An End to Perinatal HIV: Success in the US Requires Ongoing and Innovative Efforts that Should Expand Globally

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ABSTRACT

The dramatic reduction of perinatally transmitted HIV in the United States has been a striking success story in the HIV epidemic. Routine HIV screening during pregnancy followed by appropriate therapy has been extremely effective. This paper puts forth three strategies needed to maintain these gains and reach the goal of eliminating perinatal HIV: standardize medical interventions and policy changes that support perinatal HIV reduction; institute HIV screening in routine preconception care to identify HIV infection in women before pregnancy; and critically focus attention and resources on primary prevention of HIV infection in women. Healthcare providers should incorporate HIV prevention education and routine screening into women’s primary health care. Public health leaders should support and fund prevention strategies directed at young women. Successful approaches that have nearly eliminated perinatal HIV transmission in the United States offer valuable lessons that should be applied to primary HIV prevention for women in the United States and globally.

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The HIV epidemic has had few genuine success stories, but the dramatic reduction of perinatally transmitted HIV infection in the United States is one of them. At the peak of the pediatric HIV epidemic in the United States in 1992, over 945 children were diagnosed with AIDS. In 2005, the most recent data from the US Centers for Disease Control and Prevention (CDC) reported only 58 children newly diagnosed with AIDS (1). This 95% decline in pediatric AIDS is due in large part to a therapeutic intervention in which a pregnant woman with HIV and her newborn are given an antiretroviral drug, zidovudine (ZDV), to reduce the risk of transmission from the mother to her infant. With no antiretroviral treatment, the infant has a 25% risk of infection. When the mother and infant receive ZDV alone, the risk is approximately 8%, but with effective highly active antiretroviral therapy (HAART), in which multiple anti-HIV drugs are administered during pregnancy, the risk is less than 2% (2). In addition, HIV testing during prenatal care has become increasingly routine. As more women living with HIV learn of their infection during pregnancy, more receive treatment to improve their own health as well as to reduce the risk of transmitting HIV to their infants, further decreasing the number of children with HIV and AIDS.

In light of this success, the American media and even some in the maternal and child health and HIV communities have pronounced that HIV in children in the United States is a relic of the past (3). Public interest has moved from the domestic perinatal HIV problem to the global epidemic. While HIV/AIDS throughout the world – especially in limited-resource countries – deserves major attention and resources, should we be quick to turn our attention away from perinatal HIV infection in the United States and the factors that led to it in the first place? This paper presents strategies for sustaining our success in perinatal HIV prevention and stresses the crucial importance of building on these successes and supporting a proactive approach to HIV prevention in women.

The successful reduction and potential elimination of perinatal HIV transmission in the United States provides hope that, with adequate resources and attention, similar success is possible in other parts of the world. However, the US experience also provides
a cautionary note on the importance of viewing perinatal HIV prevention in the context of larger HIV prevention strategies if these gains are to be maintained. Three strategies need to be in place to continue our successes and reach the goal of eliminating perinatal HIV transmission. First, we need to institutionalize the medical interventions and policy changes that support reduced perinatal HIV transmission. Second, we should identify HIV infection in women prior to pregnancy; and third, we must focus seriously on reducing HIV infection among young women. While this article focuses on the experience in the United States, the lessons learned may be applicable in many parts of the world.

PERINATAL PREVENTION AS THE STANDARD OF CARE

Prenatal prevention activities are accepted as the standard of care in the United States, but we need to ensure that prenatal HIV testing is universal and that HIV testing during labor and delivery is available if women have not had prenatal care. In its April 2003 initiative, "Advancing HIV Prevention: New Strategies for a Changing Epidemic" (AHP) (4), CDC stressed again the importance of routine HIV testing of all pregnant women during prenatal care. CDC recommends "opt-out" testing where women are notified that an HIV test is part of a standard panel of prenatal tests and are given the opportunity to decline. Consent is inferred in the general consent for care, as with other prenatal screening tests (5). When done appropriately, this approach helps to make HIV testing routine while protecting a woman's autonomy. This same approach is supported by the American College of Obstetricians and Gynecologists (6,7) and the American Academy of Pediatrics (6) as well as the Institute of Medicine (8). In addition, a number of cost–benefit analyses indicate that universal screening of pregnant women for HIV infection would result in enormous overall savings for the healthcare system (9–11). For example, one study found cost savings under most of the assumed conditions that were evaluated. In the basic model, 656 pediatric HIV infections would be prevented annually, resulting in a net cost savings of $38.1 million (12).

CDC now also recommends that HIV testing be included as a part of routine medical care in all healthcare settings after the patient is notified that testing will be performed unless the patient declines (5).
That is, HIV screening would be conducted on the same voluntary basis as other screening tests (4). Making HIV testing a routine part of health care, and a key component of preconception care for all women, increases the likelihood of identifying young women with HIV infection before pregnancy. Routine HIV testing will allow women the opportunity to use their knowledge of their HIV status when considering their reproductive life plan, potentially reducing unintended pregnancies among HIV-infected women (13). Routine HIV testing provides an opportunity to offer interventions that will improve the woman’s health as well as the health of any future children.

POLICY RESPONSES

State-level policy changes and legislative action to support these approaches, especially in regard to perinatal prevention, have produced results. Laws in New York and Connecticut that mandate HIV testing of newborns whose mothers’ HIV status is unknown have had the effect of increasing prenatal HIV testing rates (14) – the time when interventions are most effective (2). Illinois’s recent laws provide that all pregnant women be counseled about HIV and offered HIV testing – a common requirement in a number of states. In Illinois, however, the law also requires that hospitals offer a rapid HIV test during labor when medication to reduce HIV transmission can still be provided and mandates a rapid HIV test of the newborn when the mother’s status is unknown (15). Oregon (H.B.706 73rd Leg., Reg. Sess. 2005) and Florida (H. 1,399 Reg. 2005 Florida) recently changed their state laws on HIV testing to allow for an “opt-out” testing approach in prenatal settings. Florida, which historically has been second only to New York in the number of pediatric AIDS cases, also requires that women be offered a second HIV screen, during the third trimester, to identify women who seroconvert after an initial prenatal test.

While legislation can help to standardize prenatal HIV testing, it can be a lengthy and cumbersome approach to ensuring that testing is made available to all pregnant women. Further, we do not yet have clear evidence of which policy interventions are most effective, and different interventions may be more or less effective in different environments, depending on such factors as HIV prevalence and the
political climate in the state. It is not likely that any single testing policy would be adopted across all US jurisdictions.

Regarding legislative directives, for HIV testing to be universal, prenatal providers need the education and support to encourage their patients to be tested. Studies have shown that a provider’s recommendation and encouragement are critical factors in a woman’s decision to be tested (16,17). Providers also need to have referral resources readily available for women with positive tests and for those in need of more extensive counseling and support.

Additionally, for prenatal HIV testing to be universal, we need to ensure that pregnant women access prenatal care. We must make our prenatal settings accessible, welcoming, and supportive for the highest risk women. In a recent study interviewing HIV-positive women who had repeat pregnancies but had not sought prenatal care, the women interviewed, who were at high risk of transmitting HIV to their infants, reported that they avoided prenatal care (18). They understood the risk of HIV transmission to their infants, but they had experienced disrespect and disregard for their privacy in previous encounters with the health and social service systems, and so kept away from them. Until our highest risk women, including recent immigrants, homeless women, and women using drugs, feel welcome and supported in prenatal care settings, they will continue to avoid care—putting their own health and their infants’ health and well-being at risk.

**HIV Prevention Targeted to Women**

Policy responses related to prevention of perinatal HIV transmission have focused on interventions in pregnancy and in the perinatal period. Based on those successes, we urge that the focus on prevention be expanded to primary prevention of HIV in order to reduce the number of new HIV infections in women. The growing incidence of HIV among young women, and particularly young women of color, is a public health crisis on its own, compounded by its potential implications for HIV in children. The HIV/AIDS epidemic among women of childbearing age continues to grow. In 2005, 11,710 female adults or adolescents in the United States were diagnosed as HIV infected (1). Women, who made up only 8% of the US AIDS population in 1985 (19), accounted for 19% of the cases by
2005 (1). Most AIDS cases in women are diagnosed between ages 25 and 44 years, indicating that they were infected some years earlier. In 2004, teen girls represented half of the AIDS cases in young people 13–19 years, and young women accounted for 37% of HIV cases among those aged 20–24 years (20). Startlingly, in 2002, HIV was the leading cause of death for African-American women aged 25–34 years (21). Many women with HIV get their diagnosis during pregnancy when we can offer effective interventions to protect their infants but can no longer protect them from HIV infection. While antiretroviral medications can offer improved quality and length of life for persons living with HIV, HIV disease remains a burdensome chronic illness.

In response to these statistics, we need to focus attention and resources on preventing HIV infection in women, particularly young women and women of color. The critical importance of implementing without delay HIV prevention strategies targeting women and girls is also being raised in the global discussion of HIV, where the number of HIV infections in women and girls is also rising at an alarming rate (22). Preventing HIV infection in women is not only the most effective way of preventing HIV in children, but also it refocuses the discussion from viewing women as "vectors of transmission" to recognizing women as inherently valuable individuals in every society. HIV prevention strategies for women need to be multifaceted, recognizing that power inequalities, poverty, and violence in women's lives must also be addressed if interventions are to be successful (23,24).

We need to support interventions – both medical and behavioral – that are as effective at preventing HIV infection in women as those that have successfully decreased HIV in children. While we have antiretroviral interventions to reduce the risk of mother-to-child HIV transmission, similar antiretroviral interventions are not currently available to prevent HIV infection in women. Studies of vaccines, medications, and microbicides have yet to demonstrate efficacy in preventing HIV in women, although some promising possibilities are being explored.

Primary prevention strategies that have been shown to be effective with young women and women of color need to be broadly implemented. Well-designed research studies have found that targeted interventions aimed at populations of young people make
a significant difference in decreasing HIV risk behavior (25–28). A systematic review of HIV behavioral interventions identified 18 "best-evidence studies;" of those, eight focused exclusively on women or adolescent females at high risk. Most interventions identified included technical, personal, or interpersonal skills (29). Other useful studies look not only at HIV but also other STDs, for example, a skill-based HIV/STD intervention, which provided information and taught skills necessary to practice safer sex, reduced sexual risk behaviors and the STD rate among African-American and Latino adolescent girls in clinics (25).

Young women's vulnerability to HIV is complicated by issues of low self-esteem and powerlessness, which effective interventions also address. Another study of African-American adolescent girls found that STD/HIV preventive interventions may be more effective if they target self-concept as opposed to only self-esteem, incorporate an Afrocentric approach, and focus on enhancing several attributes of partner communication about sex, including self-efficacy of condom use negotiation (27). These issues may be especially important in minority communities, where the rate of AIDS diagnosis for African-American women is as much as 25 times that of white women (30). These primary prevention strategies for young women need to be supported with expanded funding to reach the populations at risk. Widespread application of successful prevention approaches for young women in the United States may also provide a basis for developing primary prevention strategies for women elsewhere in the world.

THE ROLE OF THE HEALTHCARE PROVIDER

Healthcare providers can play an important role in reducing HIV in young women by incorporating primary HIV prevention and routine HIV screening into women's primary health care. Providers' professional associations can play a critical part by endorsing CDC's recommendations (5) or drafting guidelines of their own, such as those put forth by the American College of Obstetricians and Gynecologists (31). Offering HIV testing in the primary care setting can help providers start the discussion with their patients about HIV prevention. Including HIV testing in routine care for men as well as women provides an opportunity to identify individuals at risk of or
infectected with HIV, many of whom do not know their status. Normalizing routine HIV testing will not only help decrease the stigma associated with HIV testing but also empower women to expect and request HIV testing as a routine part of care, as American women now expect Pap smears and mammograms. In his 2006 State of the Union Address, President Bush called for an increase in the availability of HIV testing and followed up with a proposal for an initiative to overcome domestic HIV/AIDS challenges. He proposed directing over $90 million to test persons who do not know their HIV status in areas of the country with highest rates of newly discovered cases and the highest suspected rates of undetected cases (32).

THE ROLE OF PUBLIC HEALTH LEADERSHIP

Public health leaders can play a pivotal role in reframing and refocusing the discussion about HIV prevention in women and children. In the absence of legislative mandates, local public health leaders can develop and promulgate their own guidelines for their constituents. To respond effectively to the needs of women, we will need – to borrow a hockey analogy – to “move to where the puck is going,” that is, to anticipate the HIV prevention needs of young women and design and fund strategies that respond to those needs. Public health leaders need to provide the vision and support to reach this vulnerable population. In addition, they need to help educate primary care providers about their critical role in preventing HIV infection in young women. Importantly, they need to ensure that uninfected children who have received antiretroviral prophylaxis receive long-term follow-up to evaluate any potential for delayed effects. Finally, public health leaders need to support the allocation of funds that specifically direct primary prevention messages and activities to young women – not after the problem has reached crisis proportions – but now when the opportunity exists to intervene as the needs are identified.

Prior policy literature has often treated primary prevention in women and prevention of perinatal HIV transmission as independent of each other. We argue that the prevention of HIV is a continuum and that an increased emphasis on prevention in women, critically
important on its own merits, also strongly supports the success in reducing perinatal transmission.

The successes in preventing HIV in children are fragile ones. As we have learned from experiences in the United States with other diseases such as tuberculosis, when eradication efforts are taken for granted, they are often short-lived. We must continue the efforts that led to the decline in perinatal HIV transmission in order to solidify those achievements. However, we must also turn our attention to effective prevention strategies with women before they are infected with HIV. The successful approaches that have nearly eliminated perinatal transmission in the United States offer valuable lessons that can be applied to primary prevention for young women, namely that a concerted and long-standing public health effort is essential. Now is not the time to back away from ambitious goals. Rather, we should expand our efforts to completely eliminate perinatal HIV transmission while at the same time building on our success to date to develop effective prevention strategies to help women before they are infected with HIV. It is time to build on our successes, not simply applaud them. The US experience in reducing perinatal HIV transmission holds the promise for sharing with our colleagues around the world not only the lesson that success is possible, but also that perinatal prevention can be a platform on which to build effective primary prevention programs for women.

DISCLAIMER

The findings and conclusions in this report are those of the author(s) and do not necessarily represent the views of the Centers for Disease Control and Prevention/the Agency for Toxic Substances and Disease Registry.

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