Interpersonalizing AIDS: Attending to the personal and social relationships of individuals living with HIV and/or AIDS

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──────────── ABSTRACT ────────────

This article introduces the special issue on HIV and AIDS in the context of personal and social relationships. Four major themes are first highlighted: (i) the changing nature of HIV and AIDS to long-term, chronic illnesses; (ii) the importance of personal and social relationships for those living with these illnesses; (iii) the effects of these illnesses on the personal and social relationships of minorities and women, in particular; and (iv) the continuing stigma and coping with stigma that permeate the lives of those living with HIV and/or AIDS. A conceptual approach is introduced to frame research on the personal and social relationships of those with HIV and/or AIDS. The articles and commentaries in the special issue are then introduced and discussed in the light of that conceptual approach. This article concludes with a call to focus additional attention on the personal and social relationships of those living with HIV and/or AIDS.

KEY WORDS: AIDS • ecological perspective • HIV • minorities • personal and social relationships • stigma • women

The AIDS pandemic has now entered its third decade and shows no signs of abating, especially at the global level. Despite our inability to solve the AIDS crisis, we have, over the course of that time, learned much about how AIDS is caused, how it can be prevented, and how to offer care to those affected by it (e.g., Bartlett & Gallant, 2000; Sepkowitz, 2001). Although such medical and health care research is vital, researchers also should devote more attention to the personal and social relationships of individuals living with the disease.

This special issue is intended to fill that gap by highlighting research that focuses on the personal and social relationships of those infected with and affected by HIV and/or AIDS. Individuals with HIV infection, besides living with a potentially life-threatening and long-term disease, face many social challenges, including the impact of the disease on their personal relationships with intimate partners, friends, family of origin and of choice, neighbors, co-workers, health care professionals, and acquaintances, among others. In turn, the nature and quality of those relationships (e.g., the extent to which they provide social support) may influence how well one copes (e.g., physically, psychologically, and relationally) with HIV and/or AIDS. This special issue, therefore, is devoted to understanding HIV and AIDS in the context of personal and social relationships.

Four major themes characterize the articles in this special issue, each of which we examine below. First, HIV and AIDS are now considered chronic, rather than short-term, illnesses. Second, the extended life expectancy for those living with HIV and/or AIDS places even greater significance on their personal and social relationships. Third, given the way in which AIDS has crept into many populations, the personal and social relationships of women and people of color deserve particular attention. Fourth, stigma and coping with stigma continue to permeate the personal and social relationships of those living with HIV and/or AIDS. After reviewing these themes, we describe a conceptual framework that offers a broad ecological approach focusing on four contexts for such research. We then introduce and discuss the articles in this special issue in the light of those themes and contexts.

Contextualizing HIV, AIDS, and personal and social relationships

The changing nature of HIV and AIDS
At the 1996 International Conference on AIDS in Vancouver, the focus of researchers' discussions of the epidemic changed dramatically with news of new treatment options for individuals with HIV and/or AIDS. For the first time since the onset of the epidemic in the early 1980s, living with HIV and/or AIDS was viewed as a type of chronic illness as a result of new drug combinations known as antiretroviral 'cocktail' therapies or highly active antiretroviral therapy (HAART). For some people who take these drug cocktails, the HIV virus can be reduced to very low, even undetectable levels. Such remarkable effects led Catz and Kelly (2001) to recently

conclude that '[al]though AIDS continues to take many lives, new treatments hold out the promise of longer and healthier life for some persons with HIV disease' (p. 841). It is important to note, however, that these drugs do not work for all people, present substantial difficulties (e.g., problematic side-effects and prohibitive costs), and have only been studied for a few years. Nonetheless, the success of antiretroviral drugs has reframed AIDS (particularly in countries in which these medications are widely available) into a disease that is chronic – similar to other long-term illnesses such as some cancers or diabetes – rather than fatal. Early in the epidemic, an AIDS diagnosis meant a fairly short life expectancy and many people with AIDS soon became disabled or died relatively quickly. The appropriate focus at that time was on dealing with serious medical problems, physical disability, and imminent death. People now recognize that individuals living with HIV and/or AIDS need a wider range of services, including housing, social support, and added transmission prevention efforts (e.g., Catz & Kelly, 2001; Greene & Cassidy, 1999).

The needs of many individuals with HIV and/or AIDS today are, thus, not the same as those of the 1980s or even early 1990s. Psychosocial issues for those individuals have changed, in part, due to changes in drug treatments (Kobayashi, 1997). Catz and Kelly (2001) identified four areas of psychological issues raised by HIV treatment advances, including:

> potential adjustment and coping challenges faced by persons living with HIV in this era of new HIV medical advances, issues related to patient adherence to new HIV treatment regimens, sexual or drug use risk behavior among HIV-seropositive and seronegative persons, and the emerging nature of HIV as a serious, chronic, but often manageable disease. (p. 841)

The studies reported in this special issue were conducted either shortly before or during this shift to a long-term disease course. With the remarkable changes in treatments over recent years, many individuals living with HIV and/or AIDS are functioning at a much higher level than previously. With this increased life expectancy has come the need to understand more fully their personal and social relationships.

An emphasis on relationships
Although personal and social relationships have always been crucial for people living with HIV and/or AIDS, the shift to a long-term disability makes such relationships even more important, if only because those relationships will potentially last longer. For example, individuals with HIV and/or AIDS may begin or end a number of intimate relationships and struggle with all of the issues that may characterize such relationships, including whether and how to engage in sexual behavior. Many resources have been spent targeting risky HIV-transmission behaviors, but 'risky sexual behavior does not exist in a vacuum, and as such must be examined within its developmental, social, and psychological contexts' (Ickovics, Thayaparan, & Ethier, 2001, p. 818; also see Kalichman, 2000). Additionally,

HIV-disclosure issues continue to be important, with some individuals delaying sharing their HIV diagnosis until they are very sick (Greene & Faulkner, 2001). Individuals with HIV and/or AIDS may also re-enter (or never leave) the workforce, spending a significant portion of their time there and developing close relationships with co-workers.

Researchers, therefore, have turned their attention to the study of the personal and social relationships of those living with HIV and/or AIDS. For instance, at the macro level, scholars working from a cultural perspective have shed light on the 'reciprocal connections among the physical, psychological, and societal worlds of health by linking the body, mind, and collective' (Frey, Adelman, & Query, 1996, p. 396). That perspective has led some scholars to argue that AIDS has become a defining feature of the body politic that has, literally and symbolically, refigured social reality (see Frey et al., 1996; Gagnon, 1989, 1992; Herdt, 1992). At an intermediate level, several scholars have started to explore ways in which people with HIV and/or AIDS can and have engaged in social practices designed to meet their individual and collective needs. Brashers and colleagues (e.g., Brashers, Haas, Klingle, & Neidig, 2000; Brashers, Haas, Neidig, & Rintamaki, this issue), for instance, have explored the collective practices of ACT UP (AIDS Coalition to Unleash Power; www.actupny.org) and the effects of participating in such activism on the self-advocacy of people with HIV and/or AIDS. Adelman and Frey (1997, 2001; see also Adelman & Schultz, 1991; Frey et al., 1996; Frey, Adelman, Flint, & Query, 2000; Frey, Query, Flint, & Adelman, 1998) have studied the collective social practices of people with AIDS who live in a residential facility, focusing specifically on how those practices help to create and sustain community life and are related to individuals' perceived health behaviors. Several researchers have also studied the impact of HIV and/or AIDS on family functioning (e.g., Forehand et al., 1998; Miles, Burchinal, Holditch-Davis, Wasilewski, & Christian, 1997; Pequegnat et al., 2001). Finally, at a micro level, several researchers have explored the nature and effects of social support practices, or lack thereof, in general for people with AIDS (e.g., Barbee, Derlega, Sherburne, & Grimshaw, 1998; Cline & Boyd, 1993; Crandall & Coleman, 1992), as well as, more specifically, social support groups for people with AIDS (e.g., Cawyer & Smith-Dupre', 1995; Daniolos, 1994). There are also research programs focusing on the effects of HIV disclosure on relationships by Derlega and Winstead (e.g., Derlega & Winstead, 2001; Derlega, Winstead, & Folk-Barron, 2000), Greene and colleagues (e.g., Greene & Faulkner, 2001; Greene & Serovich, 1996), Hays and colleagues (e.g., Hays et al., 1993; Hays, Turner, & Coates, 1992), and Marks and colleagues (e.g., Marks, Richardson, & Maldonado, 1991; Marks et al., 1994).

This special issue is intended to complement and extend these and other investigations by providing another forum for such research. Accordingly, all five articles in this special issue contribute to understanding how individuals with HIV and/or AIDS negotiate some aspect of their personal and/or social relationships. It is especially important that this forum is

presented in a scholarly journal such as the *Journal of Social and Personal Relationships*, which emphasizes relationship concerns. Until now, the *Journal of Social and Personal Relationships* has not examined in significant detail the personal and social issues of those living with HIV and/or AIDS. Hence, we offer this special issue to inform scholars who read this journal about the significance of this research and perhaps even inspire some to move in that direction.

Increased attention to other populations

The demographic profile of the HIV and AIDS epidemics in the U.S. and around the world has shifted dramatically. At the global level, through December 2000, of the 34.7 million adults living with HIV and/or AIDS, 16.4 million (47.3%) were women (UNAIDS, 2001); in the U.S., at the end of 1999, 26% of persons living with AIDS were women (Centers for Disease Control and Prevention [CDC], 2001a). Women, therefore, constitute a significant portion of the population affected by HIV and AIDS.

Even more staggering is the impact of HIV and AIDS on minorities. In the U.S., the estimated percentages at the end of 1999 of persons living with AIDS were 40.6% Blacks, 38.2% Whites, and 19.7% Hispanic (CDC, 2001a). New HIV-infection rates, however, show even more dramatic racial shifts, with 54% of new infections occurring among Blacks and 19% among Hispanics, despite the fact that they represent only 13% and 12% of the U.S. population, respectively (CDC, 2001b). In new HIV-infection cases among women, 72% are among Blacks and Hispanics; among men, that figure is 70% (CDC, 2001b). Finally, AIDS is now the leading cause of death of Black men and minority women between the ages of 25 and 44 (CDC, 2001a). As these and other figures show, HIV and AIDS constitute a disproportionate threat to minorities.

Given these demographic shifts, the personal and social relationships of women and minorities living with HIV and/or AIDS take on increased significance. Three of the articles in this special issue, consequently, focused on these populations: Song and Ingram investigated the social interactions of African Americans (predominantly women) who were HIV positive; Leslie, Stein, and Rotheram-Borus studied the coping styles of women with HIV or AIDS (predominantly Hispanic and African American); and Schrimshaw and Siegel explored how mothers with HIV disclosed the diagnosis to their children. These studies, thus, reflect the increased significance of understanding the personal and social relationships of the many populations affected by HIV and/or AIDS.

The continuing effects of stigma

The fourth and final theme is the role of stigma in the personal and social relationships of those living with HIV and/or AIDS. Much has been written about the highly charged social and political contexts in which these illnesses are embedded (e.g., Herek, 1999; Shilts, 1987; Watney, 1994) and the resulting stigma attached to those who have them (e.g., Bateson & Goldsby, 1988; Crandall & Coleman, 1992; Gagnon, 1989). These problems are still

present today, forcing individuals with HIV and/or AIDS to struggle on a daily basis with how to manage the stigma (Alonzo & Reynolds, 1995; Bauman, Camacho, Forbes-Jones, & Westbrook, 1997; Fife & Wright, 2000; Sowell et al., 1997). Stigma affects people's decisions to disclose the disease to others, the social support they do or do not receive, how they cope with the disease, and, ultimately, their identity (Leary & Schreindorfer, 1998). For instance, because of stigma, many people with HIV conceal their infection to avoid potential negative consequences, which, in turn, may lead to psychological and physical costs associated with the burden of maintaining that secret (Siegel, Lune, & Meyer, 1998; also see Cole, Kemeny, Taylor, Visscher, & Fahey, 1996).

Issues related to stigma pervade the articles in this special issue and are perhaps seen most vividly in the illustrative quotes from the various interviews conducted. As these studies show, the shift toward viewing HIV and AIDS as long-term, 'normal' chronic illnesses has not always filtered down to the personal and social relationships of those living with these illnesses. Unfortunately, despite changes in the epidemic that should lead to destigmatization of HIV and AIDS, the negative effects of stigma continue to take a toll.

Those studying HIV and AIDS, in particular, need to be cognizant of not contributing, even unintentionally, to such stigmatization processes. A primary means by which stigmatization occurs is through discourse, and a number of scholars have pointed to the discourses of pollution, plague, deviance, sin, and punishment/poetic justice (e.g., 'the wrath of God') that are invoked so often in reference to AIDS (e.g., Lupton, 1993, 1994; Patton, 1990; Redman, 1991; Ross, 1989) and that have powerfully shaped people's perceptions and behaviors toward those living with AIDS (e.g., Norton, Schwartzbaum, & Wheat, 1990; Sontag, 1989). We have learned much from disability symbolism about the constitutive nature of symbols – that is, how symbols help to create and transform reality (see Frey & Upchurch, 2000; also see the articles in Braithwaite & Thompson, 2000). Much attention has been placed, consequently, on the ramifications of using a term such as 'disabled' instead of 'handicapped' or 'invalid' (e.g., Devlieger, 1999). Attention has also focused on the potential positive effects of person-first language (e.g., 'a person with a disability') in contrast to disability-first language (e.g., 'a disabled person') (e.g., Lynch, Thuli, & Groombridge, 1994; Seiter, Larsen, & Skinner, 1998).

In line with disability symbolism scholarship, we employed in this introduction person-first language (e.g., person with HIV rather than HIV-infected person). Moreover, we have worked to clarify the terms HIV and AIDS. We chose to use HIV and/or AIDS (or HIV and AIDS, when appropriate) rather than the common HIV/AIDS designation because, although people with AIDS have HIV, people with HIV do not necessarily have or have progressed to an AIDS diagnosis. We hope that this usage clarifies rather than muddies the symbolic waters.

A conceptual framework for understanding the personal and social relationships of people with HIV and/or AIDS

Few conceptual frameworks are available for understanding the personal and social relationships of those living with an illness such as HIV or AIDS. Many studies of specific variables associated with illness and personal and social relationships have been conducted, but there is much less research integrating the complex dynamics of relationships.

One potentially useful conceptual framework is that proposed by Ickovics et al. (2001) to understand HIV transmission and progression for women from an ecological perspective, including an emphasis on 'a reciprocal and bidirectional association between individuals and the social contexts in which they live' (p. 818). Four social contexts comprise this perspective: sociocultural, interpersonal, temporal, and situational contexts. *Sociocultural contexts* include culture and social class. For example, cultural norms regarding gender roles have profound effects on the potential implementation of HIV-prevention behaviors; alternately, norms or social class may affect decisions to seek health care, comply with various treatments, or disclose HIV infection. *Interpersonal contexts* include factors such as social roles and social support, and focus on interpersonal networks and potential for HIV transmission; for example, individuals may be in a primary relationship characterized by drug use and/or sexual encounters that occur outside of that relationship (known or not). *Temporal contexts* include factors such as epidemiological stage, disease stage, and life stage. What year in the epidemic a person tests positive for HIV has an effect, especially with the advent of new drug therapies; HIV as a disease also progresses such that there are more opportunities for infection later in the illness (Bartlett & Gallant, 2000). Developmental life stage also affects HIV and AIDS; for example, adolescents may be more likely than adults to experiment with sex or drugs (e.g., Arnett, 1992). Finally, *situational contexts* include factors such as pregnancy, geography, and relationship type, factors that are specific to particular groups of people and may affect their responses to HIV and/or AIDS. For example, planning for future childcare and/or pregnancy may be particular issues for mothers infected with HIV; similarly, rural and urban individuals with HIV and/or AIDS may confront differential challenges such as access to AIDS service organizations or the travel distance required to obtain health care.

This contextual framework has utility for integrating research on the personal and social relationships of people with HIV and/or AIDS, especially with respect to research that cuts across these four contexts. This type of ecological perspective explicitly requires examination of the 'dynamic pattern of *interaction* between person and environment' (Revenson, 1990, p. 66) and, therefore, examination of the dynamic relationships between and among the four contexts. Altman, Brown, Staples, and Werner (1992) have also argued for research that connects cultural and social contexts of relationships with the physical environments in which those relationships are embedded.

Persons with HIV and/or AIDS and those with whom they interact in relationships are embedded within these four contexts. Consequently, as a set, the articles in this special issue touch on all four contexts, allowing researchers to see a wider picture of how HIV and/or AIDS affect individuals and their relationships, and vice versa. The articles also show the role that personal and social relationships play at the individual, relational, and collective levels; some articles focus on individuals, some on dyads (e.g., between relational partners or between mothers and children), and one focuses on relationships at the collective level. Finally, the articles show the diverse methodological approaches that can be brought to bear to study these four contexts; several researchers, for instance, employed quantitative surveys, whereas others relied on in-depth interviewing techniques.

Overview of the articles

Given the four themes identified earlier and keeping the conceptual framework discussed previously in mind, we now turn to a brief introduction of the articles in this special issue. In each case, we try to identify the context(s) on which the authors focus.

The special issue begins with an article by Schrimshaw and Siegel, who interviewed 45 mothers about the reasons for disclosing or not disclosing their HIV diagnosis to their children, their perceptions of the children's reactions to that disclosure, and the effects of that disclosure on their relationship with the children. The researchers discovered that many mothers had disclosed the diagnosis to their children, depending, in part, on the child's age and the mother's disease stage. Mothers reported some initial negative emotional reactions to the disclosure but generally closer relationships following disclosure. The article, thus, investigates two important populations (mothers and children) affected by HIV and/or AIDS and illustrates all four contexts (sociocultural, interpersonal, temporal, and situational) of the ecological model described, with a particular focus on the interactive temporal aspects of the development of mothers' disease stage and their children's age stage.

In the second article, Leslie, Stein, and Rotheram-Borus surveyed 295 parents with HIV and/or AIDS (predominantly mothers) about their coping style, emotional distress, conflict, social support, and health outcomes. The findings showed that active coping was related to higher levels of social support, greater health care satisfaction, and less substance abuse, whereas passive coping was related to greater conflict with adolescent children and greater parental emotional distress. The researchers argue that interventions focusing on enhanced coping skills could improve health outcomes for parents with HIV and/or AIDS. This study, thus, focuses on an important population affected by HIV and/or AIDS (parents) and illustrates well both the situational and interpersonal contexts.

The third article by Song and Ingram investigates relationships among availability of social support, unsupportive social interactions, and

anxious/depressive mood for African American individuals with HIV (predominantly women). The findings showed that greater satisfaction with available social support was associated with lower levels of mood disturbance and that higher levels of unsupportive social interactions were related to higher levels of mood disturbance. This article, consequently, extends the social support literature beyond support availability or positive social support by examining, in addition, the effects of unsupportive social interactions. This study is, thus, a good illustration of the sociocultural context, as well as the interpersonal context.

The fourth article by Haas examines how various sources of social support (i.e., from partner, friends, and family) help to maintain relationships in gay male couples. Haas conducted in-depth interviews with 20 gay male couples, some in which both partners were HIV positive (concordant) and some in which only one partner had HIV (discordant). The findings showed that relational partners were the primary source of social support for both concordant and discordant couples, although couples also reported receiving social support from family and close friends. Haas discusses how social support functions at both the individual level with respect to coping with illness and at the dyadic level with respect to maintaining the couple. From an ecological conceptual perspective, the study is perhaps the best illustration of the situational context given that it focuses on several aspects of relationship type.

The final article by Brashers, Haas, Neidig, and Rintamaki takes a macro-level perspective on personal and social relationships by examining the effects of participation in HIV and/or AIDS activist organizations. The researchers surveyed 174 individuals with HIV and/or AIDS (predominantly male) who were activists or nonactivists. Activists were found to use more problem-focused coping and less emotion-focused coping; they also reported more knowledge about HIV-treatment information sources and greater social network integration. The article illustrates both the situational and interpersonal contexts and encourages speculation about whether activists are predisposed to engage in collective activity or are changed by the relationships they form in such collective settings.

This special issue concludes with two commentaries that help to put the articles in context. The first commentary by Harvey and Wenzel addresses the articles from the perspective of the literature on close relationships, showing how the articles emphasize themes of self-disclosure, relationship maintenance and enhancement, coping strategies, and the effects of HIV on children, as well as some methodological issues and clinical implications of the articles. The second commentary by Elwood addresses the articles from a communication perspective by focusing (using a memorable cabbage head analogy) on how communication about sex and condom use in relationships is necessary to reduce transmission of HIV and assist with treatment.

Conclusion

The face of HIV and AIDS has changed dramatically in only a few short years from short-term death sentences to long-term chronic illnesses. Although 'how persons re-adapt from a focus on early death from AIDS to the prospect – but not the guarantee – of longer life is not yet known' (Catz & Kelly, 2001, p. 843), one of the greatest changes undoubtedly occurs in the personal and social relationships of those living with HIV and/or AIDS. Such relationships, thus, deserve increased attention; we simply must learn more about how individuals living with HIV and/or AIDS begin, manage, and change their personal and social relationships.

The articles in this special issue address important aspects of the personal and social relationships of individuals with HIV and/or AIDS. Much research remains to be done to understand their relationships, and our hope is that this special issue will encourage continued attention to this important area. There has been much talk about putting a name on the face of AIDS to personalize the disease; as the articles in this special issue show, we must concomitantly interpersonalize HIV and/or AIDS by focusing on the personal and social relationships of those so named.

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