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# **'The head that doesn't speak one calls a cabbage:' HIV, AIDS, risk, and social support in the 21st century**

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ABSTRACT

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This essay comments on articles in this special issue on HIV and AIDS in the context of social and personal relationships. Specifically, it argues that active communication about sex and condom use and equally vigorous communication regarding HIV-treatment issues is required to reduce HIV transmissions and to facilitate its treatment. In particular, the articles demonstrate that undereducated, impoverished individuals may require more active and instructional case management than their more informed and affluent counterparts.

KEY WORDS: AIDS • behavior • communication • HIV • risk

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The HIV/AIDS epidemic has frustrated researchers, caregivers, and infected individuals alike. Before the acronyms HIV and AIDS became commonplace, people died from similar symptoms but from unknown causes. Eventually, we learned what caused HIV and AIDS and how one can prevent viral transmission. In Western culture, we learned that the stigma associated with injection drug use, multiple sex partners, and homosexual sex impedes discussions of sex behaviors, HIV-prevention methods, and diagnoses of HIV or AIDS (Bennett & Travers, 1999; Derlega, Sherburne, & Lewis, 1998; Elwood & Williams, 1999; Elwood, Williams, McCoy, McCoy, & Aversa, 1999; Greene, Parrott, & Serovich, 1993; Greene & Serovich, 1998; Kellar-Guenther, 1999).

The advent of combination prescription drug therapies brought hope for people living with HIV and AIDS and for their health care providers; however, all involved became frustrated again, as the combination therapies were expensive, complicated to consume, and had an array of unwelcome side-effects. Not surprisingly, many people taking these

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prescription drugs did not comply with their treatment regimens (Greene & Cassidy, 1999; Liu et al., 2001; Murri, Ammassari, & Antinori, 2001; Schilder et al., 2001). Concurrently, almost everyone seemingly lapsed in regular condom use and the prevention of other behaviors that risk HIV transmission (Crepaz et al., 2000; Elwood & Williams, 1999; Hoffman & Cohen, 1999; Klevens, Fleming, Neal, & Li, 2001; Lert, 2000). Subsequently, HIV infections increased exponentially among African American women, Latinas, and young men who have sex with men (Campsmith, 2001; Dufour et al., 2000; Miller & Neaigus, 2001). Similar to the earlier discovery that interventions based on the health belief model (Janz & Becker, 1984) were not optimally effective in preventing HIV transmission (Fishbein, 1997; Zimmerman & Vernberg, 1994), researchers and practitioners again were disappointed that more recent theories and models for prevention and care neither motivated condom use nor facilitated adherence to prescription therapies (Gillespie, 1997; Zimmerman & Vernberg, 1994).

### **Communication, situations, HIV, and AIDS**

Increasingly, we have realized that we must consider all situations in which HIV occurs – in other words, the physical environments, personal motivations and physical behaviors of individuals and the motivations and behaviors of others within those physical environments, and the mutual influence all have on one another (Elwood, 1999b). In fact, Magnusson (1981) argued that we cannot understand human behavior without understanding the various situations in which such behaviors occur. More specifically, we need to examine and to illuminate the role of human communication in these situations because human beings communicate to influence other people's behavior. People not only communicate to influence people's attitudes and behaviors at any given moment, but also communicate to explain their motivations for previous behavior and the influences that they believe their symbolic and physical behaviors had on others (see Elwood, 1999b).

Attention to a particular area of communication study, social support, has grown as we consider the situations of HIV treatment and prevention. For example, Kalichman, Heckman, Kochman, Sikkema, and Bergholte (2000) interviewed 113 people with HIV and, perhaps, AIDS aged 45 and older and found that those who reported contemplating suicide perceived themselves as receiving significantly less social support from friends and family than did those who did not contemplate suicide (see also Heckman et al., 2000). Heckman, Kelly, and Somlai (1998) also found that perceived lack of social support was one statistically significant predictor of individuals with HIV continuing to engage in high-risk sex with a greater number of male sexual partners. Fleishman and colleagues' (2000) survey of 140 individuals with HIV determined that we simultaneously must consider coping, supportive relationships, and conflictual relationships to understand how people adjust to this chronic illness.

The need for social support also applies to HIV prevention. When I directed a community-based survey research center for drug abuse and HIV issues, a 14-year-old girl continually asked for possible inclusion in research projects for which she could receive an honorarium for her time. A runaway with little means for financial support and little prospect for family reconciliation, she informed me that she was having unprotected sex with males infected with HIV so that she would become infected herself and, thereby, become eligible for a monthly stipend, medical care, a housing allowance, and respectful asexual attention from the people who provide those services (Elwood, 1999a). Frankly put, she perceived HIV as the means to receive social support and a regular income. Her case vividly reinforces research by Schuman and associates (2001), who interviewed 871 women with HIV and 439 demographically and behaviorally similar women without HIV. On the basis of those interviews, the authors posited that women both living with or at risk of HIV perceived a need for and used mental health services in association with feelings of social isolation.

The articles in this special issue illuminate our understanding of social support for people with HIV and/or AIDS and their respective situations. These articles also provide us with new ways to understand *risk* and *behavior*. For example, Schrimshaw and Siegel interviewed 45 mothers with HIV to determine whether and why they disclosed their infection to their children. Ordinarily, self-disclosure of traumatic or secretive information produces observable health benefits; self-disclosure has also been linked, albeit less consistently, to improved psychological health (e.g., Sherman, Bonanno, Wiener, & Battles, 2000). For these mothers with HIV, the *risk* involved with self-disclosure involved not the chance of HIV transmission, but other, more personal, dangers. According to the authors, the mothers understood that 'disclosure carried risks, including rejection, stigmatization, anger, and discrimination.' Mothers reported not disclosing their infection to their children because the mothers wanted to protect their children from peer discrimination and fear regarding their mothers' health or demise.

On the whole, mothers who reported disclosing their HIV infection to their children also reported that these children adjusted well over time; only some mothers reported that their children experienced temporary distress, such as separation anxiety. One particularly heartening report was the children's perceived behavioral improvement in response to their mothers' self-disclosure; for example, one daughter's behavior improved so significantly that her teachers telephoned the mother repeatedly with good reports. Perhaps even more intriguing is the motivation that these mothers most frequently reported for disclosing their HIV infection to their children: as one mother frankly told her daughter, 'You can't go out there and be promiscuous and have unprotected sex because you could end up like mom.' By conducting extensive interviews of mothers with HIV, this study responds to the changing demographics of the epidemic and suggests the regular integration of parenting issues in HIV case management and care.

Haas also explored social support, in this case, among gay male couples. According to Haas, 'Couples reported that illness-related and relationship maintenance behaviors became intertwined within their relationship.' Perhaps because HIV and AIDS are so closely integrated into gay men's self-identity as gay (Botnick, 2000a, 2000b; Sobnosky & Hauser, 1999), Haas reported that the couples perceived 'HIV as yet another relational stressor' rather than as a stressor of more epic significance. Given this finding, the author suggested that researchers explore 'whether gay couples coping with HIV could learn to recognize and utilize illness-related social support in their efforts at relationship maintenance.' He intriguingly compared his findings with those from previous research that found wives who were hospitalized for heart attacks resumed their household duties shortly after returning home, whereas husbands in the same situations resumed their household tasks once they had recovered completely (Coyne & DeLongis, 1986). Haas suggested that the proscribed gender roles that frequently constrain heterosexual relationships less frequently distinguish gay romantic partnerships. The public emergence of committed gay relationships presumably provides the opportunity for each couple to forge its own unique rules for relationship and household maintenance. Indeed, one hopes that the lessons Haas provided from this exploration of HIV serodiscordant and seroconcordant couples' recountals of their personal lives can be applied to all couples – straight and gay, with or without illness – to facilitate constant relationship-edifying behaviors rather than behaviors that maintain relationships only during crises.

As with the two articles just reviewed, Leslie, Stein, and Rotheram-Borus's work reflects the evolution of the HIV epidemic. These researchers interviewed 429 New York City parents with HIV who had adolescent children and found that using more active coping strategies to acquire HIV care directly predicted more satisfaction with health care and fewer substance abuse problems.

In a similar vein, Brashers, Haas, Neidig, and Rintamaki found 'substantive differences between activist and nonactivist individuals living with HIV or AIDS.' Specifically, the authors explained that activism and self-advocacy were associated with forceful coping strategies and knowledge of HIV-information sources. Interestingly, activists not only vigorously negotiated their own rights and care, but also regularly sought treatment information from traditional and nontraditional sources. For activists, it seems that what constitutes risky behavior is to keep silent and to remain ignorant of emerging HIV-treatment information. Brashers et al. conducted their research with educated and, frequently, active individuals. Their colleagues in this special issue conducted their studies with people who were quite different.

Song and Ingram conducted research with 116 African Americans with HIV and found that unsupportive social interactions were associated with greater mood disturbance. The authors carefully noted that their research participants were impoverished, undereducated African Americans with HIV. They also might have noted that there are few groups of U.S. citizens

who endure more stigma than members of this group, and that people who endure poverty, ignorance, *and* disease – and the stigma attached to them – likely will require active, instructive, and patient case management.

### **Interventions that promote active communication strategies**

The implications of these articles lead me to combine current wisdom and common sense, much like early HIV-prevention materials informed their audiences to 'wear your rubbers,' 'get your rest,' and 'eat your vegetables.' Before I graduated elementary school, let alone thought about a graduate education, my Sicilian grandmother taught me an essential truth: *La cappa chi non parla se chiamina un cocozzo* – the head that doesn't speak one calls a cabbage. This is a particularly witty bit of wisdom, as, in Sicilian, to be called a *cabbage head* is also to be called 'crazy' or 'off your rocker.' In other words, one is crazy not to give voice to issues of import, and there are few issues as important as edifying loved ones, getting necessary medical care, and protecting children from HIV infection.

The articles in this special issue demonstrate the collective need to promote interventions that foster active communication strategies to facilitate HIV and AIDS treatments and to prevent HIV transmission. We have fragmented systems of health care delivery and insurance coverage. Those who speak – loudly and often – stand the best chance to obtain the care they require. Those who do not speak risk not obtaining access to the care they need and, possibly, their survival. As the studies in this special issue demonstrate, parents who actively negotiated their HIV-related health care reported fewer destructive behaviors and fewer symptoms. Such active parents presumably will endure longer and will have longer periods to enjoy their children. The mutual support of romantic partners also ensures family endurance during illness and congenial periods during relative wellness. This mutual support occurs when romantic partners describe their needs, abilities, and desires for another's behavior within the relationship, as Haas's participants told him, 'We talk about it' and 'I ask him.' Talking about issues is important, particularly in terms of promoting safer sexual behaviors.

It is one talent to know how to use a condom; it is another equally important talent to be able to negotiate its usage. Our cultural reluctance to discuss sex frequently precludes people from negotiating safer sexual acts, especially condom use for intercourse. It is a noble, if tragic, act for mothers to reveal their HIV infection as an HIV-prevention intervention with their children. Nevertheless, such communicative behaviors – from mother to child, between partner and partner, among public health professionals and their clientele – can be powerful and lasting interventions. The articles in this special issue demonstrate that only through human communication can individuals precipitate the social support necessary to increase the quality of care for those living with HIV and/or AIDS and to reduce the number of HIV infections, and cabbage heads, in the 21st century.

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