced an initial stage in the disclosure process of telling no one, often corresponding to several months of nondisclosure. There is a growing body of research on how people decide who to tell about their HIV infection (see Chapter 8; Greene & Serovich, 1996; Hays et al., 1992; Marks, Bundek, et al., 1992; Serovich, Kimberly, & Greene, 1998). Findings indicate that people disclose their HIV/AIDS status very selectively.

There are benefits and risks to self-disclosure, and people must balance the competing need to maintain privacy and control and the need to share information (Chapter 8). HIV-positive individuals struggle with decisions to disclose in such a way that they may receive support but avoid negative consequences associated with AIDS (see Greene & Serovich, 1996; Yep, 1993). Clearly, disclosure is a double-edged sword: It is possible to lose social support through disclosure, yet potential support can also be eliminated through failure to disclose (Hays et al., 1992). Benefits from disclosing include such things as feeling loved and accepted, gaining information, and making safer sex decisions. Conversely, there are risks for HIV-positive individuals who disclose their serostatus, and decisions to disclose are likely to be filled with fear and anxiety (Marks, Bundek, et al., 1992; Yep, 1993). The potential impact of such disclosures is wide ranging, from ostracism in interpersonal relationships to self-identity crises, from threats to basic survival (loss of employment, housing, insurance, or health care) to loss of social support. People must see benefits in disclosure before being willing to expose themselves (Hays et al., 1992).

Petronio's (1991) theory of boundary management (similar to the analysis of privacy regulation in Chapter 8) describes how people control potential risk to self when disclosing. Individuals erect a metaphoric boundary to protect themselves and reduce their chances of losing face. The risks associated with disclosing HIV infection are tremendous, perhaps leading to more rigid boundaries (little or no disclosure). Yep (1993) applied this theory specifically to the potential vulnerability of disclosure of HIV infection. Because disclosure is a relational event, variables associated with both the sender and receiver need to be examined (Yep, 1993). Data presented in this book (Chapters 8 and 10) show how individuals must perceive a positive response or some benefit from disclosure before they are willing to disclose.

Although we know more about disclosure of HIV infection than previously, little is known about *how* disclosure choices are made. It is likely that these decisions are made after careful consideration and with a great deal of selectivity (see Greene & Serovich, 1996; Marks, Bundek, et al., 1992; Simoni et al., 1995; Yep, 1993). The factors in decisions to disclose to one target person (e.g., mother) are likely to be different than those used in deciding on another (e.g., partner). Members of the marital subsystem (lovers, spouses, ex-spouses, friends) have been viewed as the most appropriate targets for disclosure of HIV infection, with the nuclear family (e.g., parents, siblings, children) rating next highest (Greene & Serovich, 1996; Marks, Bundek, et al., 1992; Serovich & Greene, 1993; Simoni et al., 1995); lowest-rated targets were extended family and the general public.

Serovich, Greene, and Parrott (1992) looked at the potential recipient of HIV-testing information. Individuals overall reported most desire to restrict access to HIV-testing information to the general public, less to the community, and least (or more access) to the marital subsystem. Serovich and Greene (1993) expanded this work by looking at potential family targets for release of HIV-testing information. Overall, participants reported most support for access to HIV-testing information to the marital system (e.g., lovers, spouses), moderate to the nuclear family (e.g., mother, son), and least to the extended family (e.g., aunt, mother-in-law). Greene and Serovich (1996) replicated these studies and reported HIV-infected persons also have clear distinctions in perceptions of appropriate recipients of information about HIV infection. In addition, HIV-infected persons reported less desire (compared with other groups) for disclosure of HIV infection across all subsystems. Similarly,

Marks, Bundek, et al. (1992) reported that HIV-positive persons were highly selective in choosing targets of disclosure and tended to inform significant others (parents, friends, and lovers) more than nonsignificant others (employers, landlords, and religious leaders).

Expectations regarding partner's response is the first factor a discloser takes into account before sharing (Petronio, 1991). Kimberly et al. (1995) reported that women specifically cited the expected response from the target as a reason for disclosing or not disclosing their HIV infection. If a person anticipates that the recipient will respond negatively (e.g., with hostility, judgmentally, or with ignorance) or neutrally to disclosure, she or he will probably choose to withhold the information. It may be necessary, given a topic as sensitive as AIDS, for a person to be relatively certain of a positive response before disclosing HIV infection.

Perception of a relationship is also likely to be a significant determinant of willingness to disclose HIV infection. In addition to the role a relationship (for example, sister) plays, the quality of that relationship is likely to differentiate relationships. For example, a person can have varying degrees of relational qualities with a sister, and this perception of the relationship may be a deciding factor in disclosure. A person would be unlikely to disclose information as sensitive as HIV infection to someone with whom she or he had a poor relationship.

Disclosure may be a means of obtaining social support, and social support may serve a significant role in mediating between stress and health (Albrecht & Adelman, 1987c; Greenblatt, Becerra, & Serafetinides, 1982). Disclosure of traumatic experiences has been reported to reduce stress (Greenberg & Stone, 1992; Pennebaker, 1989) and physical and mental health problems (Pennebaker, 1990; Susman, 1988). In addition, satisfaction with social support among HIV-positive men increases both psychological (Kelly, Chu, & Buehler, 1993; Zich & Temoshok, 1987) and physical (Hays et al., 1992; Zich & Temoshok, 1987) well-being.

This book has provided significant information that will contribute to understanding how disclosure functions for HIV-positive people. Disclosure may play a helpful role in coping with disease and diagnosis by opening opportunities for support but may add stress due to stigmatization, discrimination, and relationship disruption (see Chapter 8). Next, we will discuss research presented on coping with HIV.

## Coping

Coping with HIV/AIDS is important in understanding social interactions for HIV-infected people. Problem-solving coping is generally associated with positive health and medical conditions; avoidant coping is generally associated with psychological distress and poor outcomes (see Chapter 9). Avoidant coping may have some positive short-term effects, but long-term adjustment is associated with approach-oriented coping (see results of the meta-analysis by Suls & Fletcher, 1985).

There are contradictions in the literature on the effects of illness on relationships. Clearly factors of stress and resources are crucial in determining the effects of HIV on relationships. Disrupted relationships have been documented as responses to the burden of HIV infection (Chapter 9). HIV/AIDS affects not only the infected person but those close to him or her, especially partners, family, and friends. There is not as much research on the effects of HIV/AIDS for partners of infected persons (for exceptions, see Chapter 9 and Folkman, 1997), although relational quality is thought to be one of the most important components in coping with relationships.

Relationships are affected differently by illness at different stages. Coping is expected to vary with stage of disease for both the partner and the infected person. The initial effects of HIV infection may include less physical disturbance but more psychological stress; later, physical and financial stress may increase as well. Moore et al. (Chapter 9) found that increased disease stage leads to more depressive symptoms such that both members of a couple are negatively affected by the illness.

This book points to the need for more study on progression or stages of coping (Chapter 1). It would be expected that, with changes in disease progression, coping might need to shift. With newer treatments, these coping strategies may become even more important. Next, we will discuss research presented on social support.

## Social Support

Potential sources of support for HIV-infected people can be lost through nondisclosure, stigma, or negative coping strategies. There are different kinds of social support, often dichotomized as instrumental (e.g., money or child care) and expressive (e.g., affection or sympathy).

Physical and mental effects of social support have been documented, with less social support related to more depression and increased social support linked with better health. The unmet social support needs for HIV-infected persons, along with the collapse of traditional institutions that are supposed to provide support (see Dane & Miller, 1992), have created a need for innovative kinds of structures and groups to provide services (see Chapter 7).

Distressed people have a general idea of the form of support they want (see sensitive interaction systems theory, Chapter 5), but these support needs are not always met. A common response to HIV infection is lack of social support from family members (see Metts, Manns, & Kruzic, 1996). HIV-infected persons often feel abandoned by families, and in gay communities, social networks have been ravaged by AIDS. In response to absence of support, AIDS organizations began to provide self-help groups. As of this writing, there is limited documentation of the effectiveness of such groups, although they provide both formal and informal support (see Chapter 7).

HIV-infected persons receive support from a range of people. Friends' and health care workers' support is generally perceived as helpful, but lovers were viewed as mixed on helpfulness. Interestingly, not much family support was viewed as helpful. Barbee et al. (Chapter 5) provide details about what constituted unhelpful support, such as escape behaviors and dismiss or avoidant behaviors, and unhelpful solace. Specific recommendations for helpful behaviors are also provided. These findings indicate that well-meaning people (especially family) can botch attempts at support; Barbee et al. recommend asking HIV-infected persons what kind of support would be helpful.

One of the strengths of this book in terms of social support may be the specific identification of failed attempts at social support. This can provide guidelines for those attempting to offer support. Partners and family members generally want to be supportive; however, social support interactions can sometimes be less than helpful. Family members dealing with their own sense of impending loss and grief may not be in the best place to offer the support desired by HIV-infected persons. Social support in the form of advice, tangible assistance, and emotional support will not always be wanted or helpful (Chapter 5). Social support will remain a crucial issue for HIV-infected persons. Next, we will discuss research presented on identity.

## Identity

Based on what was been reviewed earlier (stigma, self-disclosure dilemmas, coping problems, and loss of social support), it appears that HIV-infected persons need social support to restore or bolster self-esteem, create meaning during crisis, and gain control over their lives. Formal support can have a positive effect on identity, and formal support groups can increase a positive sense of self (Chapter 7).

For HIV-infected persons, one goal is normal treatment (Chapter 2). Stigmatized people have lower self-esteem, and stigma may be a stressor that leads HIV-infected persons to commit suicide. Identity is central for HIV-infected persons, and they often end up "passing" and covering to protect their identity. Being stigmatized may also function to protect one's self-esteem (Crocker & Major, 1989) because any negative feedback can be attributed to their HIV infection (Chapter 10). The effect of others' reactions on self-esteem and self-concept cannot be underestimated.

In this section, we have discussed research presented in the book for stigma, self-disclosure, coping, social support, and identity. Each of these variables is discussed in different chapters and plays a significant role in social aspects of HIV and in the model presented by Derlega and Barbee (Chapter 1). All of this research leads to a better understanding of the social consequences of HIV infection.

## Special Issues for HIV-Positive Persons, Their Families, and Helping Professionals

In this section, we will discuss how the information presented in this book can help HIV-positive persons and their significant others in coping with HIV/AIDS. In addition, the information presented may help professionals such as therapists and health care workers assist HIV-positive persons and their family and friends. The information can also be used by HIV/AIDS community organizations, HIV message designers, and public policy makers.

As a reminder, each subpopulation infected with HIV is different and cannot always be discussed together because perspectives of the disease and needs are different by group (see Chapter 3). For example, in Chapter 4, Rose indicates that black gay men create meanings of HIV that may be different from others; therefore, the process by which they

cope with their infection and are affected by stigma is very different from that of white gay men. Similarly, Hispanic females experienced higher levels of depression and less intimacy in their relationships compared with white or black women (see Chapter 9). Therefore, it is imperative that implications and suggestions made here are used only in light of the person in individual context.

## *HIV-Positive Persons*

As we mentioned in the beginning of this chapter, for people living with HIV/AIDS, this is an optimistic, exciting, yet challenging time. New medical therapies and treatment possibilities are proliferating at a rapid pace. Although hope prevails, the somber reality is that a cure has not yet been developed. Until a cure is available and HIV is eradicated, there are a number of recommendations that emerged from the research in this book that might be particularly helpful for HIV-positive persons as they cope with their illness. HIV/AIDS is more than a medical phenomenon, as it has significant social implications.

Obtaining social support is imperative for both the emotional and physical health of HIV-infected people. Support can be garnered from professionals, personal social contacts, or through community agencies. Professional support can be in the form of psychotherapy, spiritual guidance, or other healing specialists. HIV-positive individuals may experience support from friends, formal or informal support groups, and/or community organizations as being the most beneficial. Extending the social support network beyond partners and family members will be crucial. This is especially important if HIV takes on a more chronic, long-term nature because the role of support groups and other formal systems of support may need to be used to an even greater degree.

Along with social support, the coping strategies HIV-positive persons adopt play significant roles in psychological adaptation. More specifically, active coping strategies appear to be more helpful than avoidant coping strategies. Active coping strategies include developing problem-solving abilities and help-seeking behaviors as well as acquiring information-seeking and verification skills. Each of these approaches indirectly promotes self-reliance, self-respect, and the development of optimism. Although avoidant coping behaviors might produce short-term relief, HIV-positive persons are encouraged to seek programs that offer problem-solving-focused skill development. Likewise, helping professionals

should offer programs with an active-coping-based curriculum to help HIV-positive persons better handle stressful situations.

One way active coping skills can be used is with medical personnel. Because changing medical protocols can be confusing and cumbersome, HIV-positive persons need to develop strategies for obtaining clear and concise medical information from health professionals. This includes information about available treatment options and the consequences associated with each protocol as well as any associated side effects. For example, many treatment protocols have medication schedules that are quite complex and confusing. New routines around meals and sleep may clash with established work or leisure schedules. Because compliance with medication schedules is required for satisfactory medical results, the ability to gather this information is imperative for HIV-positive persons. Thus, active coping skills may be pivotal for persons to feel in control of their medical treatment and demand the most accurate information.

#### *Family Members and Significant Others*

Throughout the book a few general conclusions emerged concerning family members of HIV-positive individuals. Family members are not always viewed as particularly helpful to HIV-positive persons. Before drawing conclusions about family members too quickly, however, several issues should be addressed. As Leary and Schreindorfer (Chapter 2) point out, HIV-positive persons experience direct results of stigma, but family members can be stigmatized by association. Therefore, for some family members, the externalized result of stigma by association might be the appearance of being cold and unfeeling. If this is the case, family members might find solace in support group or therapy settings.

Furthermore, if we accept Rose's conclusion in Chapter 4 that helping HIV-positive persons derive meaning from their association with HIV is useful, then a similar strategy might be used for family members. Family members might search to derive meaning from having an HIV-infected member and by doing so help to acknowledge the fear, sorrow, and anger they might harbor. It is also possible that family members lack the knowledge and skills to assist the HIV-positive member. If this is the case, family intervention strategies might include the provision of support groups, which could serve as a source of information about HIV,

support for personal grieving, and the opportunity to develop effective helping skills. Family members must seek social support themselves, not just for the infected person, especially if they are primary caregivers.

Both partners and HIV-infected individuals become more depressed as the disease progresses (Chapter 9). Given this, significant others must not ignore their own mental health and coping difficulties. In fact, both members of a couple, despite the HIV status of either individual, should seek clinical assessments, interventions, and follow-ups routinely. Efforts made to provide support groups for partners and spouses should be encouraged and tailored to different couple types. For example, support groups for gay male partners would involve significantly different issues from those for interracial, heterosexual, or lesbian couples.

Many children of HIV-infected women may be hidden victims of this disease. Some mothers may be unable to accurately assess the needs of their children due to being overwhelmed, overburdened, and/or depressed. Others, mainly therapists and health care workers, will have to be aware of the needs of these children and make sure the children are adequately cared for both emotionally and physically. Overall, the results of these studies bring to light the need for therapists to take a global and systemic view of the life of HIV-positive persons to make sure the overall health of their families and networks are being served. If the needs of these networks are met and satisfied, it is plausible that the mental and physical health of HIV-positive persons will also be positively affected.

#### *Helping Professionals*

*Helping professionals* is defined here as any professionally trained mental health worker, including individual counselors, social workers, psychotherapists, psychiatrists, and marriage and family therapists. Helping professionals may also be health care practitioners and HIV/AIDS service organization workers. Furthermore, *client* can mean not only an HIV-positive person but a partner or spouse, family member, or friend.

The work presented in this book gives therapists guidance for developing more sophisticated skills and treatment plans for working with HIV-positive persons and their support networks. For example, Collins (Chapter 3) points out that support received from the gay community is very important for various coping outcomes for HIV-infected gay men.

She found gay pride positively related to having a constructive life focus and the development of new relationships. Furthermore, having pride in being homosexual was strongly associated with several indicators of coping and social support. Therefore, therapists should assess the degree to which gay men are connected with the gay community and assist with social identification whenever possible. Undoubtedly, encouraging HIV-positive men who are homosexual to reach out and become involved in the gay community may be a treatment strategy that is underused. Helping professionals should be aware, however, that because of stigma there may be a tendency for some to withdraw from the gay community. Helping professionals should help clients resist withdrawing from community interaction and support.

Derlega et al. (Chapter 8) provide therapists and health care workers with useful tips and guidelines when working with HIV-positive persons around the process of disclosure. The reasons for disclosure provided by Derlega et al. can help therapists explore with clients reasons, fears, expectations, successes, and doubts about disclosing. For example, therapists working with newly diagnosed individuals as they struggle with competing disclosure needs could empower clients with reasons why others have chosen to disclose or not disclose. Therapists could also facilitate discussion of effective steps in the disclosure process (see Kimberly et al., 1995) and reactions of family members to disclosure of an HIV-positive diagnosis (Serovich et al., 1998). In fact, provision of each of these experiences of others can help HIV-positive clients further clarify their own decision-making processes.

Health care workers are frequently the bearers of bad news to HIV-positive persons. Typically, initial diagnoses, test results, and difficult treatment decisions are shared by and with doctors, nurses, and/or social workers. Because the implications of many of these decisions are difficult and painful, health care practitioners can find themselves offering solace to grieving patients and family members. Professionals should attempt to provide very practical assistance, such as suggestions for how to solve a particular problem, or be emotionally available and reassuring of patients (Chapter 5).

If new treatment regimens are as beneficial for a longer life as promised, then health care workers and helping professionals will be building longer relationships with their patients. In fact, health care workers are likely to become emotionally closer and more involved with patients by

helping them comply with medication schedules and assisting with strategies for handling complicated side effects. Health care workers are also more likely to become sources of information and referral on related matters such as nutrition and exercise. Health care workers will need to be more equipped with helpful strategies to assist patients. In addition, hospital social workers or therapists should be aware of the emotional needs of health care workers as they become more entwined with the lives of patients.

### *Public Education Campaigns*

Public education campaign designers can play a key role in the fight against stigma surrounding intravenous drug users, sex workers, homosexuals, and others considered "marked." Stigma management strategies for public education campaigns can be successful if they reduce notions that HIV-positive persons "pose a threat" to the health and well-being of others, deviate from group standards, do not contribute to society, or elicit negative emotions (Chapter 2). An example of an HIV-positive person being portrayed in positive light is a Nike running shoe advertisement that features an HIV-positive marathon runner. In this advertisement the runner is obviously health conscious, appears to enjoy a particular sport, and is ambitious. Here is a positive portrayal of an HIV-infected person following a dream undeterred by his infection. Messages in the form of advertisements, health promotion campaigns, or public education messages that emphasize positive qualities of HIV-infected persons should be encouraged and supported.

The relationship between stigma and homophobia arises in many of these chapters. Therefore, campaigns to reduce the fear of homosexuals should be pervasive and should target populations shown to be more homophobic than others. For example, as Rose (Chapter 4) points out, homophobia may be especially prevalent in minority, ethnic, or underserved populations. Men are also more likely than women to express negative attitudes toward homosexual men (Kite & Whitley, 1996). Given these findings, public education campaigns should be directed toward outlets such as churches, magazines, or other venues with a large ethnic or male following. In effect, specifically targeted anti-homophobia campaigns are needed to help reduce AIDS-related stigma.



It is also important to remember that besides reducing stigma in the general public, positive messages can help families and HIV-positive persons in reducing stigma. If stigma damages many more people than those infected, as Leary and Schreindorfer (Chapter 2) suggest, campaigns may be the most important tool for fighting stigma. Because it is unlikely that new treatment regimes will significantly reduce the stigma associated with homosexuality and HIV, public education about sexual orientation issues is important.

### *Community HIV/AIDS Organizations*

Community HIV/AIDS organizations are the front-line source of support, education, resources, and information for HIV-positive persons, family, and friends, as well as the general public. Obviously, their work would be costly and burdensome without the help of volunteers who fill the roles of buddies, community speakers, and risk-reduction specialists. For many organizations, these persons are the backbone of the organization and unquestionably the driving force behind the fight against the spread of HIV.

There are a number of implications from this book that are applicable specifically to community organizations. Helpers/volunteers should be adequately prepared for the fact that relationship quality between helper and client diminishes over time (Chapter 6). Training for volunteers, no matter their role, should incorporate a sense of realism about what to expect, including personality clashes, lack of client appreciation, and possible client death. Preparation could be accomplished by having experienced buddies and HIV-positive persons speak directly to this issue at training group meetings.

HIV-prevention programming clearly needs to be tailored to specific communities of people. A strategy or program designed for gay men might not work or have relevant characteristics for black gay men, older adolescents, or women. Although a contextual approach to prevention efforts is important, certain successful characteristics of HIV programming with one population are worth experimenting with in others. For example, according to Rose (Chapter 4), programs that increase self-esteem, self-worth, and provide meaning for gay men tend to increase optimism and self-respect. Although increasing self-esteem in gay men was found to be important, such results could also have a significant impact

for women, children, or African American male populations. The mechanism by which such components are incorporated into programming efforts need to be contextually sensitive and deserves further research attention.

Much like health care workers, if HIV/AIDS becomes a chronic illness, community organizational staff are likely to become more involved in the lives of HIV-positive clients. In addition, new interventions and strategies for helping their clients deal with disease uncertainty, obtaining new drug therapies, disclosure, and stigma will have to be developed and implemented.

### *Public Policy and HIV Prevention*

There are implications for health message design from these chapters. Stigma associated with HIV/AIDS may contribute to unwillingness to disclose HIV infection or reduced social support. More effort to reduce stereotypes will be crucial in controlling the spread of HIV/AIDS. The moral problems associated with HIV/AIDS are complicated by the effects of social stigma and labeling. Specific campaigns portraying how families are affected by HIV/AIDS and the support families can provide might be useful in reducing this stigma and labeling. There is also evidence that different messages should be created for women and men and, probably, messages that differ by race and sexual orientation as well.

Reducing stigma is quite a challenge, as it will require undoing decades of policy (e.g., as it has with race relations). One example of a stigma-reduction intervention was quite successful. Monteith (1993) gave feedback to undergraduates about their prejudice, making their homophobia seem nonnormative, and was able to demonstrate later reduction in prejudiced attitudes. It might be possible to use the same sort of technique with HIV-positive persons. To reduce stigma, forcing people to confront disassociation views might also work: for example, requiring people to interact with HIV-infected persons.

### **■ Conclusions and Future Research**

Providing conclusions for a book on the social aspects of HIV is a difficult task, as HIV/AIDS continues to change. New information about

treatments may cause significant shifts in many relationships described here, as this is a rapidly changing area. Even with new and radically different treatments, however, the contributions of these chapters are especially significant because they focus on how people with HIV interact with others and how others respond in light of their HIV infection. One aspect consistent in this work was the role of stigma and how stigma could vary by subgroup. Stigma affects how HIV-infected people live with the disease, specifically their disclosure, social support, coping strategies, and identity.

There is a need to continue to examine the role of gender in social aspects of HIV/AIDS. Women and men are clearly affected by HIV/AIDS differently, from coping strategies to media images. Over 50% of HIV-positive women have children under the age of 18 (Ickovics & Rodin, 1992), and this will be crucial to consider. Yet, there has been only limited systematic research on women (for exceptions, see books since 1994). The gay community is also discussed rather thoroughly in this book, but there is no mention of the effect of HIV/AIDS on lesbians. Lesbians form significant portions of volunteer networks, and the "gay community" label may overlook their role. The Fall 1996 issue of *Women's Health* was devoted to lesbians and HIV/AIDS, but even so, more than black gay men, heterosexual women, or children, lesbians with HIV/AIDS are invisible.

Demographic findings related to HIV/AIDS can also be overlooked in attempts to see patterns or similarities in HIV-infected persons. Researchers must look at junctures including such issues as income, race, and gender. For example, who pays for medications, and with what insurance? New treatment options provide great promise, but is it possible that new treatments will be used primarily with certain racial or socioeconomic groups? All of these questions point to the continued importance of considering demographics. Race differences are important because they have created invisible groups of HIV-infected persons. An example highlighted in this book is black gay men who face unique challenges in confronting their infection. It is easy to downplay the role of economic factors and lack of formal education, but not often mentioned are sexual abuse, physical abuse, and drug or alcohol addiction (see Chapter 4).

Cultural differences are also not well understood in HIV infection generally. As Michal-Johnson and Bowen (1992) state, "HIV has had a

far more profound effect in communities of color and in the gay community than in any others in the United States" (p. 147). If culture is to be an organizing concept for AIDS interventions, clearly AIDS public service announcements do not meet this standard (see Freimuth, Hammond, Edgar, & Monahan, 1990). Freimuth et al.'s content analysis of AIDS public service announcements shows that they are targeted for general audiences and avoid explicit language, and this clearly does not meet long-standing recommendations for culturally sensitive, group-specific prevention messages.

With new treatments for HIV/AIDS changing rapidly, it seems imperative that therapists, health care workers, community organization personnel, and message designers work more closely together to address emerging challenges. These issues could include compliance with medical regimens (see Greene & Cassidy, in press), symptom management, and the need for new disease prevention strategies. Therapists could be invaluable resources for health care workers as they struggle with client compliance (and vice versa). Health care workers could, in turn, be providers of important information to public health campaign strategists. In essence, new challenges ahead could be faced more adequately if interests and knowledge of the perspectives were more closely aligned. The time for separate, field-specific work has clearly passed.

Another area where professional cross-fertilization of ideas will become important is in the development of prevention strategies. There is a fear that if the eradication agenda is promoted, HIV/AIDS prevention strategies will not be effective. Specifically, individuals might regress to past riskier behaviors once the perception of HIV/AIDS as lethal lessens. This is of particular concern because, although the level of HIV in the body can be reduced with new drug therapies, it is not totally eradicated. In fact, the terminology commonly used that HIV is reduced to "undetectable levels" is very misleading. HIV may be undetectable only because we lack sophisticated instruments to measure HIV below certain levels. It does not mean that HIV/AIDS is eliminated from the body. Therefore, not only do the general public and individuals most at risk need to be properly educated about this new era of HIV/AIDS, creative and powerful prevention efforts are still needed.

For too long, relationships of HIV-infected people have been ignored; the emphasis has been on prevention and treatment. What has been overlooked is how HIV-infected people live on a daily basis and

how the infection affects their lives. The chapters in this book provide a good start in examining the social and relational consequences of HIV/AIDS. Future research on HIV/AIDS must incorporate factors such as gender and race in explaining the effects of new treatments. This is an area where more research would be especially useful. If HIV-infected people will be living longer, healthier lives, then the importance of understanding social aspects of the disease becomes even more pressing.

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## Contents

Preface	ix
<i>Valerian J. Derlega</i> <i>Anita P. Barbee</i>	
1. What Is the Impact of the HIV Infection on Individuals' Social Interactions and Relationships? An Introduction	1
<i>Valerian J. Derlega</i> <i>Anita P. Barbee</i>	
2. The Stigmatization of HIV and AIDS: Rubbing Salt in the Wound	12
<i>Mark R. Leary</i> <i>Lisa S. Schreindorfer</i>	
3. Social Identity and HIV Infection: The Experiences of Gay Men Living With HIV	30
<i>Rebecca L. Collins</i>	