Understanding the Promise: Considering the experiences of women living with HIV to maximize effectiveness of HIV prevention technologies

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Abstract:

The United States' HIV response was designed primarily to meet the needs of single men without dependent children and its prevention strategies focused primarily on individual behavior change with little attention to the social, cultural and economic factors fueling HIV risk, especially among indigent and marginalized women. In 2012, the President's Advisory Council called for an updating of the National HIV/AIDS Strategy's Implementation Plan to "achieve specific, targeted and measurable goals for reducing HIV incidence and... improving health care access and health outcomes for women living with HIV."

Women living with HIV and those at highest risk of HIV generally live side by side in the same communities and under the same conditions, separated in status only by a positive HIV test and its consequences. Thus, women openly living with HIV constitute an identifiable and accessible source of first-hand information regarding the barriers that keep women out of HIV prevention and care. Their insights, rooted in lived experience, can vitally inform the development of realistic HIV prevention goals and strategies for the successful integration of HIV prevention into the services already accessed by high-risk women. Their expertise, however, is largely untapped.

In this article, women living with HIV summarize the substantial deficits that exist with regard to woman-focused HIV prevention efforts nationally and the policy and practice changes needed to reduce the domestic impact of the HIV epidemic on women and girls. They also outline opportunities for movement in this direction as implementation of the National HIV/AIDS Strategy proceeds.

HIV prevention research and campaigns in the U.S. focus primarily on men who have sex with men (MSM). Yet women living with and at high risk for HIV also have primary and secondary HIV prevention needs. In 2012, the HPTN 064 ISIS study (Hodder et al., 2012) demonstrated that in parts of the US, women were experiencing HIV incidence rates similar to those found in the Democratic Republic of Congo and Kenya, rates five times higher than previous estimates of HIV incidence among Black women calculated by the US Centers for Disease Control and Prevention (CDC). The
study also showed substantially lower rates of condom use among its participants than among the
general U.S. population. Despite this compelling evidence that a domestic women-focused HIV
prevention effort is needed, the first-ever US National HIV/AIDS Strategy (NHAS) failed to address these needs meaningfully.

In the US, the HIV response was originally designed to meet the needs of single men without
dependent children. Its approach to prevention still focuses chiefly on individual behavior change
(condom use, reduction in number of sexual partners, etc.) and tacitly assumes individual control
over sexual decisions. Women’s HIV risk, however, is predicated on structural and societal factors
that often preclude control over when and how sex occurs and whether a condom is used
(Pulerwitz et al., 2002, 2010). Although women account for approximately one in five new HIV
infections in the US, (Kaiser Family Foundation, 2013) HIV prevention efforts targeting women were
largely unaddressed by the NHAS. The focus is sufficiently androcentric that the President’s Advisory
Council on HIV/AIDS (PACHA) issued a 2012 resolution (President’s Advisory Council on HIV/AIDS,
2012) calling for revisions to the NHAS Implementation Plan that would include metrics to measure
progress in reducing new infections among women and girls.

US-funded programs in countries where women bear a disproportionate burden of the HIV epidemic,
such as the President’s Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight
AIDS, Tuberculosis and Malaria (GFATM) actively support innovative prevention approaches for
women. This article, informed by the expertise of women living with HIV, discusses how the NHAS
could more effectively address women’s prevention needs domestically. As Laurel Sprague of the
Global Network of People Living with HIV (GNP+) explains, “People living with HIV know better than
anyone where the current programs fall short, where prevention programs fail, what social support
works and what doesn’t…” (Sprague, 2012)

**Background**

Most US women with HIV were infected through heterosexual sex (The Henry J. Kaiser Family
Foundation [KFF], 2013). Socioeconomic factors (including poverty, limited health care access,
stigma, intimate partner violence) that hinder HIV prevention efforts among women also inhibit
access to testing and subsequent HIV care and treatment (Amaro, 1995).

Thus, the demographics of women living with HIV and those at highest risk of HIV describe a
single population divided only by receipt of a positive HIV test – predominantly poor and
predominantly women of color. In a study looking at the ten urban areas with the highest domestic
HIV prevalence, 71% of women with HIV were Black (CDC, 2011). Of all ISIS participants
(selected because of their elevated HIV risk), 88% were Black. (Hodder et al., 2012) Also, 44% of
participants had incomes below $10,000 annually. (Hodder et al., 2012)

This pattern of female HIV acquisition matches global patterns. In 2012, the UNDP’s Global
Commission on HIV and the Law observed that 98% of all HIV-positive women live in developing
countries and most of the 2% living in developed countries are poor (UNDP, 2012, p. 62), adding
that poverty, gender inequality and gender-based violence “undermine women’s and girls’ ability to
protect themselves from HIV infection and cope with its consequences.” (UNDP, 2012, p. 8)

To maximize effectiveness for women, HIV prevention efforts must shift from an emphasis on
changing individual behavior to changing the social and structural realities that fuel HIV risk.
Founded in 2008, the Positive Women’s Network of the United States of America (PWN-USA)
advocates vigorously for this approach. Its members are women living with HIV, including
transgender women, of diverse age, race, ethnicity and socio-economic backgrounds. PWN-USA maintains that, without conscious movement toward HIV prevention, treatment and care that works for women and is accessible to women, neither domestic nor global HIV responses can succeed. (PWN-USA 2011, 2012)

What Women Need

“Until we change redefine vulnerability and change the social and economic context in which women live, work, play and love, we will fail to achieve prevention justice for women”


Because they come largely from the same communities as women at highest risk of HIV, women living with HIV are an identifiable and accessible source of expertise, capable of offering first-hand guidance in the design and implementation of HIV prevention research and programming. Adherence to anti-retroviral (ARV) treatment regimens, for example, results in viral suppression and effective secondary prevention. But a recent report by PWN-USA indicated that less of half of US women with HIV who are engaged in care have been counseled on the benefits of treatment as prevention. (PWN-USA, 2013) – indicating that stigma towards HIV-positive women’s sexuality may preclude effectiveness of secondary prevention efforts for women living with HIV. (PWN-USA, 2013)

The most immediate and effective routes to making HIV prevention work better for women include:

1. integrating HIV prevention and care services with screening and interventions for violence, trauma and sexual and reproductive health (SRH) services;
2. interventions to remove structural barriers that place women at risk; and
3. meaningful involvement and leadership of women living with HIV in setting the research and implementation agenda as biomedical prevention tools are developed and introduced.

These echo recommendations made by women living with HIV internationally. Over 800 women from 96 countries were asked in regional consultations to identify their “Top Priorities for Positive Change.” Respondents named “inclusive and holistic services” as their first priority in all regions (Athena Network documents - Virtual Consultation - HLM, 2011). Reducing violence in women’s lives appeared in the top four priority categories in five of the eight regions. HIV-positive women in South America noted that “[a]lmost no HIV prevention or care program is directed to reduce the vulnerability [sic] conditions in which women acquire HIV....” They add that “[l]inkages of HIV services that address sexual, physical and psychological violence are fundamental for women and girls.” (Women’s Priorities - Latin America, 2011)

The Global Network of People Living with HIV (GNP+) has further asserted that “[l]eadership of people living with HIV in NPT [New Prevention Technologies] research and development continues to be crucial, particularly now as scientists, researchers and advocates explore the possibilities of ARV-based prevention, specifically pre-exposure prophylaxis (PrEP) and some microbicides.” (Global Network of People Living with HIV, 2010)

Integrated Services

In discussion of HIV services, integration is defined as the “reorganization and reorientation of policies, programs and services to ensure the delivery of a set of essential interventions as part of
the continuum of care for HIV prevention, care and treatment.” (Hardee, Gay, & Dunn-Georgiou, 2009, p. 6). An optimal model facilitates delivery of multiple services to the same patient by an interdisciplinary team of providers – allowing for greater cost efficiencies, streamlined service delivery, and improved health outcomes, while reducing the odds of unaddressed needs progressing into health problems that undermine the value of the care provided. (Fleischman, 2012)

Because they often provide for children’s needs before their own, (Vyawaharkar, Moneyham, & Tavakoli, 2007), most women at highest risk of HIV have neither the time nor resources to access family planning services, HIV testing, and violence-prevention services in multiple settings. (Hackl KL, Somlai AM, Kelly JA, 1997). In 2010, fewer than 20% of the five million U.S. women who accessed publicly funded family planning services received HIV tests, a vital service omitted due to lack of a holistic approach (Fowler, CI, Lloyd, SW, Gable, J, Wang, J, and Krieger, 2011).

Similarly, providers may miss detecting health risks affecting women in abusive relationships if they fail to screen for intimate partner violence (IPV). Fewer than 10% of HIV service providers screen for IPV (U.S. Department of Heath and Human Services, 2009) despite evidence that women living with HIV are twice as likely to have suffered from IPV as the general population of women, and that trauma and violence lead to poor health outcomes among HIV-positive women (Machtinger, Wilson, Haberer, & Weiss, 2012).

Full implementation of the Affordable Care Act (ACA) in 2014 will bring many women better access to preventive health services including free HIV testing, violence prevention and counseling, and sexually transmitted infection (STI) counseling (U.S. Department of Heath and Human Services, 2012). However, sixteen state governors have indicated they oppose the ACA’s Medicaid expansion provision that would expand essential services to low-income women.(Kaiser Family Foundation, Nov 2013) Three of these states are among the ten highest in HIV incidence. (Kaiser Family Foundation, March 2013)

These domestic deficits are ironic given that the U.S. Agency for International Development (USAID)’s guidance directs PEPFAR program managers to integrate violence prevention and treatment services into their programming and notes that “[v]oluntary family planning should be part of comprehensive quality care for persons living with HIV” and access to it should be assured by co-location and/or strong referral systems to SRH care. (Office of the U.S. Global AIDS Coordinator, 2011)

To achieve such integration, providers will need funding to expand their capacity and cross-train staff. With training, staff can be equipped to appropriately discuss SRH needs, sexual and drug use behaviors, HIV risk or HIV care needs (if living with HIV), and violence in the lives of clients. However, funding for such training has traditionally been siloed rather than comprehensive, and is on a downward trajectory.

The White House Working Group on the Intersection of HIV/AIDS, Violence Against Women and Girls and Gender-Related Health Disparities announced its intention to i) increase training, capacity building, and technical assistance for providers to better equip them to provide services at this intersection, ii) increase outreach and education iii) integrate HIV testing and IPV screening services in health care settings, and iv) improve care and treatment provided to women with HIV who have experienced violence (Rosenthal & Colfax, 2013). Adding metrics and milestones measuring progress in this direction to the NHAS Implementation Plan would substantiate this commitment.

Half of all people with HIV in the U.S. reside in the southern states but only one-quarter of doctors
with HIV expertise practice there (Hiers & Valdiserri, 2012). In 2012, the US government established a 3-year, $44 million initiative to reduce “HIV-related deaths and related health disparities among racial and ethnic minorities” in the region by expanding uptake of HIV testing, care and prevention services (McAllaster, 2012). Many HIV-positive Southerners rely on physicians located 2-3 hours away. While tele-medicine may hold some promise to address these barriers, service integration would go further toward making care more widely available.

Another federal initiative, the 12-Cities Project, addresses HIV prevention objectives in impoverished urban areas across the country. Through the “Linkage to Life” initiative, grantee organizations identify “gaps in healthcare, social, and supportive services for high-risk families living with HIV/AIDS or at risk of HIV infection.” Addressing “system and service fragmentation,” grantees are then charged with establishing a resource network to meet clients' needs (ONAP, 2012).

**Women-specific HIV Prevention Tools**

Reliance on male condoms is problematic because many women risk violence, abandonment, and/or loss of housing when negotiating condom use, and because condoms are not a viable option for women living with HIV who want to conceive. Cicely Bolden’s murder by a partner following voluntary disclosure of her HIV status illustrates the violence women may face when voluntarily disclosing. (“Texas man confesses he stabbed HIV+ girlfriend to death,” 2012)

Prevention tools that afford a range of reproductive choices and can be used without a partner’s active involvement are key to correcting the gender-based inequality in HIV prevention. Microbicides, designed to reduce HIV risk when topically applied vaginally or rectally, are under development. The first microbicide may be considered for regulatory approval in South Africa in 2014 if research confirms its effectiveness. But US funding for microbicide research and development has been decreasing since 2010 and microbicides are mentioned nowhere in the 2012 NHAS Implementation Progress Report (AVAC, 2012) Long-acting biomedical HIV prevention tools that permit conception should also be explored for women.

Female condoms remain inaccessible to many women who need them. The number distributed in the U.S. tripled between 2010-2011 (Rubin, 2011), largely due to localized efforts promoting distribution in several major cities (Sun, 2012). Mathematical modeling showed that one such initiative in Washington DC prevented sufficient new HIV infections to save at least $12-$15 for each dollar spent on the program in future HIV-related health care costs (Holtgrave et al., 2012). The modelers concluded that, as one element of a comprehensive program, female condoms are “acceptable, effective and cost-saving.” (Terlikowski, 2012) Like microbicides, female condoms are not mentioned in the NHAS Implementation Progress Report.

The NHAS Update reports that multi-disciplinary technical consultations have been convened to "identify surveillance strategies and research agendas to better characterize the extent and burden of HIV/AIDS among [racial and ethnic groups] that represent a small share, nationally, of the U.S. epidemic...“ (ONAP, 2012) While these will undoubtedly provide useful information, surveillance strategies or research agendas regarding data on women, a much larger population segment, are noticeably absent. Sentinel surveillance and other tools are needed to collect accurate data on HIV among sex workers, transgender women, and other populations that have not been adequately counted.
Implications for Practice and Policy

Making the domestic HIV response more effective for women requires political will, as indicated above. Movement toward the integration of services essential to women is beginning and, with sufficient advocacy pressure, could accelerate as the Affordable Care Act is implemented. Similarly, persistent advocacy is required to expand and improve women’s access to a range of HIV prevention options. The following are additional areas in which substantive changes in policy and practice are needed. None of these are adequately addressed (and some, including sex work, are omitted entirely) in the current NHAS.

Access to women-centered substance dependency treatment

When drug dependency is treated as a crime rather than a public health issue, women are less likely to seek treatment for fear of losing their jobs, children and/or homes. Access to residential programs that meet women’s needs (such as childcare) are scarce and often of inadequate duration (Kumpfer, 1991). This makes it impossible for many women to get the timely, targeted and adequate addiction treatment they need to decrease HIV risk (Des Jarlais & Semaan, 2008) (“Women and Treatment | The White House,” n.d.).

Transgender health expertise

Transgender women’s HIV infections go undiagnosed twice as often (57% vs. 27%) as the national average, largely due to clinicians’ lack of competency in transgender health and the dearth of trans-friendly HIV testing sites and targeted programs (Sevelius, Keatley, & Gutierrez-Mock, 2011). The Federal Bureau of Health Professionals currently provides webcasts to its grantees to broaden their HIV professional training (ONAP, 2012). Webcasts by experts on transgender care should be included and funding for transgender-specific HIV prevention programs across the country expanded.

Decriminalize sex work

Criminalizing sex work dehumanizes sex workers, fosters neglect of their health needs, and undermines public health efforts. In many jurisdictions, police still use possession of multiple condoms as evidence of prostitution, forcing sex workers to choose between protecting themselves and risking arrest and/or prosecution (McLemore, 2012) (Turkewitz, 2012). These tactics endanger lives, violate human rights, and waste resources devoted to funding HIV prevention outreach services.

Adequate care and services for incarcerated women

The HIV risk faced by incarcerated women could be reduced by provision of job training, substance use treatment, mental health services, linkage to health care, and programs to maintain family and community ties (Kramer & Comfort, 2011) (Whitten, 2011). Simple steps such as initiating Medicaid enrollment prior to release could facilitate access to basic health care and prevention services. A cross-agency Re-entry Council has also been established to “address the myriad issues” faced by formerly incarcerated people living with HIV but its action is only likely to be useful if it results in investment in these essential services (ONAP, 2012).

Comprehensive sex education in schools

Nationally, 30% of youth (ages 13-24) living with HIV are female. HIV’s increasingly female face among youth is most common in areas with the least age-appropriate, comprehensive sex education-
39% of all Black and Latino youth with HIV in Mississippi are female (MSDH, 2011). (Comprehensive sex education is defined as a program that promotes both abstinence and the consistent use of condoms and other contraceptive methods among youth who are sexually active.) (Kirby, 2007). The President agreed to eliminate federal funding for “abstinence-only” sex education in 2009 but $50 million was allocated to abstinence only programs in 2010 (Rabin, 2010). Of the 30 states receiving this funding, 14 were in the southern U.S. (ONAP, 2012) (Haggerson, 2012).

Conclusion

The NHAS Update notes that the “CDC awarded $55 million over five years to 34-community-based organizations to expand HIV prevention services for young gay and bisexual men of color, transgender youth of color, and their partners.” (ONAP, 2012) This latter statement encapsulates the primary flaw in the NHAS. Women are more than partners and mothers of children. Women’s needs are not well served by plans in which they are present only by implication -- as “partners” and as members of “communities of color” but not as people with their own unique constellations of needs and rights. Additional research into new HIV prevention technologies that support realization of women’s sexual and reproductive health and rights, including freedom from violence, is urgently needed to ensure effectiveness of HIV prevention efforts for women. In addition, programs must be set up to accommodate the realities of women’s lives. These goals can best be achieved through: i) meaningful involvement of women with HIV in setting the research and implementation agenda for new prevention technologies and programs, ii) removal of structural barriers to access for women, and iii) integration of service delivery for sexual and reproductive health, HIV prevention and care, and violence intervention.

The clock is ticking. Every 35 minutes a woman in the US acquires HIV. This will not change until life circumstances for women at highest risk of HIV change and until our HIV prevention response changes to match their lives.

References


Author Descriptions:

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