Commentaries

Human Rights Is a US Problem, Too: The Case of Women and HIV

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A B S T R A C T

Overall, US AIDS incidence and mortality have shown significant declines since 1996, probably because of new antiviral therapies. For women, however, these benefits have been much less pronounced than for men. At the heart of women's HIV risk is gender-based discrimination, which keeps women, and especially women of color, poor and dependent.

Although human rights issues are often linked with AIDS issues abroad, in the US they receive insufficient attention in our response to women's HIV risk. Advocacy from public health professionals is needed to overcome the longstanding paternalistic attitudes of federal agencies toward women and to change the paradigm of women's HIV/AIDS prevention and care. Examples of unjust and punitive social policies that may affect women's HIV risk include the 1996 welfare policy legislation, drug treatment policies for women, and women's access to medical research and technology.

The overriding public health response to AIDS consists of behavioral interventions aimed at the individual. But this approach will not successfully address the issues of women with AIDS until efforts are made to eliminate society's unjust and unhealthy laws, policies, and practicies. (*Am J Public Health*. 1999;89:1479–1482)

The end of 1996 brought us optimism about the US AIDS epidemic in the form of new HIV therapies that stalled the onset of AIDS. The overall annual incidence of AIDS decreased by 6% that year.[1] But behind the widely publicized overall population curve showing a clear downward turn lay the divergent—and much less publicized—effects among those whose HIV infection rates have in fact been greatest throughout the 1990s: the poor, persons of color, and women. In 1996, annual AIDS incidence and mortality for men dropped 8% and 26%, respectively, while for women, incidence rose by 1% and mortality dropped by only 12%. Between 1995 and 1998, the incidence of AIDS was reduced by 38% in men but only 20% in women—making gains among women only about half those among men.[1–3]

At the heart of these diverging epidemic curves is the issue of medical access for US women infected with HIV, the vast majority of whom are poor.[4,5] Moreover, 81% of women recently diagnosed with AIDS are Black or Hispanic. Nationwide, a third of Black women head single-parent households and half of the Black children in these households live below the poverty line, making these the poorest population subgroups listed by the US Census.[6] Medical access issues in the developing world routinely make headlines—most recently, debates over a reduced zidovudine (AZT) course to decrease the vertical transmission of HIV—but in the United States, this problem has received scant attention. The same invisibility that plagued the first US women to develop AIDS in the 1980s—when women "didn't get AIDS"—continues now for tens of thousands more, nearly 20 years into the epidemic.

Although drug use can be considered to have driven the epidemic of the past decade, the pivotal role of sexual transmission for women, as female partners of drug users, has until recently been consistently underrecognized at the national level.[7,8] AIDS case reports, which hierarchically classify the inferred mode of HIV exposure, place heterosexual sex only after other major AIDS "risk behaviors," ensuring that it will be the most likely to be underestimated. Instances of women who inject drugs—always with their own needle (which they never lend to anyone) or with a new needle—but contract HIV through sex with their partner are routinely entered into AIDS databases as cases *due to injection drug use*. Despite this relationship of inferred to real risk (accounting for an AIDS case), many validation studies on AIDS statistics have sought to corroborate risky sexual behavior, while few have sought to corroborate inferred exposure to HIV through risky drug practices. Moreover, AIDS case reports are likely to be incomplete; identifying one HIV "risk factor" considerably dampens enthusiasm to search for others. The lack of immediate and sustained attention to heterosexual risk in the epidemic's early years has had dire consequences for women, since to effectively change the nature of these risks requires a long-term national commitment to overturn formidable societal traditions, practices, and policies that are harmful to both men and women.

Changing the Paradigm: HIV, Women, and Human Rights

Women's rights have always been directly tied to the level of their health and well-being, just as, more broadly, human rights are inextri-

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cably linked to public health.[10,11] Laws and policies controlling access not only to contraception, abortion, and information on sexuality but also to education, property and divorce rights, and employment can either undermine women's autonomy and health or, in the words of the recent International Conference on Population and Development, empower women to become "full and equal members of society."[12] The actions (frequently but inappropriately reduced to the term "behaviors") required to block the spread of HIV cannot be divorced from the context of sex inequality and its ensuing dependencies, power imbalances, and threats of violence—in short, the effects of women's status worldwide as second-class citizens. A recent survey found that the prevalence of HIV was more strongly associated with poverty than was infant mortality,[13] a traditional public health indicator and one keenly sensitive to women's societal status.

Yet, despite the universality of issues confronting women, and their recognition in other parts of the world, the nature of US prevention programs has not changed substantially. Advocates' attempts to inject urgency into this country's response to the issue of women and AIDS, and to change the paradigm of our national response toward AIDS, have most often been met with bureaucratic indifference. As a consequence, we now register alarming increases in the prevalence of HIV/AIDS among poor women. Many studies have found that for drug users, the prevalence of HIV among women exceeds that among men and greatly exceeds that among men who have sex with men.[14–16] Annual incidence rates reaching 4%—similar to those found in Brazil and some African countries—are now found in some US research cohorts of women at high risk of HIV infection from crack or injection drug use and sexual behavior.[17]

Public Policy and HIV/AIDS in Women

In this issue of the Journal, Wise et al.[18] look at the potential impact on reproductive health of the 1996 welfare legislation, the Personal Responsibility Work Opportunity and Reconciliation Act (PRWORA), which is up for renewal in 2002. The ways in which they indicate that the 3-year-old policy might affect certain key reproductive health indicators include through changes in the social conditions of women, the imposition of work requirements, and diminished access to health care. A similar research agenda—one concerned with the effect of welfare policy on HIV/AIDS outcomes for women—is crucial if we hope to amass a diverse and compelling body of evidence to advocate effectively against these and other punitive and unjust social policies.

How could welfare policy have an impact on the HIV/AIDS epidemic among women? To Wise and colleagues' list of potential pathways, I would add the effect on women's autonomy per se. Although defining autonomy across disciplines will pose a methodological challenge, it is clear that by increasing or decreasing a woman's overall autonomy—or, conversely, her reliance on a male partner(s)—welfare policy directly affects HIV incidence. Raising a woman's prospects of education, job training, or employment and providing free child care will better equip her to leave a risky or harmful relationship, to enter drug treatment, or to insist on use of condoms even when the consequences are the loss of a relationship. On the contrary, a social policy that effectively reduces her autonomy not only compromises her potential contribution to society but also is likely to increase the rate of HIV infection. Moreover, it will increase the incidence of AIDS by decreasing women's access to (and time for) effective HIV therapies (or therapies to reduce the risk of vertical transmission), especially those with complex regimens, which are challenging even to persons with a lot of leisure time.

Previously, welfare provided one of the few options for battered women to establish an autonomous, safe life for themselves and their children, especially in view of increasing evidence that poor women may be more likely to be abused than their middle- or upper-class counterparts.[19] The effect of the new welfare law will be to potentially increase the number of women living in serious danger of assault, rape, HIV and other sexually transmitted disease infections, and death. Furthermore, under the harsh stipulations of PRWORA, by which women risk losing their children if they work and losing their work if they tend to their children, dependence on a partner with income, regardless of whether he is violent or involved with drugs or whether his income is generated legally becomes perhaps the only rational solution. Jeopardizing this relationship by demanding that the partner use condoms is completely out of line with a woman's strategic interests. Furthermore, under PRWORA policy, time will become increasingly unavailable for women's own health care needs and those of their children[20]—not to mention for education, job training, or drug treatment programs.

Numerous related social policies, also punitive in their response to poor women's needs, have a direct impact on risk of HIV infection. An example is in the area of drug treatment and women, where treatment sites that accept women, and especially pregnant women, are still severely limited in number. As a further disincentive to women's rehabilitation, many states take custody of the children of drug-addicted women who are seeking treatment. Finally, very few women-oriented treatment models are available.

Access to Medical Care, Research, and Technology: Regulatory and Prevention Policy

It is in the area of access to medical care, research, and technology, however, that the contrast between the gains of the gay male advocacy community of the 1980s and those of advocates for poor women of the 1990s may be most apparent. Studies comparing rates of health care utilization by HIV-infected women and by uninfected women at high risk of HIV infection reveal higher rates of primary care and routine gynecologic visits for the HIV-infected group,[21] another measure of how primary prevention is failing. But care of HIV-infected women, many of whom are isolated and without adequate time or social support to seek care, is still thought to be highly inadequate, a contention bolstered by earlier analyses of access to monotherapy.[22] A recent study showed that actual implementation of the PACTG 076 (perinatal AIDS clinical trials group) guidelines aimed at reducing transmission of perinatal HIV is limited for women who are not connected to health care institutions, either as clinical study subjects or as recipients of methadone treatment.[23] From here, it is an easy leap to the inference that many HIV-positive women are still not receiving the benefits of antiretroviral treatment.

Furthermore, even for women who have health insurance and seek care, there is evidence of discrimination in the more aggressive treatment for the terminal stages of the disease available to men than to women.[24] Are these disparities due to perceptions of women as too "delicate" or "fragile," an image that we as women have historically battled to obtain our proper rights and opportunity? Or is this triaging directly related to the assessment of what a woman's life is worth? The well-organized and well-funded efforts of gay men in the 1980s improved access to unapproved or foreign HIV/AIDS treatments, expanded conventional notions of clinical trials, and helped create antidiscrimination policies and laws. In the present epidemic, those most directly affected are women of color, politically powerless women, and women busy resisting America's "war on the poor."[25] The role of public health

workers as advocates for poor women has become central.

Paternalism and Women's "Fragility"

Even advocates' most modest demands have fallen largely on deaf ears; one of these demands is to expand research on and access to barrier methods other than the male condom that could help women reduce the risk of HIV infection.[26] But the tone of federal public health prevention messages—like that of current welfare policy—is punitive and rigid. These messages insist that women convince men to wear male condoms 100% of the time or refuse sex; failure to do both—although this is more the rule than the exception, especially among women at greatest risk of HIV infection[27]—is not even taken into consideration. Lack of adequate contact between the policymakers and the women at greatest risk of HIV infection creates a void of ignorance about the real context of women's risk. Because the void is often filled with notions that are more fantasy than fact, women are effectively abandoned by national agencies charged with helping them stay healthy. These women thus pay daily in new HIV infections for social policies that have made it extremely difficult for them to leave a noncompliant or violent partner.

The female condom, whose potential to reduce the risk of HIV infection has been grasped by international agencies like the World Health Organization as well as organizations in many developing countries, receives little backing either financially or ideologically by federal public health agencies and their prevention campaigns. Where leadership *is* shown in using this new protection technology—whose acceptability, studies show, is greatest among women at highest risk of HIV infection—is at local levels.

Although a prevention philosophy based on harm reduction (which maximizes flexibility by giving choices in protection, ordered from most to least efficacious) has been successfully used to minimize drug-related risks, key federal public health agency figures responsible for funding research and setting policy, at both the Centers for Disease Control and Prevention and the National Institutes of Health, reject this approach for safer-sex messages. Some charge that sexual harm reduction counseling is unethical, but the ethics of providing women with *no* choices in protection never enters the debate. As a result, clarification of the role of existing women's barrier methods (like the diaphragm and spermicides) in preventing HIV infection is at a virtual standstill, beset by political and personal battles at the highest levels. Although federal regulations do exist to "fast track" the approval process of the Food and Drug Administration (FDA) for new barrier methods that might reduce women's risk of infection from HIV and other sexually transmitted disease,[28] they have been ignored for 10 years. Research on potential vaginal microbicides to prevent HIV infection is likewise moving along with no sense of urgency, reflecting the same historical preoccupation with women's "fragility." In stark contrast to the strategy of gay men in the epidemic's early days—to get *some* AIDS treatment on the market, even if it was not perfect—is the continuing preoccupation of those funding current microbicide work to identify the "ideal" microbicide.

Complementing the preoccupation with women's fragility is an all-too-familiar paternalism affecting work in this area, which holds that women cannot understand "too much" information and that they are inept when it comes to the use of devices, in this case devices that require touching their genitals. These themes permeated FDA hearings on the female condom earlier this decade, where expert committee members expressed serious doubts about poor women's ability to insert the device. This same skepticism was apparent in FDA hearings on the contraceptive cervical cap in the 1980s, and it is now reborn in the federal response to providing women's barrier methods as options for HIV sexual risk reduction.

With HIV prevention policy and research strongly influenced by notions of women's fragility and their tendency to become easily confused, women are literally "protected to death." Would those setting policy ever tolerate similar restrictions on their information or options and limitations on their autonomy to act, particularly when the stakes were so high?

The Need for an Ecologic Public Health Response

Considering the abounding evidence of structural obstacles preventing women, and especially poor women, from staying uninfected with HIV, it is noteworthy and disturbing that the US public health response has been confined largely to behavioral approaches, rather than community empowerment[29] or other ecologic[30] approaches. The meager funds that exist to prevent HIV infection are spent mainly on interventions driven by a limited set of behavior change theories, which have been repeatedly criticized for not being an appropriate or adequate response to the context of women's HIV risk. The goal of these interventions is to improve a woman's "self-efficacy" for practicing HIV protective behaviors. Influencing "culture" and society per se (and its racism or sexism) is seen as outside the domain of current behavior models.

No one would argue against efforts to strengthen women's ability to cope with societal injustice, seek out healthy choices from among the choices available, and stand up for the respect they are due in relationships. But as the mainstay of a public health movement to reduce a woman's risk of HIV infection, these efforts are wholly inadequate. A concerted public health effort is now needed to attack the institutions, customs, laws, and policies—or, in the words of Jonathan Mann, "societal risk factors"[31]—that restrict a woman's autonomy.

Recognition of the need for an ecologic framework in our response to HIV/AIDS may be part of the necessary paradigm shift for work in the AIDS field, but why should AIDS once again be "exceptional"[32] in this regard? The historical mission of public health has been to target the underlying cause of disease more than the causes in individual cases.[33] The public health community's responses to problems of tobacco, violence, and diet have all involved multilevel interventions. The tremendous success of the movement to reduce tobacco-related morbidity and mortality can be traced to a steady emphasis on regulatory and economic interventions, in addition to workplace smoking restrictions and educational efforts. In retrospect, it is clear that attempts to create new community norms about smoking, as a single strategy, were doomed to failure in the context of the tobacco industry's advertising budget, estimated at $3.9 billion annually in 1993.[34]

Conclusion

Voices calling for wider-than-individual approaches in the US HIV/AIDS prevention paradigm, and citing the need for community-level interventions, signal a step in the right direction.[35–37] But true empowerment is achieved in tying community education efforts to the struggle for structural change.[38–40] Education and consciousness-raising by themselves have the capacity to augment despair if oppressive and harmful societal structures do not also change. A woman who learns to "say no" and to walk out of her relationship with a violent partner will be only as successful as society's policies of protection of battered women allow her to be. Drug-addicted women with children will have real access to rehabilitation only if treatment sites can accommodate those children. Finally, women who cannot yet leave harmful

relationships must have protection options available to boost their chances of remaining uninfected with HIV until they *can* leave.

Examples of a structural approach to HIV/AIDS from beyond our borders include the community organizing of prostitutes in Calcutta, where 30 000 women members of a collective demanded and obtained police protection from violence, created grassroots literacy projects, formed a financial cooperative, and pressured brothels to adopt uniform condom requirements for clients.[41] Other examples, targeting other ills, include efforts to instigate community policing against wife-battering in Peru[42] and the ability of Senegalese women, through community action, to overturn long-standing practices of girls' genital excision.[43]

Let us use these examples as inspiration in confronting AIDS in the United States. The business of public health, in fighting this epidemic, is the business of targeting unhealthy norms, attitudes, policies, and law, in culture and in society. For women, this work is vastly more important than targeting individuals, and it will bring long-term gains far beyond improved HIV/AIDS indices, not only in public health but also in its allied struggle, that for human rights. □

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