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Multiple Determinants, Common Vulnerabilities, and Creative Responses: Addressing the AIDS Pandemic in Diverse Populations Globally

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Abstract

The AIDS epidemic has been fueled by global inequities. Ranging from gender inequality and underdevelopment to homophobia impeding health care access for men who have sex with men (MSM), imbalanced resource allocations and social biases have potentiated the epidemic's spread. However, recognition of culturally specific aspects of each microepidemic has yielded development of community-based organizations, which have resulted in locally effective responses to AIDS. This effective approach to HIV prevention, care and treatment is illustrated through examples of community-based responses in Haiti, the United States, Africa, and other impoverished settings.

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INTRODUCTION

The AIDS epidemic has been fueled by global inequities. Ranging from gender inequality and underdevelopment to homophobia impeding health care access for men who have sex with men (MSM), imbalanced resource allocations and social biases have potentiated the epidemic's spread.[1–3] However, recognition of culturally specific aspects of each microepidemic has yielded development of community-based organizations, which have resulted in locally effective responses to AIDS. Successful responses have often grown out of community engagement with vulnerable populations, a shared sense of purpose by a committed cadre of change agents, and creative interactions with civil society, governments, and the international donor community. Clear understandings of how the epidemic was being expressed in each affected population, resulting in successful local mobilization, informed the case studies below. Strong community-based responses to the pandemic have also had wider applicability, by creating new institutions capable of dealing with other health care crises and underdevelopment and by confronting misogyny and homophobia, which decrease access to care. Thus, acute responses to AIDS by groups as diverse as Haitian physicians, gay and feminist activists in the United States, and local nongovernmental organizations focused on family health in lower- and middle-income countries have matured into multiservice institutions that deal with a wide set of related issues, including social justice, nutrition, and primary health care, as well as human rights for racial, ethnic, sexual, and gender minority populations.

COMMUNITY RESPONSES TO POVERTY AND MARGINALIZATION IN HAITI

In 1980, while developing a program for children with acute diarrhea at the State University Hospital in Port-au-Prince, Jean (Bill) Pape was called to see cases of adult male patients with severe, unresponsive, chronic diarrhea and wasting. Other colleagues noted increases in young adults presenting with Kaposi sarcoma and *Candida esophagitis*. On May 2, 1982, along with other Haitian health professionals, Pape and his colleagues formed the Haitian Group for the Study of Kaposi's Sarcoma and Opportunistic Infections (GHESKIO) in collaboration with Cornell University and the Haitian Ministry of Health.

Although originally formed to study the epidemiology, clinical features, and treatment of HIV/AIDS and related infections,[4–7] GHESKIO has since become a cornerstone in the implementation and evaluation of HIV prevention and care in Haiti. Today, the country has 176 HIV testing centers and 86 antiretroviral therapy clinics. GHESKIO directly treats or supervises 50% of HIV-infected patients nationwide and is the largest provider of TB services, treating more than 1,200 patients for TB each year.[8] GHESKIO has also been instrumental in bolstering HIV care and treatment following the 2010 earthquake. Thus, from an isolated community-based response to a single infectious pathogen, GHESKIO has created a model for the delivery of comprehensive and integrated services to a wide array of disenfranchised Haitians.

Another model of community-based health care delivery has been developed by Partners In Health (PIH), which started providing antiretroviral therapy to patients living with HIV/AIDS in rural Haiti as early as 1997. *Accompagnateurs*—as community health workers are called in Haiti—were the backbone of the PIH approach then and remain so to this day. Trained and stipended, *accompagnateurs* provide directly observed therapy and

"wraparound" services—from helping patients pay for transportation or day care to offering psychosocial support to diagnosing and treating TB, sexually transmitted infections, and opportunistic infections (OI).[9] PIH also applied this model to the HIV Equity Initiative, a groundbreaking program to provide free comprehensive HIV care and treatment in impoverished settings. The results were promising: treatment outcomes were as good as anywhere in the world with high adherence and sharp reductions in mortality and incident OI; only 6% of patients required a change in regimen.[10] A number of PIH AIDS patients began working as *accompagnateurs;* many still do.

Today, PIH serves some 2.4 million patients in more than 76 health facilities in 12 countries in the Americas, sub-Saharan Africa, and the former Soviet Union, and compensates close to 15,000 staff, almost all of them working not far from where they grew up. In every country, PIH uses the same care delivery model, built on strong partnerships with local governments, institutions, and communities, and above all, on *accompagnateurs,* who have adapted programs to local challenges and competencies—to help improve health outcomes and raise the standard of care available to the poor and marginalized.

ADDRESSING BLACK WOMEN'S VULNERABILITIES TO HIV LOCALLY AND GLOBALLY

Globally, women and girls represent more than half of those living with HIV/AIDS.[11] For women of African descent who are living with HIV/AIDS, the common causes of vulnerability far outweigh regional and national differences. African women continue to disproportionately represent more than half of the HIV/AIDS cases in sub-Saharan Africa, and similarly, African American/black women, especially those in the South, represent two thirds of all women living with HIV/AIDS in the United States.[12] Many of the social and structural drivers that contribute to the unique vulnerabilities of black women are the same regardless of geography, culture, and sociopolitical environments. In the United States and in sub-Saharan Africa, women's vulnerabilities to HIV and AIDS are driven by poverty and economic dependence, violence in conflict and nonconflict situations, limited access to sexual and reproductive health services, and multiple stigmas associated with sexuality and sexual health issues, especially HIV and AIDS.[13–16]

SisterLove was developed as a culturally specific response to the AIDS epidemic for southern black women, using group support and skills building to help empower women to make safer choices for themselves. Working with communities of the most vulnerable women in Atlanta, Georgia, SisterLove has developed innovative, evidence-informed, community-based interventions that address HIV prevention, HIV-related stigma, and treatment adherence. In recent years, SisterLove has expanded its mission, partnering with community leaders and furthering its work in South Africa. Although originally founded as a local response, SisterLove exemplifies how a local response specific to one locality can evolve into one that influences the discourse about sex roles and economic power in other nations.

GAY MEN'S RESPONSES IN DEVELOPED COUNTRIES

Because MSM in urban centers in the United States and Europe were among the first individuals to be identified with AIDS and soon saw severe devastation in their communities, they developed some of the earliest community-based responses to the epidemic, launching the Gay Men's Health Crisis long before the US government provided any funding for supportive services. The perception that antiretroviral drug development and clinical trials were proceeding too slowly, given the gravity of the health emergency, led gay

activists to create the AIDS Coalition to Unleash Power (ACT UP), which became a model for health care advocacy globally.

Specialized centers of excellence have also been developed to address the unique clinical needs of MSM and other sexual and gender minority patients. Leading examples include: Fenway Health in Boston (www.fenwayhealth.org),[17] the Albion Street Clinic in Sydney, and multiple centers in Europe, Canada, and other settings in the developed world.

Despite these advances, HIV continues to spread rapidly among MSM in the United States, Europe, and other developed countries.[2,3,18] Part of the disproportionate spread is biological (ie, anal intercourse is a much more efficient means of HIV transmission than heterosexual sex[19]), and part is behavioral: Some gay men have more sex partners than other people and may meet partners in settings that facilitate rapid spread of HIV (eg, bath houses and sex parties). Structural factors also facilitate the spread of HIV among MSM (ie, in growing up in a heteronormative society, the childhood of MSM and other sexual and gender minority youth is usually stressed by increasing self-awareness of being different and not conforming to societal ideals).

Prevention interventions for MSM should help individuals address their personal challenges by providing culturally tailored mental health and substance use treatment (which have been shown to be more effective than using approaches designed for the general population.[20] But individual approaches have their limitations if root causes of social stress are not addressed; homophobia and institutional barriers to optimal care must be thought of as part of the "prevention package."

ADDRESSING HEALTH DISPARITIES OF BLACK MSM

Although black MSM represent less than 1% of the US population, they constitute more than 25% of those who are becoming infected with HIV.[18] Data suggest that assortative mixing (ie, having more black MSM partners than partners from other racial/ethnic groups) causes delays in accessing services for HIV and sexually transmitted infections in environments perceived to be homophobic and/or racist and has played a major role in concentrating the epidemic among black MSM.[21–22] Black MSM are more likely to enter care with more advanced HIV infections as well as with untreated sexually transmitted infections, resulting in a therapeutic response that is less robust and a greater likelihood of transmitting HIV to a greater number of partners during the period the infected MSM were unaware of their HIV status. Coupled with the economic disenfranchisement of many black MSM, experiences of racism in the majority gay community and homophobia in the black community may further exacerbate alienation from the health care system.[23–24] Culturally tailored programs are needed to encourage trust and engagement and to facilitate the willingness of black MSM to be tested, treated, and stably linked into care.

Community-based responses to deal with the disproportionate AIDS epidemic among black MSM have included national initiatives, such as the Black AIDS Institute (www.blackaids.org), as well as highly localized efforts grounded in minority-based institutions such as the Multicultural AIDS Coalition in Boston (www.mac-boston.org).

In an effort to bolster research about black MSM and HIV/AIDS, the National Black Gay Men's Advocacy Coalition (NGBMAC; www.nbgmac.org) and the Black Gay Research Group (BGRG; www.thebgrg.org) have facilitated dialogue with the National Institutes of Health (NIH) and with academic and public health researchers, and have educated local communities, resulting in new research collaborations such as HPTN 061, an NIH-funded study of the social and sexual networks of black MSM, including an assessment of the role

of peer health system navigators[25] in linking at-risk and infected black MSM with the necessary clinical, prevention, and social services needed for healthy living.

EMERGING RESPONSES TO GLOBAL MSM

Although MSM were the first group to be recognized with AIDS, the focus of epidemic control has centered on heterosexuals in the developing world because of the disproportionate disease burden in the general populations of many sub-Saharan African countries and the misperception that the only HIV-affected MSM were urbanized gay men living in resource-rich settings. However, improved surveillance has documented that in many parts of the world, HIV prevalence among MSM is greater than in the generalized epidemic or for other populations at high risk of acquisition of HIV infection (eg, female sex workers). In low- and middle-income countries, HIV prevalence in MSM has been estimated to be more than 19 times greater than in the general population.[1] Geographically, disproportionate numbers of MSM exist in Latin America (eg, Mexico), the Caribbean (eg, Jamaica), Asia (eg, Thailand), and some parts of Africa (eg, Senegal). More than half of the people living with HIV in Latin America are MSM, and MSM constitute the majority of people with HIV in several Asian countries as well as a substantial minority in several African nations, nations that have hitherto focused on their heterosexual epidemics.

Over the past few years, several remarkable changes have provided hope for the future of HIV prevention for MSM in lower- and middle-income countries. Starting with South Africa, full civil enfranchisement of MSM offers new opportunities to provide direct prevention messages that engage MSM to increase HIV testing, enrollment in care, and treatment. The advances in civil rights have been accompanied by increased recognition of donor programs, such as the United States President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, Tuberculosis and Malaria, that MSM are a key population requiring focused resources worldwide. Local clinical initiatives, such as the Men4Heath Ivan Toms Clinic in Cape Town, the Silom Clinic in Bangkok, Transgender health services inside Condesa Clinic in Mexico City, and IMPACTA in Lima, have responded to MSM needs for culturally sensitive programs to facilitate their engagement in care and research. Also recently, the US-based AIDS Healthcare Foundation has shared its Men's Wellness Centers model internationally, in settings such as Zona Rosa in Mexico City and Guayaquil in Ecuador.

Other countries have started to follow some of these examples, although only when given international grants to do so. Despite increasing resources focused on MSM in the global epidemic, enhancing access to health services will not immediately result in decreased HIV incidence, since services and laws do not mitigate social stigma and homophobia overnight, and in high-prevalence settings, it will take time for incidence to drop meaningfully. Nonetheless, these changes, together with increased access to HIV testing with effective linkage to ART for HIV-infected MSM, augur well for a future in which the epidemic will be attenuated among MSM across the globe.

CONCLUSIONS

Despite the different circumstances resulting in concentrated HIV epidemics in many parts of the world, some common themes have emerged. Addressing poverty and underdevelopment, which can help decrease the spread of HIV infection and which needs to be integrated into any epidemic control strategy. Hungry people may be less inclined to worry about safer sex if condom use is not incentivized. Programs that enable people to survive HIV with antiretroviral therapy but that do not address concomitant local communicable diseases will not enhance human development and are unlikely to be

successful in arresting local epidemics. Fortunately, increasingly, international donors are recognizing the complexities of HIV, whose spread is fueled by social inequalities and the disenfranchisement of vulnerable populations. International donors are also responding to the epidemic's challenges with integrated programs that address structural and communal issues as well as broader health concerns. Respect for the autonomy and rights of women and sexual and gender minority persons are also essential if the epidemic is to come under control. Although the toll that it has exacted is terrible, it has also forced formation of new coalitions, and their creative responses have led to new models for care delivery and new understandings of the importance of respect for human rights as a cornerstone of public health practice.[26] The work is ongoing, and hopefully, we will continue to learn from each other in order to ultimately check this challenging scourge.

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