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The pregnancy decisions of HIV-positive
women: the state of knowledge and way
forward

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Abstract

Despite the growing number of women living with and affected by HIV, there is still insufficient attention to their pregnancy-related needs, rights, decisions and desires in research, policy and programs. We carried out a review of the literature to ascertain the current state of knowledge and highlight areas requiring further attention. We found that contraceptive options for pregnancy prevention by HIV-positive women are insufficient: condoms are not always available or acceptable, and other options are limited by affordability, availability or efficacy. Further, coerced sterilization of women living with HIV is widely reported. Information gaps persist in relation to effectiveness, safety and best practices regarding assisted reproductive technologies. Attention to neonatal outcomes generally outweighs attention to the health of women before, during and after pregnancy. Access to safe abortion and post-abortion care services, which are critical to women's ability to fulfill their sexual and reproductive rights, are often curtailed. There is inadequate attention to HIV-positive sex workers, injecting drug users and adolescents. The many challenges that women living with HIV encounter in their interactions with sexual and reproductive health services shape their pregnancy decisions. It is critical that HIV-positive women be more involved in the design and implementation of research, policies and programs related to their pregnancy-related needs and rights.

The pregnancy decisions of HIV-positive women: the state of knowledge and way forward

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Abstract: *Despite the growing number of women living with and affected by HIV, there is still insufficient attention to their pregnancy-related needs, rights, decisions and desires in research, policy and programs. We carried out a review of the literature to ascertain the current state of knowledge and highlight areas requiring further attention. We found that contraceptive options for pregnancy prevention by HIV-positive women are insufficient: condoms are not always available or acceptable, and other options are limited by affordability, availability or efficacy. Further, coerced sterilization of women living with HIV is widely reported. Information gaps persist in relation to effectiveness, safety and best practices regarding assisted reproductive technologies. Attention to neonatal outcomes generally outweighs attention to the health of women before, during and after pregnancy. Access to safe abortion and post-abortion care services, which are critical to women's ability to fulfill their sexual and reproductive rights, are often curtailed. There is inadequate attention to HIV-positive sex workers, injecting drug users and adolescents. The many challenges that women living with HIV encounter in their interactions with sexual and reproductive health services shape their pregnancy decisions. It is critical that HIV-positive women be more involved in the design and implementation of research, policies and programs related to their pregnancy-related needs and rights.* © 2012 Reproductive Health Matters

Keywords: HIV, AIDS, sexual health, reproductive health, human rights

Women constitute nearly 52% of the estimated 32.8 million people living with HIV globally.¹ With the advent of antiretroviral therapy and with continued channeling of resources into HIV services, greater numbers of HIV-positive women are living longer, healthier lives. As a result, they must contend with a range of longstanding and new issues affecting their sexual and reproductive health – including their needs, rights and desires related to pregnancy. Despite the number of women living with and affected by HIV, their meaningful participation in research, policy and programmatic decision-making has been limited.

A 2010 conference on “The Pregnancy Intentions of HIV-Positive Women: Forwarding the Research Agenda,” highlighted the needs, rights, decisions and desires of HIV-positive women before, during and

after pregnancy. The resulting report underscored the need for further research across a range of topics.² Building on the body of knowledge presented at the conference, the review of the literature captured in this article summarizes relevant research advances since the conference report was published. Findings are chiefly organized according to four types of pregnancy-related issues: seeking to prevent pregnancy; coerced sterilization; safer pregnancy; and pregnancy termination. A separate section discusses health system interactions, including those relating to HIV testing; integration of services; health worker attitudes; stigma and discrimination; and vulnerable populations. Gaps are identified in the peer-reviewed literature, as well as the abstracts, websites, and publications of relevant organizations, and attention is drawn to the ways in which the

voices of HIV-positive women have been absent from these pregnancy-related discussions.

Methods

The final report² and issue papers^{3–6} summarizing the literature presented at the above-mentioned conference served as the starting point. A systematic search was conducted of literature published between December 31, 2009, the endpoint of the systematic literature review for the conference, and July 1, 2011. Inclusion and exclusion criteria were used to determine relevant publications within each category (Figure 1).

Figure 1. Inclusion and exclusion criteria

Inclusion criteria:

Studies were considered for inclusion if they were written in English, Spanish, French or Portuguese; and published between December 31, 2009 and July 1, 2011.

A study was included in the review if, having read it, we answered “yes” to one or both of the following questions:

1. Is there a primary focus on the needs and rights of HIV-positive women?
2. Does the study contain information specific to pregnancy prevention, coerced sterilization, safer pregnancy and/or pregnancy termination?

Exclusion criteria:

A study was excluded from the review if, having read it, we answered “no” to any one of the following questions:

1. Are the aims and objectives of the research clearly stated?
2. Is the research design clearly specified and appropriate for the aims and objectives of the research?
3. Do the researchers provide a clear account of the process by which their findings were acquired?
4. Do the researchers share enough data to support their interpretations and conclusions?
5. Is the method of analysis appropriate and adequately explained?

Source: Dixon-Woods M, Cavers D, Agarwal S, et al. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. BMC Medical Research Methodology. 2006 Jul 26;6:35.

The search strategy drew on various resources in addition to indexes of peer-reviewed journals to capture research findings that were not reflected in the peer-reviewed literature. Specific terms were used to search Pubmed, Web of Science and the abstract databases of the 2010 International AIDS Conference and the 2011 Conference on HIV Pathogenesis, Treatment and Prevention.* We also scanned the websites and online publications of international and regional (but not national) health- and HIV-related non-governmental organizations, donors and United Nations agencies to identify additional articles of interest.

Two researchers independently assessed a randomly selected 10% of all titles/abstracts retrieved by the search. There was adequate concordance between those chosen for inclusion with a kappa statistic of 0.62. Results were compared and disagreements resolved before the remaining items retrieved were reviewed by a single researcher. The full text of each article was reviewed, and the inclusion and exclusion criteria were applied to determine which articles should be part of the analysis. Through this process, 214 articles were selected (Figure 2). Findings were then summarized and key publications cited.

Findings

Review findings are presented by the types of pregnancy-related intentions and desires that women with HIV might want to fulfill. The review emphasizes the most recent literature on the health, wellbeing and decision-making agency of women themselves, rather than infant and child outcomes. The influence and involvement of women's partners are discussed only to the extent that they are considered in the articles reviewed. Crosscutting health system issues are addressed separately and specific country examples, as relevant, are highlighted.

HIV-positive women wishing to prevent pregnancy

The ability of a woman to prevent unintended pregnancy is a key element of her sexual and

*Search criteria for the searches of PubMed, Web of Science and the abstract databases of the 2010 International AIDS Conference and the 2011 Conference on HIV Pathogenesis, Treatment and Prevention can be viewed at <http://globalhealth.usc.edu/Home/Research%20And%20Services/Pages/~media/192A5B2C1AA34C0D8961F0C31344CD74.ashx>.

Figure 2. Final citations for review

reproductive rights regardless of HIV serostatus. For many women globally, unmet need for contraception persists, particularly in resource-poor settings,^{7,8} and the rate of unplanned pregnancies is high.⁹ Emergency contraception in particular is still not widely available in many countries, often because it is not registered despite being included in the World Health Organization (WHO) List of Essential Medicines.¹⁰ This literature review identified three key methods used by HIV-positive women wishing to prevent pregnancy: hormonal contraception, condoms and microbicides.

The role of hormonal contraception in pregnancy prevention for HIV-positive women is unclear because there are unanswered questions about its interactions with HIV. The most recent WHO guidelines do not classify HIV infection or the use of antiretroviral drugs as contraindications for hormonal contraception in terms of either HIV transmissibility to sexual partners or disease progression.¹¹ Recent research in seven African countries, how-

ever, found that use of the injectable hormonal contraception Depo-Provera by women in HIV-serodiscordant couples almost doubled the likelihood of infection in the HIV-negative partner, irrespective of which partner was initially HIV-positive.¹² Both oral and injectable contraceptives were associated with a higher risk of transmission, but the subgroup analysis was statistically significant only for women using injectable forms. This finding may have important implications for women who live in resource-poor settings and have limited access to other forms of contraception.

Other studies, however, have not found an association between the use of hormonal contraceptives and HIV transmissibility.¹³ In light of this discrepancy, WHO convened a technical consultation in early 2012 to discuss the validity of research to date on hormonal contraception and HIV acquisition and transmission, specifically with respect to the Medical Eligibility Criteria. After extensive debate, WHO's recommendations for the use of Depo-Provera

and other forms of hormonal contraception remain unchanged: there are no restrictions on the use of hormonal contraception by women living with HIV or those at high risk of HIV. Still, the Medical Eligibility Criteria now clarify that “women using progestogen-only injectable contraception should be strongly advised to also always use condoms, male or female, and other HIV preventive measures,” while further research on the relationship between hormonal contraception and HIV proceeds.¹⁴ Adequately powered, longitudinal studies that directly assess the relationship between hormonal contraception and HIV acquisition, transmission and progression will be needed to provide conclusive evidence in this regard.¹⁵

Two other unresolved questions are whether some antiretroviral drugs make hormonal contraceptives less effective at preventing pregnancy, and whether hormonal contraceptives make antiretrovirals less effective against HIV. In light of the first risk, WHO states that “if a woman on antiretroviral treatment decides to initiate or continue hormonal contraceptive use, the consistent use of condoms is recommended.”¹¹ Furthermore, Rifampin and some other medications used to treat common opportunistic and co-infections in people living with HIV are widely recognized to alter levels of circulating hormonal contraceptives.¹¹ In sum, the use of hormonal contraception by HIV-positive women remains an area of controversy and concern, especially as more women are accessing antiretroviral therapy.

Condoms continue to be the only widely accessible and reliable method of “dual protection,” simultaneously preventing pregnancy and HIV transmission between HIV-positive women and their sexual partners. Acceptability of condoms varies among populations for a number of reasons,¹⁶ including availability of alternative contraceptive options, personal preference,¹⁷ partner preference and ability to negotiate the use of condoms or other contraceptives (particularly for vulnerable populations such as sex workers).^{18,19} Social and cultural implications of condom use such as trust and mistrust also influence uptake. As noted by Persson and colleagues, decisions to have unprotected sex are not based solely on calculations of risk, “but are shaped by complex emotions and relationship priorities.”²⁰

Some research has sought to illuminate key factors affecting condom use among HIV serodiscordant couples. Studies have documented variable patterns of condom use by serodiscordant couples in relation to whether or not the positive

partner has disclosed his/her HIV status. For example, a study in Europe found that having an HIV-positive partner who had disclosed was associated with reduced condom use.²¹ In Kenya, recent qualitative research found that the recognized need for consistent condom use in the context of serodiscordance affected sexual behaviors: it decreased the couple’s level of sexual activity and was cited as a reason for seeking concurrent sexual relationships.²² Despite earlier work in this realm, new research is needed to determine the potential role of disclosure of HIV-positive status as a determinant of condom use within HIV-serodiscordant couples.

It is important to develop and make available other acceptable female-controlled and dual protection contraceptive methods.²³ Studies have validated the acceptability of the female condom, the only female-controlled approach to dual contraception proven to be effective. However, despite advocacy efforts highlighting the unmet need for readily accessible and acceptable female contraception, particularly the female condom, its availability remains limited.^{24–26}

Some research has explored the effectiveness of the diaphragm and other cervical barriers in conjunction with microbicides to jointly prevent pregnancy and HIV acquisition,^{27–29} but the potential for a microbicide to reduce the risk of transmission from HIV-positive women to their HIV-negative partners while also preventing pregnancy has not been investigated.^{30,31} Despite studies documenting vaginal drying practices in southern Africa,^{32,33} the acceptability of gel-based microbicides used alone or in combination with cervical barriers has largely been supported by research.^{32–34} An intra-vaginal ring that would function as both a contraceptive and microbicidal agent is also under development as an alternative to barrier methods and dual-action microbicides, with the advantage that such a device can remain in place inconspicuously over extended periods of time and during multiple sexual encounters.³⁵

Despite disappointing results from recent microbicide trials, it is generally agreed that the search for an effective dual-acting microbicide should continue. WHO and HIV-related organizations have advocated for continued attention to clinical equipoise, increased transparency and the involvement of HIV-positive women in microbicide research – not only as study participants, but as members of study design, implementation and oversight teams.^{36–39} In the meantime, HIV-positive women who wish to prevent pregnancy with non-barrier methods can

consider use of different types of contraception, including intrauterine devices or sterilization depending on their desire for reversible or non-reversible methods.

Coerced sterilization

As reflected in the literature, pregnancy prevention for HIV-positive women may also occur because of coerced sterilization. Coerced sterilization refers to the act of female sterilization without consent in health care settings. This violation of human rights typically occurs when women, especially those who are poor or socially excluded, seek other health services such as abortion, caesarean deliveries, the prevention of mother-to-child HIV transmission (PMTCT) or cervical cancer screening.^{25,40–42} Those health services may be rendered on the condition that a woman be sterilized, or sterilization may simply be performed without the woman's knowledge.

Coerced sterilization is not unique to HIV-positive women, but evidence suggests that some women are sterilized against their will as a result of their HIV serostatus. One study explored cases of sterilization without informed consent in Namibia,⁴³ and a study conducted in Brazil found that health care providers played a significant role in determining whether HIV-positive women were sterilized after delivery.⁴⁴ It is possible that coerced sterilization will ultimately drive women away from needed health care services, in some cases as a result of having had this experience and in other cases out of fear of it occurring.

Advocacy campaigns spearheaded by the International Community of Women Living with HIV/AIDS have called attention to instances of coerced sterilization of HIV-positive women in Namibia,^{43,45} South Africa,⁴⁶ Thailand,^{47,48} Chile,^{49,50} Mexico^{51,52} and Jamaica.⁵³ A range of organizations, including groups of people living with HIV, have released statements and reports raising awareness and condemning the coerced sterilization of HIV-positive women. In 2010, three HIV-positive women received substantial international attention for filing suit in the High Court of Namibia in response to being sterilized without consent at public health facilities.⁵⁴ In that same year, an HIV-positive Chilean woman, with legal support from the Center for Reproductive Rights and Vivo Positivo, filed a complaint against the Chilean government in the Inter-American Court of Human Rights, claiming she was sterilized without her consent immediately after delivery. To our knowledge, the case is still pending

as of this writing.⁵⁰ In 2011, the International Federation of Gynecology and Obstetrics released updated female contraceptive sterilization guidelines that recognize coerced sterilization as an act of “violence against women.”⁵⁵

Safer pregnancy

Desire for pregnancy

Many women desire children, regardless of their HIV status. While at least one study has found that some HIV-positive women are less likely than their HIV-negative peers to desire pregnancy,⁵⁶ research from Brazil, Uganda and Zimbabwe indicates that pregnancy desires may not vary by HIV serostatus.^{44,57,58} Enhanced access to antiretroviral therapy can enable HIV-positive women to better realize their sexual and reproductive health and rights.⁵⁹ Although research suggests that neither time on antiretrovirals nor antiretroviral use itself is an important determinant of pregnancy desire,^{56,60,61} a study conducted in several sub-Saharan African countries showed that antiretroviral use is associated with significantly higher pregnancy rates.⁶²

An HIV-positive woman's desire to become pregnant appears to be influenced by a complex interconnected array of factors, with individual circumstances contributing to different outcomes in different settings. In India, for example, the desire for a male child, deaths of previous children, family size norms and cultural barriers to pregnancy termination were found to be motivating factors for having a child.⁶³ In Fiji, Papua New Guinea and Botswana the cultural obligation to fulfill the duty of motherhood was a driver of pregnancy intent.^{64,65} In South Africa,^{56,60} Uganda⁶⁶ and Zimbabwe,⁶⁷ younger age and stable relationship status were associated with pregnancy desire. Finally, not having a child with one's current partner was an important reason for pregnancy desire in Brazil.⁴⁴

Partners' desires to have children were also noted to be important determinants of pregnancy desire in Botswana,⁶⁸ Uganda,⁶⁹ and the United States,⁷⁰ highlighting the need to understand the best ways in which partners can be engaged to support the sexual and reproductive health and rights of HIV-positive women. In many cases, desires for motherhood were found to override the fear of horizontal and/or vertical transmission.^{71–74}

Emerging research regarding safer pregnancy and adolescents highlights important issues. For example, though fewer HIV-positive adolescents may desire pregnancy than their peers in some contexts,⁷⁵ it is recognized that some adolescents

do not routinely use condoms because they want children.⁷⁶ In Brazil, the median ages of sexual debut and first pregnancy were found to be similar for HIV-positive adolescents who were vertically infected and HIV-negative adolescents.⁷⁷ However, a study in Uganda found that harsh judgment of HIV-positive adolescents who become pregnant may have encouraged some HIV-positive adolescents to avoid pregnancy even if this was not their wish.⁷⁸

Given the demonstrated importance of a range of factors in women's lives for determining pregnancy intentions, any differences in pregnancy desires between women living with HIV and HIV-negative women cannot be assumed to be attributable to HIV status.

Fertility and assisted reproductive technologies

There is some evidence that HIV affects fertility.^{79–83} A study using Demographic and Health Survey data in Kenya found that HIV-positive women were 40% less likely to have had a recent birth compared to HIV-negative women with similar background characteristics. This could be a result of reduced fecundity, the reproductive choices of HIV-positive women or a combination of these and other unknown factors.⁸¹

A study of couples utilizing assisted reproductive technology found that women in couples with at least one HIV-positive partner experienced longer time intervals before getting pregnant than women in HIV-negative couples. Although pregnancy rates for serodiscordant couples did not vary with the sex of the HIV-positive partner, when both partners were HIV-positive, more assisted reproductive cycles were unsuccessful and, consequently, pregnancy rates were lower than they were for age-matched control subjects.⁸⁴

Lower fertility might be mitigated by increasing the availability, accessibility, acceptability and quality of assisted reproductive technologies. Many HIV-positive women face economic and legal barriers to accessing the technology necessary for fulfilling their desire for pregnancy. Examples include significant financial barriers in Kenya,⁸⁵ government prohibition of assisted reproductive technology for HIV serodiscordant couples in Vietnam,⁸⁶ and the exclusion of assisted reproductive technology from national strategic plans for HIV in eight countries in Latin America.⁸⁷ In the absence of access to assisted reproductive technologies, serodiscordant couples continue to pursue pregnancy despite the risk of HIV transmission. In Kenya, for

example, pregnancy has been associated with an increased risk of HIV seroconversion.⁸⁸ While the rate of transmission within serodiscordant couples in precise conditions is very low, the provision of assisted reproductive technology is still critical for enabling HIV-positive women to safely become pregnant.⁸⁹ Serodiscordant couples using assisted reproductive technologies still experience anxiety about the risk of HIV transmission, and about their own potential mortality due to HIV, even as they express excitement about their pregnancies.⁹⁰

Safer conception

For women in serodiscordant partnerships, an important component of safely becoming pregnant is reducing the risk of horizontal HIV transmission within the relationship. Peri-conception pre-exposure prophylaxis has substantial potential in this regard.^{91,92} Two recent randomized studies in Africa found that daily antiretroviral treatment can reduce the risk of HIV infection among heterosexuals engaging in high-risk sexual behavior. Both studies documented greater than 60% reduction in HIV transmission among serodiscordant couples when uninfected partners took antiretroviral regimens.^{93,94} Despite the potential of pre-exposure prophylaxis and other assisted reproductive technologies, however, their availability remains limited, particularly in resource-poor settings, and their acceptability unknown.

Attention to women's health during pregnancy

The majority of studies of HIV-positive pregnant women attempt to better understand the relationship between HIV, antiretroviral therapy and neonatal outcomes such as risk for spontaneous abortion, low birth weight, preterm birth,⁹⁵ neonatal mortality and HIV transmission. When studies evaluate pregnant women's CD4 cell counts, this information is often reported only in relation to the apparent effect on the health of the fetus, with the health status of women living with HIV not recognized as a matter of concern.⁹⁶ Some research has explored biological aspects of safer pregnancy for HIV-positive women and their babies such as the suitability of a lopinavir/ritonavir tablet as opposed to soft gel during pregnancy;⁹⁷ the potential for raltegravir to be added to PMTCT regimens;⁹⁸ optimal regimens for PMTCT including the efficacy of protease inhibitor-based combinations;⁹⁹ and antiretroviral resistance among both antiretroviral-naïve and -experienced pregnant women.¹⁰⁰ Additionally, several studies have explored the influence

JENNY MATTHEWS / PANOS PICTURES

Woman, age 24, in her fourth pregnancy, has tested HIV-positive and talks to a counsellor, Lesotho, 2009

of other factors such as poverty,^{101–104} psychosocial support for pregnant women^{105–107} and their families,^{108,109} and violence¹⁰² on women's ability to access a range of available services.

Preventing vertical transmission

Successful strategies to further decrease vertical HIV transmission via increased adherence to antiretroviral regimens and adoption of different service delivery models have been documented.¹¹⁰ Government, donor and United Nations agencies' work related to HIV and pregnancy has focused on increasing access to prophylactic antiretroviral drugs and adherence to health service programs to "eliminate" vertical transmission.^{111–119} However, concerns exist in relation to a range of programmatic efforts intended to reduce vertical transmission. Much of the research on antenatal HIV testing, for example, is related to increasing access to treatment in order to reduce the risk of vertical transmission, with limited attention to maternal health, management of the woman's HIV infection in the perinatal period or her sustained access to antiretroviral therapy.^{120–122}

Several studies in low-income settings have examined health system capacity to provide more complex drug regimes in PMTCT programs and have documented successful transitions from single-dose nevirapine to multi-drug prophylactic antiretroviral regimens.^{123,124} Moreover, recognizing the difficulty of accessing CD4 count testing in these contexts, some researchers have called for a "test and treat" approach, especially for pregnant women, whereby, once diagnosed with HIV, a woman would be initiated on lifelong antiretroviral therapy.¹²⁵ This strategy raises numerous questions. For example, a study conducted in Australia documents concerns raised by HIV-positive women regarding drug toxicity and potential harmful effects on their children's health.¹²⁶ This research highlights the importance of counseling and continued support for HIV-positive women as they navigate complex biomedical decisions.

Three studies from high-income countries where women received PMTCT interventions explored the association between vaginal births and different outcomes among HIV-positive women. Azria and colleagues found that HIV-positive women were

similar to HIV-negative women with respect to mean birth weight, simple or complex perineal laceration rates, and neonatal outcomes. Furthermore, no cases of vertical HIV transmission were reported.¹²⁷ In a study by Islam and colleagues, there were also no cases of vertical transmission among vaginal births.¹²⁸ A systematic review of the literature on the role of elective caesarean delivery concluded that the benefits of elective caesarean delivery with respect to vertical transmission continue to outweigh the risks, but noted the need for further research.¹²⁹

In 2010, formal revisions to WHO guidelines on the prevention of vertical HIV transmission changed the threshold for initiation of lifelong antiretroviral therapy among pregnant women with HIV, called for earlier initiation of antiretroviral prophylaxis among HIV-positive pregnant women who are not eligible for lifelong antiretroviral therapy, and provided additional guidance with respect to breastfeeding. Several concerns were expressed regarding how best to operationalize the latest revisions.^{130–132}

Studies have since documented challenges with respect to breastfeeding in South Africa,¹³³ Uganda¹³⁴ and Kenya,^{135,136} resulting in mixed feeding and higher transmission of HIV. Nipple shield devices to decrease breastfeeding-related HIV transmission have been shown to be acceptable but are still in effectiveness trials.¹³⁷ Evidence suggests that mastitis heightens viral loads in breast milk, thereby increasing vertical transmission,¹³⁸ and ongoing research is assessing other factors that influence HIV transmission via breast milk.^{139,140}

Research has supported the strategy of involving male partners in antenatal services as a means of preventing vertical HIV transmission,^{141–143} and non-governmental organizations^{144–146} and United Nations agencies¹⁴⁷ have advocated for this approach. PMTCT services have successfully been used as an entry point for promoting male involvement in antenatal services more broadly. Clinic invitations for male participation and couples-only counseling effectively involve men in some settings,¹⁴⁸ but several studies have noted resistance from male partners to be tested for HIV even after their female partners test positive.¹⁴⁹ In spite of a substantial increase in research exploring male engagement, questions remain as to *how* engaging men can and will improve services for HIV-positive women. Of concern, for example, is one study that found that Kenyan men influenced women to default from PMTCT programs.¹⁵⁰

HIV-positive women wishing to terminate pregnancy

For all women, the ability to safely terminate a pregnancy depends in part on the legal status of abortion where they live, as this influences whether services are clandestine and/or potentially unsafe. Furthermore, while post-abortion care can be life-saving for women who experience spontaneous abortion or for those whose only option is unsafe abortion, accessing post-abortion care, too, can pose significant problems in countries where abortion is restricted, banned or criminalized. HIV-positive women face particular unsafe abortion-related risks, and these risks are largely not addressed in the peer-reviewed literature.

Although evidence is still limited, studies are increasingly exploring the relationship between knowledge of HIV status and pregnancy termination. Two studies in Vietnam concluded that awareness of HIV-positive status was related to an increased likelihood of having an induced abortion.^{151,152} In contrast, studies in South Africa and Brazil found that socio-economic hardship and poor living conditions at the time of pregnancy were considered more important reasons to choose to abort than HIV status.^{153–155} A study in Italy identified a range of factors contributing to HIV-positive women's decision to terminate a pregnancy such as unplanned pregnancy, previous pregnancies, and disease progression, but found no association between pregnancy termination and HIV status.¹⁵⁶

The International AIDS Conference did not dedicate a session to abortion until 2010. The occurrence of the session was encouraging, but the highly politicized nature of the abortion debate necessitates deliberate and sustained attention to the links with HIV at the global level. Health-related non-governmental organizations and the United Nations have shown uneven support for this issue.¹⁵⁷ For example, recent WHO publications on unsafe abortion,¹⁵⁸ abortion care in South Africa¹⁵⁹ and the induction of labor¹⁶⁰ do not include any information specific to HIV-positive women. However, a collaborative publication by WHO, UNICEF, the United Nations Population Fund and the World Bank on packages of interventions for maternal, newborn and child health provides exemplary attention to the health and care of HIV-positive women, including access to safe abortion services.¹⁶¹

Interactions with the health system

Across the topics explored thus far in this review, the experiences of HIV-positive women as they

interact with the health system shape their sexual and reproductive decision-making processes and often influence women's ability to achieve desired outcomes. This section discusses HIV-positive women's interactions with the health system in relation to HIV testing, integration of services, health worker attitudes, and stigma, discrimination and legal barriers both in general and with specific attention to key populations. In all of these areas, the experiences and perspectives of HIV-positive women are often under-represented in the research.

HIV testing

The global policy shift from voluntary counseling and testing for HIV to provider-initiated HIV testing and counseling within the health system has led to large increases in the number of women being tested for HIV, mostly in the context of antenatal care. When WHO published global guidance on this issue in 2007, many researchers highlighted potential pitfalls related to provider-initiated HIV testing and counseling. However, there has been little attention since that time to the ways in which women's experiences and pregnancy intentions have been affected by the policy change, with studies largely focusing instead on the potential PMTCT benefits. Some researchers have begun to recognize that pregnant women, compared to non-pregnant women and to men, are disproportionately tested under provider-initiated testing, and that the experience can present additional responsibilities and challenges.^{162–164} Additionally, while several studies document high levels of acceptability with respect to provider-initiated HIV testing and counseling,^{165,166} a study from Ethiopia noted that despite three-quarters of the study population reporting satisfaction with testing services, 21% of women did not know why they were offered HIV testing during pregnancy.¹⁶⁵ Finally, other studies have begun to assess the effectiveness of linkages between HIV testing and long-term HIV care, treatment and support services.^{167,168}

Some HIV and sexual and reproductive health advocates have continued to analyze and question the shift by international donors toward provider-initiated HIV testing and counseling.¹⁶⁹ Advocacy networks have drawn attention to the fact that provider-initiated HIV testing and counseling during pregnancy can be problematic, given women's heightened vulnerability and reliance upon the health care system at that time.¹⁷⁰ Despite anecdotal evidence of drawbacks of provider-initiated

HIV testing and counseling, particularly with respect to the lack of appropriate counseling, research findings remain limited.

Integration of services

Integration of services, if appropriately implemented, may alleviate some of the challenges to women's ability to exercise their sexual and reproductive health and rights.^{171,172} Peer-reviewed literature suggests that current efforts to combine services across a health system focus on adding a specific HIV service to a specific reproductive health service (e.g., introducing HIV testing into antenatal care services) or vice versa (e.g., introducing family planning services into post-test HIV counseling). There are insufficient attempts to critically study and adopt lessons from other health systems efforts in regard to how integration can best be carried out, or to understand, incorporate and respond to the experiences reported by women themselves.^{173–175} Consequently, many service integration efforts have ignored the constraints of illiteracy and of gender norms that may pose challenges for women's autonomous decision-making. They have also not shown sufficient concern for women's sexual and reproductive health as distinct from the potential for HIV transmission to partners or children. Several organizations have devoted resources to researching and advancing the concept of family planning and HIV service integration,^{115,147,176–180} but there are still no clear-cut, context-specific models or optimal strategies to link or integrate services which adequately respond to the needs of HIV-positive women, particularly in the context of various donor priorities.¹⁸¹

Hence the rubric of integration continues to encompass a wide range of activities and often lacks the specificity required to ascertain which "integrated services" are being delivered. Integrating sexual and reproductive health services with HIV services is not the only objective; there are also efforts to incorporate tuberculosis services,¹⁸² services for survivors of gender-based violence¹⁸³ and primary health care more generally. Additional research is required on the ways in which health care services, human resources and sufficient technical capacity can be linked or integrated to provide truly comprehensive care.

There is a need for more research on how sexual and reproductive health services themselves can best be integrated. In addition, different models of integrating HIV treatment, care and support with

these services, as well as with other areas of health care, may need to be tested so as to improve the health and well-being of HIV-positive women.¹⁸⁴

Health worker attitudes

There is continued documentation in the peer-reviewed literature of negative provider attitudes towards HIV-positive women who wish to become pregnant.^{185,186} Health care providers can be an important source of information and support regarding sexual and reproductive health, and have an essential role in helping women identify contraceptive options that fit their lives. Nevertheless, health workers in Vietnam,¹⁸⁷ Thailand,⁴⁸ Jamaica,⁵³ Ukraine,¹⁸⁸ Botswana,¹⁸⁹ Zambia, Mexico,⁵² Swaziland,¹²⁰ South Africa,^{190,191} Canada¹⁹² and Mozambique¹⁹³ have been found to have negative attitudes about pregnancy among HIV-positive women. This sometimes results in advice to abstain from sex, pressure to abort current pregnancies or refusal of care. Indeed, some Indian women and Kenyan women reported not attending antenatal care or avoiding hospitals at the time of delivery because they perceived such high levels of stigma, discrimination and even hostility.^{194,195}

Studies in Brazil¹⁹⁶ and the United States^{197–200} found that many HIV-positive women want to discuss their sexual and reproductive plans with their health care providers, but do not feel comfortable doing so. In Brazil, conversations between health workers and HIV-positive women about fertility desires were found to have been initiated more often by the women themselves.⁴⁴ Despite continued advances in many aspects of the treatment and care of women living with HIV, health care providers' attitudes may still negatively impact the care that HIV-positive women seek out or receive.

The knowledge base about how best to address and support the sexual and reproductive health of HIV-positive women has evolved rapidly, and new information has not yet been fully incorporated into published advice and training materials for health workers. This can lead to the provision of inappropriate advice to HIV-positive women,²⁰¹ for example, regarding potential drug interactions or pre-exposure prophylaxis. Improving health worker knowledge and attitudes through training and mentoring with the participation of HIV-positive women has been found to significantly improve performance, particularly in relation to the frequency of sexual and reproductive health discussions between health workers

and HIV-positive women as well as in relation to confidentiality.¹⁸⁷ Non-governmental organizations have developed educational materials and training curricula on HIV and pregnancy for health workers in different contexts in order to address stigma in health settings, but these efforts have yet to be brought to scale.

Stigma, discrimination and legal barriers

Stigma manifested by partners, families, the community and the health system directly informs the specific considerations of women living with HIV who are determining or actively pursuing their pregnancy desires. Stigma has been shown to operate differently in different contexts. It may encourage desires for pregnancy when child-bearing fulfills a social role or conceals a positive HIV status,²⁰² while discouraging pregnancy when a community predominantly finds it inappropriate or "irresponsible" for women living with HIV to become pregnant.²⁰³ Furthermore, fear of potential stigma has been shown to complicate women's decisions about whether to disclose their HIV status to their partners, families and communities, especially in the context of pregnancy.²⁰⁴

A recent study documented laws and pending laws that criminalize HIV transmission and exposure in parts of Africa, Asia, Latin America and the Caribbean. The study also noted that existing laws in Europe and North America were increasingly being used to prosecute people for HIV transmission, sometimes with calls for mandatory testing of pregnant women as well as non-consensual partner disclosure by health workers.²⁰⁵ The impact of criminalization and associated laws and penalties on the willingness of HIV-positive women to become pregnant, carry their pregnancies to term, abort if they so choose, and engage with the health system more generally is an important area for investigation. Women's health and HIV advocacy organizations,²⁰⁶ in addition to UNAIDS,²⁰⁷ have drawn attention to the rampant discrimination and human rights violations these laws express and engender, as well as to the potential negative health effects, but substantive research is still needed on the consequences of criminalization, discriminatory laws, and the best ways those consequences can be addressed within and outside of the health sector.

Attention to key populations

Stigma and discrimination are especially relevant to the needs, desires and rights of key

populations as they affect pregnancy intentions. Despite recent attention to a wider range of groups in the HIV literature, the extent to which this literature engages with the pregnancy-related intentions of women who fall within marginalized groups remains limited at best. Research efforts are, however, increasingly exploring the sexual and reproductive health needs of key populations including sex workers and injecting drug users. There has also been more interest in the influence of the partners of marginalized women, with studies again including sex workers²⁰⁸ and injecting drug users,^{209,210} but the literature is extremely limited in this area.

The 2010 International AIDS Conference abstracts, in addition to giving attention to sex workers, injecting drug users and adolescents in most thematic areas, also consider the wide-ranging vulnerabilities of other marginalized groups including refugees and asylum seekers; widows; migrants and mobile populations; lesbian, bisexual, transsexual, transgender and intersex populations; indigenous peoples; those in conflict or post-conflict settings; incarcerated populations; rural populations; and people with disabilities. Yet the abstracts show a predominant concern with HIV prevention, testing and treatment among these populations, with little thought given to their sexual and reproductive health and rights. There is almost no examination of how to support fulfillment of their pregnancy intentions. HIV advocacy organizations, such as the Global Network of People Living with HIV/AIDS, have specifically called for advancing the sexual and reproductive health and rights of injecting drug users, sex workers, HIV serodiscordant couples and migrants.³⁷

Furthermore, there is growing recognition of the need to address the sexual and reproductive health and rights of HIV-positive adolescents, some of whom have been living with HIV from birth.^{179,180,211–213} Most of the literature on adolescents focuses on preventing HIV infection, with little consideration of the additional challenges faced by these young people in negotiating their serostatus and healthfully exploring their sexuality, although this is beginning to change.^{214,215} One study in Canada explored the complexities of disclosure, fear of rejection, negotiating safe sexual relationships, desires to have children and changes in risk perception over time among adolescents. The study highlighted the need for additional qualitative research to further explore the health needs of adolescent

women living with HIV, including in particular their pregnancy desires and barriers to fulfilling their wishes.²¹²

Discussion

The body of published research on the pregnancy decisions of HIV-positive women has grown substantially in the past two years. One particular trend in this literature is a shift from initial assumptions that women living with HIV would not want to have children to systematic reviews that document the myriad factors affecting women's choices related to pregnancy.

The literature also indicates that programmatic efforts to facilitate voluntary pregnancy prevention by HIV-positive women are insufficient: condoms are not always available or acceptable, and other options are limited by cost and lack of availability, as well as by uncertain efficacy. Further, the current literature overlooks the issue of condom use among HIV-seroconcordant couples, either to prevent HIV re-infection or to prevent pregnancy. Meanwhile, despite efforts by non-governmental organizations to document the extent of coerced sterilization, there appears thus far to be no research published which critically evaluates the scope of the problem regionally or globally, let alone illuminates the contributions of health care policies and providers to these abuses.

The complexities of pregnancy desire and some aspects of safer pregnancy and delivery for HIV-positive women have received substantial attention in the literature, but the majority of research remains focused on preventing vertical HIV transmission during pregnancy, delivery and breastfeeding, and on neonatal health outcomes, with no clear focus on acquiring evidence that would further advance the sexual and reproductive health and rights of HIV-positive women. While United Nations agencies, health-related non-governmental organizations and HIV advocacy organizations alike have increasingly identified a need to make assisted reproductive technologies available to HIV-positive women,²¹⁶ there has been limited dedicated attention to this area. As research protocols are designed and funded, it is critically important that efforts are made to explore technologies and approaches to conception for HIV-positive women, with attention to the ways in which these methods can be made available, accessible and affordable to women in low- and middle-income contexts. Research is also

needed to better understand the dynamics of how a woman's HIV status relates to her desire and ability to terminate her pregnancy. Being able to disaggregate unsafe abortion incidence, morbidity and mortality would shed further light on this issue. The effects on pregnancy desires of laws which criminalize abortion, as well as the effects of other harmful laws and policies, must be elucidated in order to fully understand and respond to the range of service delivery and human rights concerns facing HIV-positive women.

Moreover, attention is required to models of health service delivery that can ensure a continuum of care from the moment of HIV diagnosis onward, with an appropriate constellation of services delivered in an acceptable manner. Although guidance remains limited as to which services to link or bridge to one another and in which contexts, non-governmental organizations have been exploring ways of integrating various services. Even with appropriate services in place, their acceptability and use will continue to be driven by the interactions that women have with the health system. Special consideration should be given to the impacts of integration as they relate to HIV-positive women's pregnancy desires and pregnancy outcomes, as responses may require a fundamental reconceptualization of how HIV services are currently provided. Further research about how to alter health workers' discriminatory attitudes towards women living with HIV is also needed.

HIV-positive women who are sex workers, injecting drug users and adolescents are particularly affected by the range of issues raised in this review, and yet remain largely invisible in the current peer-reviewed literature. The apparent lack of published research on the pregnancy needs and desires of HIV-positive female drug users is a telling example.

The issues raised here – desires to have children or avoid having children, agency to realize those desires, safe pregnancy and safe abortion – impact all women, not just HIV-positive women. Researchers must therefore discern on a case-by-case basis when HIV-positive women should be conceptualized as a population facing unique social pressures, vulnerabilities and biomedical concerns, and when it is useful to consider the demographic of women more broadly so as to best understand, advocate for and provide services geared to the sexual and reproductive health and rights of all women.

There is an evident disconnect between the articulated desires of women living with HIV and the apparent assumptions made by many of those who design and implement relevant studies, policies and programs, often with a detrimental effect on how HIV-positive women interact with the health system as they pursue their sexual and reproductive choices.

Conclusions

To fully and holistically address the sexual and reproductive health needs, rights, decisions and desires of HIV-positive women in relation to pregnancy, researchers must adopt a multidisciplinary perspective that explicitly considers when and how HIV-positive women can best be supported. A multidisciplinary perspective is intended here to mean more than a superficial acknowledgment of the interests of different disciplines. The integration of different types of frameworks, methods and analyses is needed to reconcile language differences, epistemological approaches and diverging priorities. Research conducted by investigators from different disciplines, even if testing separate hypotheses, is nonetheless connected and situated within a larger body of knowledge and sphere of influence. Specificity regarding not only which disciplines are combined and how, but the conceptual framework driving the chosen approach, will be important for framing such efforts. Combining methods and disciplines in a single study can answer a broad array of questions (e.g. “why?” as well as “how many?”) with global utility. Embedding such research efforts within their local contexts allows for the use of research results by HIV-positive women, service delivery organizations and policy makers to effect changes in policy and practice.

The only way to ensure context-specific, sensitive and appropriate sexual and reproductive health research, and ultimately to ensure the quality of the policies and programs it aims to inform, is to take into account the vast biomedical, economic, political and societal forces that HIV-positive women must weigh. Most importantly, HIV-positive women must participate in all phases of developing effective research, policies and programs, from conceptualization through implementation. This process has the potential to yield new paradigms that will enable far more HIV-positive women worldwide to voice their concerns, articulate potential solutions and ultimately fully realize their pregnancy decisions.

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Résumé

Malgré le nombre croissant de femmes vivant avec le VIH et touchées par ce virus, la recherche, les politiques et les programmes accordent encore trop peu d'attention à leurs besoins, leurs droits, leurs décisions et leurs désirs relatifs à la grossesse. Nous avons analysé les publications pour vérifier l'état actuel des connaissances et dégager les domaines sur lesquels il convient de se pencher. Il en ressort que les options contraceptives pour la prévention de la grossesse chez les femmes séropositives sont insuffisantes : les préservatifs ne sont pas toujours disponibles ou acceptables, et d'autres choix sont limités du fait de leur coût, leur indisponibilité ou leur inefficacité. De plus, la stérilisation contrainte des femmes vivant avec le VIH est fréquemment rapportée. Des lacunes persistent dans l'information en rapport avec l'efficacité, la sécurité et les meilleures pratiques concernant les technologies de procréation assistée. Les résultats néonataux suscitent en général plus d'attention que la santé des femmes avant, pendant et après la grossesse. L'accès à des services sûrs d'avortement et de post-avortement, déterminant pour permettre aux femmes de jouir de leurs droits génésiques, est souvent réduit. Il faut s'intéresser davantage aux professionnelles du sexe, aux consommatrices de drogues injectables et aux adolescentes séropositives. Les nombreux obstacles que rencontrent les femmes vivant avec le VIH dans leurs relations avec les services de santé génésique façonnent leurs décisions en matière de grossesse. Il est capital que les femmes séropositives participent davantage à la conception et la mise en œuvre de recherches, de politiques et de programmes relatifs à leurs droits et besoins en rapport avec la grossesse.

Resumen

A pesar del creciente número de mujeres que viven con VIH y son afectadas por éste, en las investigaciones, políticas y programas aún no se presta suficiente atención a sus necesidades, derechos, decisiones y deseos con relación al embarazo. Realizamos una revisión de la literatura para determinar el estado actual de conocimiento y destacar las áreas que requieren más atención. Encontramos que las opciones anticonceptivas para la prevención del embarazo en mujeres VIH-positivas no son suficientes: los condones no siempre son accesibles o aceptables y otras opciones están limitadas por su disponibilidad, eficacia o costo. Más aún, se informa un alto índice de esterilización forzada entre mujeres que viven con VIH. Aún existen brechas en la información relacionada con la eficacia, seguridad y mejores prácticas respecto a las tecnologías reproductivas asistidas. Generalmente se presta más atención a los resultados neonatales que a la salud de las mujeres antes, durante y después del embarazo. A menudo se restringe el acceso a los servicios de aborto seguro y atención postaborto, los cuales son esenciales para que las mujeres puedan realizar sus derechos sexuales y reproductivos. No se presta adecuada atención a las trabajadoras sexuales VIH-positivas, usuarias de drogas inyectables y adolescentes. Los numerosos retos que encuentran las mujeres que viven con VIH en sus interacciones con los servicios de salud sexual y reproductiva influyen en sus decisiones respecto al embarazo. Es imperativo que las mujeres VIH-positivas participen más en el diseño y la implementación de investigaciones, políticas y programas relacionados con sus necesidades y derechos referentes al embarazo.