

Women, Ethnicity, and AIDS: What's Love Got to Do with It?

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This paper examines the usefulness of relationships as the critical factor in preventing AIDS for women of color. An analysis is offered of the conceptualization of issues, as well as the prevention measures and safe-sex strategies developed for gay men versus women's HIV/AIDS incidence rates. The discussion of similarities demonstrates that gender and culture play a role in the disproportionate negative impact affecting the health status of women of color. The compounding factor of poverty is considered essential to the complex situation in the ethnic minority community, resulting in a lack of public concern and a lack of community responsiveness to these women. Finally, several challenges for health researchers are presented including the need to adopt cultural sensitivity in research efforts, include researchers with an understanding of the ethnic community's perspective, and develop clearer guidelines for risk assessment.

Women's stereotypical responses have often been examined as the key to their behavior. They have been described as more caring and concerned for others, more easily influenced and suggestible, and less aggressive in social interactions than men (Eagly, 1987; Williams & Best, 1986). In spite of meta-analyses that refute much of the evidence for the claims of gender differences (Hyde & Linn, 1986), the belief in these stereotypes remains widely held. Among the strongest is an image of women perpetuated in film and fiction (e.g., *Indecent Proposal* and *Waiting to Exhale* are films about women) who will do anything for love, even sacrifice their own well-being.

Psychologists have turned to focus on relationships as a critical feature for impacting women's health-related behavior in general, and for affecting

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protective behavior with respect to HIV/AIDS in particular. Thus, the question must be raised about whether the issue is the relationship or the status of women that puts them most at risk. Ample data suggest that the roles that women (and men) play typically depend on what they perceive as suitable for the situation (Burn, 1996; Tavris, 1992). Women's roles within a heterosexual relationship are not totally defined by the individual; society has also described and prescribed what is appropriate.

Most psychological research on women and AIDS seems to make the following assumptions: (a) although high risk of HIV infection exists for women, particularly for women of color, these women are ignoring the danger for the sake of maintaining heterosexual relationships, and (b) women are at greater risk due to their failure to "take charge" in these relationships with men. Accepting the first, it seems difficult to explain how women, shown to be low risk-takers, are now placing themselves in deliberate jeopardy. Either women are willing to risk their lives to a greater degree than analysts have previously determined or they do not understand, or will not acknowledge, the extent of risk they face. Accepting the second assumption seems to suggest that the only way for women to avoid risk is to individually accomplish what the women's movement has been struggling collectively to achieve, i.e., they must take a position of authority and power *vis a vis* men. Alternatively, implementing sexually protective strategies, as many researchers have discussed, requires the involvement and the cooperation of men (for example, see Quina, Harlow, Morokoff, Burkholder, & Deiter, 2000).

I am certainly not suggesting that the two assumptions are false. With respect to the first, data confirm the risks of AIDS to women and research data demonstrate that women are not consistently taking protective actions (Gutiérrez, Oh, & Gillmore, 2000; Mays & Cochran, 1988). With respect to changing the dynamics of relationships, honesty and open communication are values that are universally admired, if not espoused. Instead of pursuing these agendas, I would like to shift the discourse to examine the relationship among class, ethnicity, and gender as factors in the risk of AIDS. I will also consider some parallels in the research and prevention efforts from the situation of gay men. From these perspectives, it may be possible to suggest additional areas of research and further assist in the development of useful strategies for women.

FOR GAY MEN ONLY—EARLY MISINFORMATION, THEN KNOWLEDGE

In the early years of the HIV/AIDS epidemic, there were many points of misinformation that were disseminated as physicians, researchers, and

those affected most searched for answers. Health officials negotiated among themselves between the choices of alerting people to the risks and the fears about causing public panic. People were constantly being reassured that AIDS was unlikely to strike them: if they were not promiscuous, if they were not gay, if they were not sexually active. Many believed that the disease would stay in the big cities, in the gay community, and among drug users. Even now, national headlines are made when adolescents in a small town contract the disease because the beliefs are still strong that only “undesirables” become infected; this does not happen to “ordinary” people.

After years of politically motivated delay, both researchers and activists came to recognize the need to change the sexual practices and behaviors of those in the population most affected. They set about this in several ways: (1) establishing programs for education and awareness (including the use of posters, advertisements in key magazines, and various public campaigns to inform about the impact of the disease, its manifestation, and the mode of transmission); (2) developing legislation to affect behavior, e.g., closing bath houses, mandating testing of blood; and (3) working to change individual behavior. While there was a considerable degree of denial (in fact, denial was a strategy adopted by some gay men), the relentless campaign of awareness, heightened by media attention to those high-status gay men who died, gradually overcame this response. It seems worth noting that the movement to promote “safe sex” among gay men and the methods that devolved from it did not include any significant discussions of differential power, gender socialization, or of who controlled whom—the focus was on preventing death.

The campaigns of advertising, fund-raising, and public awareness of the dangers faced by gay men did more than fuel the concerns of this targeted population. In addition, they brought a sense of security and relief to everyone who was not a gay man. The messages were loud and clear: pressure for safe sex was on gays, not straights; on men, not women; on promiscuous, not virtuous people. Further, it was widely believed that women need not be as concerned with safe sex, they were relatively safe from HIV infection and AIDS.

GENDER AND ETHNICITY—THE RISK FACTORS

Indeed, a major factor in the danger of AIDS faced by women stemmed from the association that the AIDS epidemic has had with gay men. AIDS was first recognized and still remains closely identified by its high incidence among gay male communities. The myth of protection for heterosexual women, however, has been shattered by the growing incidence of AIDS

contracted though heterosexual exposure as reported by the Federal Centers for Disease Control and Prevention (CDC) (Jones, 1995). Data now show that heterosexual contact drives this disease among women, with 40% of their exposure due to sex with a male partner. Until recently, injecting drug use among women was the greatest cause of exposure. Even so, sex with injecting drug users accounts for one third of the heterosexual contact cases.

In spite of data demonstrating the danger to women, many women remain faithful to the notion that their risk is low (Wyatt et al., 2000). Unfortunately, the actual risk is somewhat difficult to cite accurately and clearly for women. One reason is that CDC data are typically given as an aggregate across socioeconomic statuses. In addition, investigations by psychologists and other health researchers frequently have not included samples sufficiently representative of diversity of gender, ethnicity, and class. My own analysis of recent psychological abstracts (gathered from the CD-ROM for all abstracts in 1997 citing AIDS) showed that fewer than 12% of the 201 articles published in 1997 focused exclusively on women and only 33% of those on women of color. (See Table I for summary of abstracts.) There were also few articles that included HIV-positive individuals.

Clearly, the proportions of studies do not match women's incidence rates. "Of the 581,429 AIDS cases in U.S. residents reported to CDC through 1996, Blacks and Hispanics accounted for 53% of total, 76% of women, 79% of heterosexuals, 81% of children. Blacks and Hispanics accounted for 61% reported in 1996" (CDC, 1997a). AIDS has become the number one cause of death among African American women aged 25–44 years, as well as among African American men in the United States of the same age (CDC, 1997b). Still, it must be acknowledged that research is

Table I. Status of Gender and Ethnicity in 1997 Abstracts of Studies Relevant to HIV/AIDS from Silver Platter CD-ROM

Research Participants	Gender and Ethnicity in Journal Abstracts				Total
	No Gender Specified	Males Only	Females Only	Both	
HIV+ (ethnicity)	19	16 (3)	10 (3)	9 (2)	54 (8) 15%
HIV- (ethnicity)	32 (3)	24 (4)	14 (5)	33 (8)	103 (8) 19%
No participants (ethnicity)					44 (2) 5%
Total (ethnicity)	51 (3) 6%	40 (7) 18%	24 (8) 33%	42 (10) 24%	201 (30) 15%

creeping in the right direction. Of 954 abstracts in the PsycINFO database citing HIV in 1997, 20% ($n = 192$) also cited women, with most acknowledging some sociocultural factors; of the 946 abstracts in 1998, 23% ($n = 221$) cited women; and in 1999 from January through September, 24% of the 405 abstracts included women.

LOW SOCIOECONOMIC CLASS AND ETHNIC MINORITY STATUS: A RECIPE FOR POOR HEALTH

Poor women, particularly poor women of color, have poorer health outcomes and less adequate health care than majority women in this society. They experience higher rates of infant mortality and problem pregnancies and higher death rates and they are at greater danger for many health risks besides AIDS (McNair & Roberts, 1997). The mortality rate for breast cancer is more than one third higher for African American women than for White women (Smaglik, 1998, p. 1). Death from stroke, heart disease, and homicide more than doubles for African American women aged 25–44 years compared to the national average for all U.S. women of the same age (CDC, 1997a). Women from poor and ethnic minority families are more likely to be obese due to diet and exercise habits, to have respiratory problems due to environmental hazards, and to suffer from stress and depression.

In evaluating the health status for women of color, care must be taken not to underestimate the effects of classism and racism. The impact of the combined practices of neglect and discrimination have been documented in both nursing and medical literatures (Eliason, 1999; McKinlay, Potter, & Feldman, 1996). Differential treatment and care has been demonstrated by physicians during medical encounters, influencing both diagnosis and treatment (Floyd, 1997; Sleath, Svarstad, & Roter, 1998). Indeed, the negative impact of poverty combined with ethnic classification on health care has been obvious for many decades.

Bullough and Bullough (1971) chronicled the discrimination against Blacks and Latinos, particularly those in urban areas, based on discrimination in treatment, in health education and in the effects of medical policies. As they pointed out more than 25 years ago, poor people of color experienced to a greater extent almost every type of serious epidemic, even those that had been apparently cured or were rare for affluent White members of the population. Even now, life scientists report that socioeconomically disadvantaged groups experience disparately poorer health statuses (Olden, 1998). The discrepancies include decreased life expectancies, and higher rates of cancer, birth defects, infant mortality, asthma, diabetes, and cardio-

vascular disease. So we should not be surprised by the disproportionate impact of this new epidemic, AIDS. Indeed, we should have seen it coming.

Although researchers and their data maintain that no sexually active person is safe from infection, questions about the extent to which risk is associated with ethnicity, as opposed to poverty/class, have not been fully examined. Among the papers in this special issue and elsewhere, these statuses are at times confused, if not actually conflated. Thus, it is not obvious what differentially greater risk one has in being poor, having an ethnic identity, or both.

When no distinction is made about risk levels, consumers of data (i.e., people trying to make health decisions) are left to their own interpretations. Thus, the prevalence of some diseases among disadvantaged groups is so great that affluent people have assumed themselves to be immune. This appears to be the situation with AIDS. Recently a *New York Times* report on the epidemic of sexually transmitted diseases that contribute to cervical cancer, infertility, and infant mortality as well as to AIDS took pains to warn readers that this epidemic was not just a problem for the inner city (Stolberg, 1997). In fact, the reporter became quite explicit in making his point. He wrote, "The risk is hardly limited to African Americans or people of low income . . . Rates [of herpes] among white teen-agers quintupled" (p. 14).

There is indirect evidence that middle-class African American and Latinos have also distanced themselves from the plight of the low-income families and individuals who battle AIDS. Of course, there should be no surprise that those who have achieved a precarious level of respectability should seek to preserve it. Unfortunately preservation has at times taken the form of classism by those who are middle class and the adoption of the same stereotypes and forms of oppression used by others (Reid, 1993). Avoidance has been attributed to suspected homophobia among ethnic communities and the suspicion, fed by some religious movements, that those who contract the virus are sinners. Even the momentary enhancement of awareness inspired by the revelation that Ervin "Magic" Johnson, a basketball icon, was HIV-positive has done little to keep the face of African American and Latino AIDS sufferers in the public eye. (Arthur Ashe was viewed as one of the virtuous, but unlucky, who contracted AIDS through blood transfusion before testing of blood was mandated.) It appears that almost everyone wants to be shielded from facing his/her vulnerability and the transformation of those infected into "the other" appears very effective in this shielding strategy.

RESPONSES TO INCIDENCE AMONG WOMEN OF COLOR

There has been a steady and marked decline in society's response to AIDS during the last decade. Foreman (1994) offers two possible explana-

tions for the phenomenon. He points out that “newly recognized, rare, unfamiliar, or involuntarily borne risks often appear more threatening than those that are familiar or taken on willingly” (p. 9). AIDS is no longer new; people may dread it, but it has become one of the many dangers our society has to live with. The second point, according to Foreman, is that the visibility of the victims of a disease may be one of the significant features for developing policy. This second claim also suggests the inherent notion that virtuousness offers some protection from illness or misfortune. The phrase, “That person didn’t deserve to die,” suggests that some people do.

In our society there remains the notion that children and the elderly are among the “virtuous,” while drug users and welfare recipients get what they deserve. Clearly the sympathy and interest by a general public in people who are claiming the results due to them will be much less than if they were perceived as unlucky or unwitting victims. Women of color are easily the least visible among AIDS patients and, it can be remarked, the only group with no “celebrity” victims with which to highlight a claim to attention. Additionally, since many of the women with AIDS have been identified as drug users and/or prostitutes, they also fit into the “undeserving people” category. Thus, when we add the fact that the most prevalent victims now comprise groups with many other unmet needs, the results are predictable—a lack of public concern and a differential community response.

Lack of Public Concern

The newest statistics on HIV/AIDS incidence levels are startling, even astounding; yet there has been little real notice of these facts in the media. The disease that was labeled the “gay plague” in banner headlines has not been renamed to reflect the new demographics of its victims. King K. Holmes, professor of medicine at the University of Washington, has charged that a “conspiracy of silence” has allowed the spread of infections (Stolberg, 1997, p. 14). In fact, the notice that AIDS was now a leading cause of death in women was stuck on page four in one California newspaper (Jones, 1995). The *New York Daily News* reported the rise in incidence of AIDS among women 3 years later on page 57 (Feeney, 1998). The focus of one recent report in *The New York Times* was on the involvement of intravenous drug users and other drug users “many of whom are women” (Kolata, 1998); the report was buried in the medical science page.

Differential Community Response

There has also been a dramatically different response in the affected minority community compared with the initial response by the gay commu-

nity. Everyone may recall the reaction of the gay community in the 1980s to the realization of the attack on the well-being of its population. The embrace of those affected, the sadness, the loss feared and shared among the members was grist for Broadway drama and nightly news analysis. There appears to be no similar reaction among ethnic minority communities—no embracing and little sharing; at least nothing is being reported. An examination of the differences between the two communities will reveal that one of the most salient features may not be merely culture, but social class and political clout.

The gay male community that mobilized and issued the “call to arms” in the war against AIDS was affluent, educated, and at times accepted by the greater society. “I live in New York City; discrimination was always just a word to me,” said Paul Popham (Specter, 1985, p. 1). He was a Wall Street banker who became the chairman of the Gay Men’s Health Crisis when he saw his friends begin to die. Without the financial resources or the stature that White men could bring to the table, the minority community undoubtedly wishes to avoid becoming the target of further stigmatization, ostracism, and neglect. Further, it is not evident that calling attention to the devastation wreaked by the loss of women and children will give any advantages to the overwrought families and neighborhoods. If Rep. Henry A. Waxman (Democrat—California) was correct when he suggested that “the Reagan administration was slow to respond to this crisis because it hit the gay community hardest” (Specter, 1985, p. 1), one can again predict the disinterest in these groups who are already underserved.

WOMEN OF COLOR—CONFLICTS, CHOICES, AND CHALLENGES

Identity Conflicts

For women of color, the experience of having one segment or the other of one’s identity overlooked is common (Reid, 1984, 1993). Typically there is a submergence of gender when ethnicity or culture alone is examined; or ethnicity is ignored when gender is accepted as a factor. The lack of recognition of the duality of ethnic women’s experiences is frequently revealed in the research. For example, the *CQ Researcher* (1994) cited a 1993 Gallup Poll that found that “women” (ethnicity unspecified) perceived cancer as the most serious health threat they face. On the other hand, data in that same year from the National Center for Health Statistics (also cited in *CQ Researcher*, 1994) declared that heart disease was indeed the top killer of “women.” In these citations, “women” comprised both minority

and majority women. The grouping of White women with women of color masks the disparate perceptions and realities experienced. Indeed, uncovering the factors most relevant to women of color in AIDS, as in other areas, seems an elusive goal.

Choosing to Risk?

Studies in this issue have shown that women of color are not sufficiently risk-averse to provide them adequate motivation for insisting on condoms. It may be that they also may not have sufficient information to aid in this decision. It has been noted that much of the effective education and behavioral changes addressed to the gay community was delivered because this group was viewed as affluent, politically astute, and influential. Less effective and less energetic have been the efforts directed at the poor drug-using community or at any ethnic minority communities. Thus, there is a great need to bring resources to bear on the development of educational programs and materials targeted at ethnic minority people and women across various segments of the sociopolitical, cultural, and economic spectra.

Commercial advertisers and political advisors well know that messages that are not targeted are less effective and may actually alienate or prove counterproductive within subgroups. Can psychologists believe that the same brochure or advertisement developed for disadvantaged high school girls will successfully communicate the message to middle-class women married for 20 years? Scare tactics or threats that are not borne out have been found actually to impede behavioral changes. Information for women of color is desperately needed, but the group to which it will be directed should inform it. Women need to be apprised of their risks so they can make choices.

Challenges for the Future

From the abstracts examined on research in the area of HIV and AIDS, as well as analysis of research in other areas relevant to women (Reid and Kelly, 1994), it must be concluded that research attention to women of color is disproportionately low. Smaglik (1998) notes that the science community has failed adequately to respond to questions about what factors are relevant to ethnic populations because there has been inadequate representation of the perspectives and concerns of ethnic communities. Eliason (1999) and Stern (1986) also warned that health care professionals may impose their own cultural expectations and values on

their clients and fail to include a recognition of the client's values and feelings in making health decisions. When considering HIV-infected women of color, these warnings take on particular significance. The assumptions that health care providers may make about poor women's lifestyles, personal responsibility, and sexual habits may negatively impact the attitude, approach and treatment offered. The same assumptions by theorists and researchers also affect the quality of the information developed.

The importance of culturally sophisticated and sensitive investigators has been discussed in the past (Reid, 1994), but the goal of training sufficient numbers of minority theorists, researchers, and practitioners remains unmet. As the meager federal resources are divided among many priorities, it has been suggested that a greater representation of ethnic minority researchers should be present on review panels. Minority reviewers could help inject the concerns of the minority community and their presence could also begin to address fears that were heightened by the revelations of the Tuskegee Syphilis Study (Smaglik, 1998). [In the Tuskegee study it was revealed that medical researchers funded by the federal government knowingly infected African American men with syphilis, allowed the disease to remain untreated in the men even after treatment was available, and denied them information about the impact of the disease on their families.] Unfortunately, the real dearth of minority scientists makes a reliance solely on a minority presence extremely difficult and unrealistic to implement. Further, it must be acknowledged that since even ethnic minority researchers have been trained in the perspectives and traditions of the majority culture, they themselves will not always be able to call upon a culturally relevant interpretation.

An alternative recommendation to address the need for more sensitive perspectives was for the training of all reviewers in the determination of proper provisions to include and protect minority participants. Having personally participated in such an effort, I can attest to the unsatisfactory results that come from trying to revise the long-held attitudes and perceptions of senior reviewers. The resistance of theorists, researchers, and practitioners to engaging in what can be interpreted as self-criticism, i.e., reevaluation of their own career objectives and practices, is very strong throughout the social and medical sciences. Examples of scientific and medical beliefs held firmly in the face of contrary evidence by those who have achieved respect and eminence can be traced back to Pasteur and the many others whose names have been lost as they tried to change assumptions, practices, and beliefs.

The demands for attention to adequate medical strategies and care cannot wait until new researchers and health care providers are trained. There must be increased efforts to enhance the sensitivity of existing re-

searchers and providers along with requirements that they include ethnic minority students and collaborators in their investigations and treatment programs. Perhaps if researchers of color were made partners in programs and investigations funded for implementation within their own communities, there would be simultaneously the opportunity for training and the inclusion of culturally sensitive perspectives. The opportunities for partnerships abound if scientists would include perspectives of community agencies and community members. Such partnerships would have to provide a voice in determining process and procedure, as well as a role of respect and mutual participation, not merely a cover for business as usual.

CONCLUSIONS AND STRATEGIES

There is a serious problem affecting women of color—their failure to recognize and effectively combat the incidence of HIV/AIDS. While this situation may be influenced by the female status as it is played out in various relationships, this is not the sole reason for its intractability. Women's role relationships, like other roles, are culturally defined and reinforced by others in the society. Psychologists and other practitioners in the health care field may help to shape and redefine the options presented as women's caring and loving function or they may "buy into this role" as an unyielding representation of how women make choices and how they take health risks.

Gardner and Herman (1990) pointed out that individuals accept trade-offs in making an assessment of the risk they are willing to accept. They suggest that even people who are well informed about AIDS are willing to exchange a slight increase in exposure in return for immediate pleasure or reward. (An example of this in a different venue is the risk people take of an increased chance of a fatal accident due to speeding in order to save time or avoid the frustration in traveling.) Rational risk assessment theory assumes that it is plausible to socialize people to risk avoidance. However, the conditions for success require a minimum amount of uncertainty (Gardner & Herman, 1990). The long period currently existing between the time of the risky behavior and knowledge of its outcome is a particular problem. This time lag prevents women (and men) from knowing with confidence whether they have risked with impunity or not. Obviously, some solutions to the crisis lie in the hands of medical researchers. They might develop more efficient, speedy (even self-administered) tests, as well as improvements in contraceptive devices.

When gay men were found at greater risk, research demonstrated that safe sex practices and sex education could and did lessen the risk. For women, attention has also been directed at safe sex. Yet, most intervention

programs have been ineffective in increasing the use of condoms (Grimley, Prochaska, & Prochaska, 1997). In part, the failure may be due to information and materials not reaching the at-risk people. Perhaps new strategies, not just old ones reapplied, must be developed. For example, the campaign against breast cancer aggressively recruited women from across the nation to convey the messages about self-examination and mammograms. (One new strategy was to provide information to women in beauty shops.) Similarly, there needs to be a concerted effort to enlist and inform women of color about the strategies needed to protect them from HIV/AIDS.

The media continues to be a very effective way to alert masses of people, but a well-targeted campaign directed at women has yet to be developed. Although attention has waned and the public feels little concern or affinity with the disadvantaged people who are now the predominant victims of AIDS, psychologists may offer strategies for bringing this message to light. Of course, without political clout or wealthy financial backers, ethnic minority communities, particularly women of color, are often dependent on an agenda determined by others who may or may not see this an issue of importance. Again, the role of psychology may be paramount in developing the justification and the motivation for public sympathies and assistance. In the case of women of color, this opportunity may be reclaimed by addressing not only the issue of women's roles in all communities, but also by helping to redefine the problems that women face as low-status players in a national health crisis.

It seems clear that culturally sensitive researchers, as well as those who understand the needs and behavior of women, are greatly needed to insure that the perspectives of the community are being addressed and their values respected. Ethnic minority communities have a history of exploitation by health care professionals, so unfortunately the medical centers that should be the front line of information and support may not offer the most effective advocates. Women of color, in particular, have been stereotyped and misrepresented. The distrust aroused by majority workers cannot be overlooked; thus women of color must be encouraged and enabled, as in this special journal issue, to play a more active role in determining the directions for meeting the needs in their own communities.

The role of majority social science theorists, researchers, and practitioners can be of significant use in encouraging this self-determination. They can also avoid being misled in their interpretations of the behavior of African American women, Latinas, and others of color by reexamining their own perspectives and values. They can reject the stereotypic conceptualizations focused on romantic, lascivious, and/or irresponsible women. Instead psychologists and other social observers might develop more complex theoretical and practical understandings of the choices available to poor women and

women from ethnic families. Such understanding would move beyond the individual to include the social structure of the community and even the broader dynamics of systemic factors in the economic and political environment.

Community organizations could be charged with helping to develop strategies to aid in such efforts. Institutions that have been effective in organizing women of color for other issues could also be enlisted as advocates. This would include churches, sororities, and a wide variety of women's organizations. Finally, as we study women and the relationships that may lead to infection with HIV, we can ask, What does love have to do with AIDS? Are women of color really prepared to trade their well-being for a sexual relationship? If so, we must seek out the answers to what makes that choice seem reasonable and how to make it seem less so. If not, we must make clear the risk factors, realistic levels of probability, and the routes to alternative choices. In addressing the issues of AIDS prevention, it could be concluded that personal relationships and love do not have as much to do with the level of incidence in ethnic communities as do status, power, and information.

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