Meeting the Sexual and Reproductive Health Needs of People Living with HIV

By Heather Boonstra

hat it means to be a man, woman or young person living with HIV can be very different now than 25 years ago when AIDS was first identified, in large part because of the availability of antiretroviral treatment. For those with access to treatment services, a diagnosis of HIV infection is no longer an imminent death sentence; although still incurable, HIV now can be managed as a chronic disease. Today, the push for universal access to life-saving drugs is a major focus of attention at national and global levels. And although realization of that ambitious goal may be a long way off, especially in the developing world, significant progress in the campaign for treatment access is being made even there. The number of people in low- and middle-income countries receiving treatment more than tripled between 2003 and 2005, from 400,000 to 1.3 million.

As the prognosis for people living with HIV has improved worldwide, AIDS activists and the global public health community have increased their focus on quality-of-life issues as well as length-of-life issues. Regardless of HIV status, the ability to express oneself sexually and the desire to experience parenthood are, for many, central to what it means to be human. Therefore, acknowledging these needs and aspirations is essential to vindicating the basic human rights of HIV-positive people. At the same time, because the large majority of HIV infections worldwide occur as a result of sexual intercourse, global HIV prevention efforts must address the sexual and reproductive health needs of people living with HIV to succeed. For both of these reasons,

meeting the sexual and reproductive health goals and service needs of people with HIV must be considered a global priority.

Aspirations and Needs

The desire to have children. The intersection between HIV status and childbearing desires is complicated. On the one hand, HIV-positive men and women report strong pressure from family members, people in their community and health care providers to give up the idea of having children, either because of the risk of perinatal HIV transmission or out of concern for the welfare of children raised by parents who may die prematurely of AIDS. On the other hand, childbearing in most societies plays a central role in the social identity of both men and women, and couples are expected to have children. In that sense, it is not surprising that the preponderance of research from both developed and developing countries suggests that HIV status does not depress fertility desires.

About This Article

This article is reprinted from an In Brief published jointly by the Guttmacher Institute and the Joint United Nations Programme on HIV/AIDS (UNAIDS). It has been produced with the collaboration of EngenderHealth, the Global Network of People Living with HIV/AIDS, the International Community of Women Living with HIV/AIDS, the International Planned Parenthood Federation, the United Nations Population Fund (UNFPA) and the World Health Organization.

The bottom line is that a significant proportion of HIV-positive men and women report that they want to have a child or another child in the future. And when they are asked why, they talk about the pleasure and happiness that comes with being a parent—answers that, not surprisingly, are similar to those given by HIV-negative people. Moreover, pregnancy may be a time of high self-esteem for women, and parenting may help combat the dehumanizing effects of living with HIV for women and men. At the same time, those living with HIV who are considering parenthood raise concerns about the effect a pregnancy may have on a woman's health, the risk of transmitting the virus to their newborn, and whether they will be able to have a long, healthy life in which to love and support the child.

In fact, evidence (mostly from developed countries) indicates that pregnancy does not have an adverse effect on HIV disease progression; however, for a variety of reasons that are not entirely clear, HIV infection appears to place women who are pregnant at increased risk of complications and is regarded as an indirect cause of maternal death. A meta-analysis combining the results of 31 studies conducted in a range of countries suggests that HIV infection may be associated with increased risk of miscarriage, preterm delivery

Key Points

- Sexual expression and the desire for parenthood are central to the lives of most people. Acknowledging these aspirations is essential to vindicating the human rights of people living with HIV.
- Meeting the sexual health needs of HIV-positive people is essential to global HIV prevention efforts.
- Efforts to provide sexual and reproductive health services to HIV-positive people are impeded worldwide by weak and fragmented health systems and by sexual taboos, gender inequality, and HIV stigma and discrimination.
- Effective HIV programming demands taking advantage of the perspectives, expertise and accumulated experiences of people living with HIV.

and low birth weight, although these associations are not strong.

Fortunately, the risk of perinatal transmission of HIV is below 2% with antiretroviral treatments, safe delivery and safe infant-feeding; absent these critical interventions, the risk ranges from 20–45%. But because low-income countries often lack the infrastructure to deliver even relatively modest interventions, progress in expanding access has been slow. At the end of 2005, fewer than 10% of HIV-positive pregnant women were estimated to be receiving services to prevent mother-to-child transmission of HIV, resulting in 1,800 infants born with HIV every day.

Men and women living with HIV who are considering becoming a parent—biologically or by adoption—clearly need special counseling and support; however, there are other issues as well. Studies suggest that HIV may have an adverse effect on both male and female fertility. In addition, there is the issue of how HIV-discordant couples-in which one partner is infected and the other is not—can safely pursue pregnancy. Artificial insemination can reduce the risk of infection when the woman is HIV-positive. Pregnancy is more problematic, however, when the man is HIV-positive. In this case, couples can reduce the risk of transmission by limiting unprotected sex to the short time during a woman's menstrual cycle when she is fertile and her partner's viral load is undetectable; because experience with this technique in resource-limited settings is lacking, the World Health Organization (WHO) considers it to be "inadequate for making recommendations." Another option is "sperm washing," a process in which sperm are separated from HIV-causing agents in seminal fluid before being used for insemination; however, this technique is currently too costly for many people with HIV, especially those in low-resource settings.

The need to prevent unplanned pregnancy and childbearing. Many people living with HIV will want to prevent pregnancy, either to time and space their childbearing or to avoid it entirely. Because condoms are the only method that protects against HIV and other sexually transmitted

infections (STIs), WHO recommends that providers encourage men and women with HIV who are seeking to avoid pregnancy to use condoms, with or without another contraceptive method. According to WHO's Medical Eligibility Criteria for Contraceptive Use, hormonal methods (such as oral contraceptives, injectables, implants, emergency contraception and the vaginal ring) are appropriate for women with HIV, including those who take antiretroviral drugs. For women receiving treatment, however, potential drug interactions should be considered in light of the fact that the limited data available suggest that some antiretroviral drugs may alter hormonal blood levels in women using oral contraceptives and possibly other hormonal methods. The IUD can be used by women with HIV, but insertion is not recommended for those who have developed AIDS and are not on antiretroviral therapy. Female sterilization and vasectomy are additional

options, except for women and men with an acute HIV-related illness; in such cases, the proce-

cases, the procedure should be delayed until the condition is resolved. Spermicides—as well as diaphragms and cervical caps, which are used in conjunction with spermicides—are not recommended for women living with HIV, on the basis of findings

that question the safety of nonoxynol-9.

However, even among those who use contraceptives, many women with HIV inevitably will have and may seek to end an unplanned pregnancy. Both early surgical abortion and medication abortion are considered safe for women with HIV; if provided by a qualified professional using standard techniques in sanitary conditions, injuries and deaths are rare. Unsafe abortions, which are risky for all women, are particularly dangerous for women with HIV, because of these women's somewhat increased risk of infection and hemorrhage.

To preserve their health and rights, people living with HIV must be able to make informed decisions about their sexual and reproductive health

and have access to appropriate services.

Concerted actions on several fronts may be needed: to ensure that men and women with HIV are not coerced or pressured into terminating a pregnancy or into using certain contraceptive methods, such as sterilization; to expand contraceptive services; to offer psychosocial support for men and women contemplating childbearing; and to provide nondirective, nonjudgmental and confidential counseling to HIV-positive women, including those faced with unplanned pregnancies. And where unsafe abortion exists, governments must try to create a consensus in favor of addressing its harmful social and health consequences.

The ability to protect sexual health. Because people living with HIV may have compromised immune systems, they are biologically more vulnerable than others to certain STIs. In addition, it

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is theorized, but not proven, that they may be at risk of reinfection with another strain of HIV. "Safer

sex" practices can reduce an individual's risk of HIV and other STIs. Currently, this is best accomplished by using male or female condoms, although some sexual behaviors (such as non-penetrative sex) can also reduce risk.

[Even as the AIDS vaccine field progresses, research is currently underway on a range of new prevention technologies. Perhaps most notably, scientists in several countries are working to determine whether tenofovir, an antiretroviral drug used to treat HIV disease, is safe and effective for use as an oral preexposure prophylaxis, while other researchers are investigating microbicides, gels or creams that prevent the transmission of HIV and other STIs when applied topically.]

Individuals tend to increase their condom use after learning their HIV status. Correct and consistent condom use over long periods, however, is difficult for most people, and even the most well-intentioned may experience prevention

"fatigue." Some people living with HIV report not using condoms because their partners also have HIV or because they or their partners refuse to use the method. Some may be reluctant to disclose their HIV status or negotiate condom use with their partners for fear that it would raise suspicions about infidelity, cause conflict or violence, or lead to the end of the relationship. Discordant couples may forgo condoms when they think the HIV-positive partner's viral load is too low to permit transmission. This may not in fact be the case, however, and it also leaves them at risk of STIs if the couple is not monogamous and of unintended pregnancy if no other contraceptive method is used. Finally, even highly motivated condom users may be stymied by the cost or simple lack of availability of male or female condoms.

HIV prevention programs aimed at people living with HIV are a critical component of HIV prevention efforts. People living with HIV, however, need support from all levels of society to practice such services are not delivered in a vacuum. They are set against a backdrop of large-scale challenges that impede service delivery and people's ability to access health care. At the same time, meeting the sexual and reproductive health needs of people living with HIV could make an important contribution to resolving these overarching challenges.

Weak health systems. First, the health services of many countries have been badly undermined by inadequate investment over decades and by the burden of AIDS itself. Virtually everywhere, there is a shortage of available health care personnel. And where personnel are available, some have received no training or even basic information about HIV and sexual and reproductive health. Moreover, health care providers in low-resource settings often lack basic supplies, such as needles, gloves and alcohol swabs, that allow them to take universal precautions, making them all the more reluctant to provide sexual and reproductive health services to people living with HIV.

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prevention. At a minimum, they need access to health services and to providers of both HIV services and sexual and reproductive health services who are capable and sufficiently trained to meet their needs. Providers must be comfortable talking about sexual intimacy, risky behaviors and other sensitive issues with their clients—some of whom may be youth, men who have sex with men, sex workers or injecting drug users. In particular, young people and men traditionally have not been the targets of sexual and reproductive health programs, and their needs have been largely ignored in the body of research on sexual and reproductive health for people living with HIV. It is crucial that providers offer youth-friendly services and recognize men's needs in their own right.

Overarching Challenges

Clearly, there is a compelling need for specific services that address the sexual and reproductive health of people living with HIV. Of course, These problems are exacerbated by the fact that sexual and reproductive health services and HIV services have generally evolved as separate and parallel programs, often resulting in sharp divisions between these two areas among donors, within country governments and in frontline service provision.

Breaking down these barriers and finding ways to provide more integrated services for people living with HIV could play an important role in strengthening fragile health care systems and in bridging the divide between sexual and reproductive health and HIV. Other key actions, such as intensified training and ensuring safety in the workplace, would go a long way toward improving the quality of care for people living with HIV.

Social and cultural issues. The second overarching challenge to effectively meeting the sexual and reproductive health needs of people living with HIV is a set of interlocking social issues that

degrade people and impede their access to services: sexual taboos, gender inequality, and stigma and discrimination around HIV itself. HIV programming is hampered by these persistent, deepseated social and cultural factors; at the same time, dealing with these issues through HIV programming would make for a more just world.

In many societies, even talking about sex is taboo. Because many policymakers may not want to be perceived as promoting sexual activity, they may be reluctant to expand the capacity of health care providers to effectively provide women with HIV are among society's most vulnerable individuals and are already struggling against adverse conditions such as poverty, oppression and discrimination.

Social attitudes and biases are reflected in policies that target people living with HIV, despite the fact that 189 countries at the United Nations (UN) General Assembly Special Session on HIV/AIDS in 2001 committed themselves to ensuring that people living with HIV and AIDS experience "the full enjoyment of all human rights and fundamental freedoms." (This state-

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sexual health services to people—especially youth—living with HIV. This is a serious mistake. Failure to acknowledge the central role that sexuality plays in the lives of virtually all people, including people living with HIV, is self-defeating. What is also self-defeating is failure to realistically confront HIV as an STI. Not only is this an obstacle to innovation where integration is concerned, it may also exacerbate the spread of HIV. This problem is made worse by persistent gender inequalities. In particular, women's inability to have control over their sexuality and sexual experiences not only increases their chances of acquiring HIV, but also undermines their ability to cope with the social, economic and physical impacts of HIV.

Finally, HIV-related stigma and discrimination are pervasive at the national and local levels.

Judgmental attitudes toward people living with HIV persist, making it difficult for people with HIV to disclose their status for fear of hostility or discrimination and of negatively affecting the quality of care they receive. Far too often, health care professionals have refused to care for HIV patients, disclosed clients' HIV status without consent, provided highly directive counseling on contraceptive methods and pressured women to undergo abortion or sterilization. All of this is compounded by the fact that many men and

ment was reaffirmed at the 2006 UN General Assembly High Level Meeting on AIDS.) Governments have an obligation to devise laws and policies that create a safe and secure environment and to protect the rights of HIV-positive individuals to make free and responsible choices for their sexual and reproductive health.

Moving Forward

In designing policies and programs to address the sexual and reproductive health needs of men and women living with HIV, policymakers, public health experts and national-level program planners must, of course, consider the best available scientific data. To be successful, they must also take advantage of the perspectives, expertise and accumulated experiences of people living with HIV. Associations and networks of HIV-positive people and community-based organizations run by and for people with HIV have a key role to play at all stages in the process—from program and policy design to the delivery and evaluation of sexual and reproductive health services. This includes involving HIV-positive men, women and youth in decisions about how and which services should be made available—for example, whether services are offered through a referral system or by adapting existing health services, such as family planning programs, programs for the prevention of mother-to-child transmission of HIV or

drug rehabilitation programs. Moreover, governments and donors must invest in the capacity of organizations run by and for people with HIV to participate fully in policy and program design of sexual and reproductive health services.

Three decades into the global AIDS pandemic, it is abundantly clear that enormous challenges remain, both in containing and reducing HIV infection rates and in helping people with HIV live longer, healthier lives. At the same time, the picture for people living with HIV is getting brighter. For a growing number of people with access to life-saving antiretroviral drugs, HIV is now a chronic disease rather than an imminent death sentence. Because sex and childbearing are central to the lives of almost everyone, including those living with HIV, effective programs must

fully accept the human right of HIV-positive men and women to decide whether and when to have children and to pursue a safe and satisfying sex life. At the same time, HIV prevention programs must actively involve people living with HIV, working with them to decrease the risk of transmitting the virus to others while also making sure that HIV-negative people share in that responsibility. In support of their efforts, governments and policy-making bodies at all levels also need to take into account—and begin to meaningfully address—the sexual and reproductive health needs, aspirations and rights of people living with HIV. Not only do the lives of people with HIV stand to benefit, but global HIV prevention efforts and the health and well-being of the entire global community will benefit as well. www.guttmacher.org