Engaging HIV Care Providers in Conversations With Their Reproductive-Age Patients About Fertility Desires and Intentions: A Historical Review of the HIV Epidemic in the United States

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Provider-initiated conversations with people living with HIV about reproductive plans are lacking. Providers must know whether their patients want to bear children to tailor treatment and refer for HIV preconception counseling to help achieve patients' reproductive goals while minimizing transmission to partners and children. The early focus on men who have sex with men largely excluded consideration of the epidemic's impact on reproductive health. We used a historical review of the US epidemic to describe the problem's scope and understand if this legacy underlies the current neglect of reproductive planning. Drawing on peer-reviewed literature, we discuss key themes relevant to assessing and understanding attention to desires for children among HIV-positive people. We conclude with recommendations for addressing persistent stigma and enhancing patient–provider communication about reproductive intentions. (*Am J Public Health.* 2013;103:1357–1366. doi:10.2105/AJPH.2013.301265)

We reviewed the literature on childbearing desires among people living with HIV to understand to what extent and why such desires have not been appropriately addressed in the public health response to HIV. We briefly explain why appropriate attention to fertility desires among people living with HIV should be a public health priority. We then present the results of a historical review of the HIV epidemic in the United States focused on reproductive desires for biological children. From the early epidemic up to the current context, we document a critical unmet need for reproductive planning, including research on this topic. We present evidence that (1) reproductive desires among people living with HIV have been largely ignored historically, (2) HIV-positive women and men desire to have biological children, and (3) despite recent attention to fertility intentions in research, patient–provider communication about safer childbearing remains limited according to the few published studies available.

Drawing on this history, we discuss 3 key reasons for the lack of attention spanning across the 3 decades of the epidemic: (1) the initial focus on men who have sex with men (MSM) because of the early epidemiology of the epidemic, (2) subsequent focus on infants and sexual partners because of legitimate concerns about vertical and horizontal transmission before the development of antiretroviral therapy (ART) and HIV preconception strategies, and (3) a legacy of stigma that persists despite medical advances that make childbearing among people living with HIV much safer. We recommend a series of strategies for addressing this unmet need.

Roughly three quarters of more than 1 million people living with HIV in the United States are of reproductive age.[1,2] Similar to persons who are not infected with HIV, research suggests that people living with HIV have desires and intentions to have biological children that warrant adequate attention and available high-quality reproductive health care from HIV providers. In a seminal study published in 2001, Chen et al. reported that among 1421 HIV-positive women and men from a nationally representative sample of adults in the United States receiving medical care, 29% of women and 28% of men desired children in the future.[3] More recently, a study of HIV-positive women in a Baltimore, Maryland, clinic (mean age = 32 years) documented that 59% desired to bear future children.[4] Despite these desires, a few recent studies suggest that reproductive counseling has yet to become a standard component of routine HIV clinical care in the United States.[5–7]

Why is this a concern? For one, providers must know whether their HIV-positive patients want to bear children to tailor treatment options and refer patients for HIV preconception counseling to meet their childbearing desires while preventing HIV transmission to partners (horizontal transmission) and children (vertical transmission). In addition, there is the need to ensure that services adequately respond to the sexual and reproductive rights of people living with HIV.[8,9]

Although there has been recent recognition that the reproductive intentions of people living with HIV have been largely neglected with consequences for public health and human rights, there has not been a historical review to explore the past and current scope of this problem or discuss why this need remains unmet in the United States. To enhance provider communication with HIV-positive patients of reproductive age about their reproductive desires and intentions, these gaps must be addressed. Therefore, we explored 3 aims. First, we turned to the history of the epidemic in the United States to understand the scope of the need for reproductive planning for people living with HIV. Second, using this historical context, we explored the reasons underlying the current challenge. Third, we considered strategies for meeting this need.

Our analysis focuses specifically on desires to have biological children among people living with HIV. However, nearly half of all pregnancies in the United States in 2006 were unintended,[10] indicating that the need for routine reproductive planning certainly extends beyond people living with HIV. Several of the concluding recommendations can apply to the general population more broadly. The review and recommendations also focus on women and men who have sex with women as having biological children is a more relevant reproductive health concern for these populations than for MSM. Much of this article presents data on HIV-positive women because of the very limited research on childbearing desires among HIV-positive men and HIV-negative women in relationships with HIV-positive men. We recognize, however, the importance of this issue for these populations and highlight the need for future research. Finally, to ensure focus, we have limited the review to the desire for biological children and childbearing; thus, pregnancy prevention is not discussed. It is likely, however, that many of the conclusions and recommendations will apply to pregnancy prevention or spacing—the more commonly emphasized dimensions of family planning.

We also focused on the US epidemic for several reasons. Increasingly, research on the fertility intentions of people living with HIV occurs in low-resource country contexts and rightfully so because of the magnitude of the epidemics in these settings.[11,12] Much of the historical literature, however, discusses the epidemic in the United States, and even in this high-resource setting, HIV persists as a public health challenge. According to the Centers for Disease Control and Prevention (CDC), there were an estimated 47 500 new HIV infections in 2010. Of these, 63% stemmed from male-to-male sex and 25% occurred via heterosexual transmission.[13] Women constituted an estimated 20% of the newly infected persons in 2010, 64% of whom were Black women[13] who must not only contend with HIV-related stigma but also with marginalization in the form of sexism and racism.[14] With this epidemiology and its implications, the lack of attention to the epidemic's impact on women, men who have sex with women, and reproduction must be addressed.

METHODS

We searched peer-reviewed English-language literature reported in PubMed and Google Scholar from June 1981, when the first report of AIDS was published, to May 2012 using keyword combinations related to HIV, childbearing, and communication (e.g., "HIV," "AIDS," "fertility intentions," "fertility desires," "pregnancy," "reproduction," "reproductive health," "childbearing," "prevention of mother-to-child transmission," "antiretroviral therapy," "communication," "discussions," "preconception counseling"). Our interest was in scientific attention to this issue so we did not search non–peer-reviewed literature. We excluded articles focused on assisted reproductive technologies or contraception in the context of HIV as well as articles that examined the effect of HIV or ART on fertility or the effect of pregnancy on HIV disease progression. We did not include empirical studies with populations at risk for HIV because of risky behaviors (e.g., injection drug use) but not infected with HIV. Because this was not a systematic review, some relevant articles may not have been captured in the literature search.

We identified and categorized 41 articles specifically related to assessing and responding to desires for children among people living with HIV as (1) early epidemic, 1981–1991 (n = 5), (2) changes in the epidemic, generally 1992–2006 (n = 18), and (3) current context, 2007 to May 2012 (n = 18). (See appendix, available as a supplement to the online version of this article at http://www.ajph.org, for a complete listing of categorized articles.) We based temporal categorization on the date(s) of data collection if provided in the methods or the publication date. We also identified and included additional articles relevant to but not specifically about desires for children among people living with HIV (e.g., articles about perinatal transmission, ART, or the epidemiology of HIV among women) but did not categorize these.

Upon reviewing these publications for epidemiological, clinical, and sociocultural information, we identified key themes relevant to assessing and understanding attention to desires for children among people living with HIV (or lack thereof) across the history of the epidemic.

RESULTS

Herein we describe themes for each phase of the epidemic, drawing upon the literature captured in the review as well as some additional publications, including key institutional documents. We also summarize the state of the discourse and research on this topic from the early epidemic through the changes in the epidemic to the current context.

Early Epidemic

HIV was first recognized in the United States in 1981 among MSM and was early on described as a gay-related disease, and an epidemic of stigma, in large part because HIV-related stigma is exacerbated by stigma associated with same-sex intercourse and drug use.[15] An analysis of HIV incidence from the period 1978–1999 found that incidence among MSM was as high as 5 to 20 infections per 100 person-years in the early 1980s.[16] Documented infection rates among women were, on the other hand, relatively low.[17] The low rate of infection among women may have been attributable to underdiagnosis as women were presenting with different AIDS-related illnesses compared with men (e.g., ovarian cancer). In addition, guidelines on universal counseling and voluntary HIV testing for pregnant women were not rolled out until later.[18] Not surprisingly because of the early known epidemiology, HIV/AIDS was essentially first introduced as a concern predominantly of MSM (and to a lesser extent intravenous drug users and individuals who received blood transfusions). Scant attention was paid to transmission of the virus via heterosexual intercourse or the impact of HIV infection on reproduction.

The earliest peer-reviewed article we identified on the reproductive decision-making of HIV-positive persons was published in *Journal of the American Medical Association* in 1989,[19] almost 10 years after the first published report of AIDS. This study reported how knowledge of HIV status influenced the decision to continue or terminate a pregnancy by comparing 28 HIV-positive intravenous drug users to 36 HIV-negative intravenous drug users. Fifty percent of the HIV-positive women chose to terminate the pregnancy compared with 44% of the HIV-negative women. The authors concluded that HIV status was not sufficient for explaining differences in reproductive decision-making and that it is necessary to examine social and behavioral contexts, such as relationship status, family pressure, and religious beliefs.[19]

Several conceptual articles around this time grappled with provider approaches to reproductive decision-making for women living with HIV.[20–22] In 1990 Arras raised the question "Is it ethical to counsel them [women] to avoid conception or, if pregnant, to abort?" and concluded that some type of nondirective counseling (e.g., providing factual information regarding all options related to pregnancy or childbearing or helping the client understand the meaning of various options) is the most appropriate approach.[21(p353)] At the same time, though, another author noted that the current discourse related to AIDS and reproductive decision-making threatened the well-established practice of nondirective counseling.[22] More than 20 years ago, these thought pieces recognized a challenge related to communication about childbearing for people living with HIV that, to some degree, persists today.

Changes in the Epidemic

Feminization of HIV. Key demographic changes in the epidemic have made reproductive health needs among women, men who have sex with women, and men who have sex with women and men increasingly important to address. Over time heterosexual transmission of HIV has increased, resulting in higher infection rates among women.[23,24] AIDS cases attributed to heterosexual activity in the United States increased 130% in 1993 compared with 1992.[25] Furthermore, between 1991 and 1995 the number of AIDS cases diagnosed among women increased by 63%. This increase was more than any other population group, regardless of race or mode of exposure to HIV.[23] This "feminization of HIV"[26] continued; in 2010 women accounted for 20% of new HIV infections in the United States,[13] compared with 7% of reported AIDS cases in 1985.[27]

Focus on infants and sexual partners. Along with the increase in heterosexual transmission of HIV and rise in the number of women infected came challenges related to perinatal transmission, transmission to uninfected sexual partners, and infected parents' ability to care for children.[28,29] In 1985 research suggested that "mothers are the likely source of infection" in non–transfusion-related cases of AIDS in infants.[30(p363)] At this time before ART, the rate of mother-to-child transmission of HIV in the United States ranged from 15% to 30%.[31] In 1992 the rate of AIDS cases among infants was 8.9 per 100 000 births.[32] Researchers used a mathematical model to predict the number of youths whose mothers died of AIDS in the United States and estimated that by the end of 1995, maternal deaths caused by the epidemic would have orphaned 24 600 children and 21 000 adolescents.[33]

These legitimate concerns about transmission and mothers' health led to a focus on protecting the health of infants and partners at the expense of appropriately attending to HIV-positive patients' reproductive desires. In 1985 the CDC put forward recommendations that discouraged childbearing among HIV-positive women.[34] State health departments adopted such recommendations and many were even more directive in their statements, urging women living with HIV not to become pregnant.[22] The director of the CDC AIDS program articulated the assumption in 1988 that HIV-positive women would not want children: "Someone who understands the disease and is logical will not want to be pregnant and will consider the test results when making family planning decisions."[20(p321)] Although such institutional positions and individual-level attitudes about childbearing were understandable with the transmission risks during the pre-ART era, the literature reviewed suggests that the public health response was to ignore or outright discourage reproduction. This response essentially stigmatized childbearing among people living with HIV.[35] Appropriate nondirective counseling about the risks associated with conception, pregnancy, and childbearing was not a standard practice of care because of the risk of transmission at this time.

Antiretroviral therapy. The advent and scale-up of life-prolonging ART and related prevention of mother-to-child transmission (PMTCT) programs has given hope to people living with HIV wanting biological children in the future.[9] The use of ART has resulted in a substantial decrease in the risk of mother-to-child transmission to as low as 1% to 2% with appropriate treatment regimens and infant feeding strategies.[36–38] With this development, PMTCT efforts have been remarkably successful. From 1993 through 1997 the percentage of perinatally exposed infants born to mothers who received an HIV test before delivery increased from 70% to 94% and the percentage receiving zidovudine, the first antiretroviral drug available, increased from 7% to 91%.[32] As a result, the rate of HIV infection among infants dramatically declined. In 1991 an estimated 1650 infants were infected compared with 2004 when 41 cases of pediatric perinatal infection were identified.[39]

With this decline in mother-to-child transmission because of ART use, policies related to pregnancy among HIV-positive women have shifted to be more supportive of desires for children. In 1995 the US Public Health Service recommended nondirective reproductive counseling,[18] and the CDC's revised recommendations released in 2001 also stated that HIV-positive women should receive information about all reproductive options and should be counseled in a manner that is a respectful and supportive of their decision.[40]

The availability of treatment also has resulted in those with HIV living longer, healthier lives. Essentially, the roll-out of life-prolonging combination antiretroviral therapy in 1996 was a turning point: HIV transitioned from being a death sentence to a chronic condition that could be managed long term.[41] The life expectancy of a young person (aged 20 years) on ART has been estimated to extend about 50 years beyond initiation of therapy.[41,42] The life-prolonging effect of treatment minimizes concerns about the ability of HIV-positive parents to care for their children that was a central concern before the advent of ART.

Moreover, this extended life expectancy means a longer reproductive period for persons living with HIV, particularly for the increasing numbers of young people infected. Between 2006 and 2009 overall HIV incidence did not significantly change in the United States; the incidence among those aged 13 to 29 years, however, increased by 21%.[43] It is important to note that the Women's Interagency HIV Study, a cohort study of the natural history of HIV infection in women in the United States, found that since ART became available, the live birth rate among HIV-infected women increased by 150% compared with only a 5% increase among similar non–HIV-infected women during the same period.[44] Another analysis found that compared with the year 2000 there was approximately a 30% increase in the number of infants born to HIV-infected women in 2006.[45] Such findings likely reflect the impact of ART on reproductive decision-making, particularly among younger women, associated with the 2 changes noted here: decreased risk of perinatal transmission and increased life expectancy.

Limited attention to reproductive decision-making. Despite these changes in the epidemic that make provider attention to patients' reproductive desires and intentions a critical component of HIV care, scientific attention to the reproductive intentions of people living with HIV remained limited from 1992 to 2006. The 18 relevant studies that we identified point to the importance of addressing the desire of people living with HIV for biological children (see appendix available as a supplement to the online version of this article at http://www.ajph.org). A 1994 article on policy, ethics, and reproductive choice called for provider discussion with patients about medical facts, psychosocial issues, and family and relationship contexts as a more appropriate approach to addressing pregnancy desires than outright discouragement of childbearing.[46] A study of HIV-positive, methadone-using women (n = 126) published the same year highlighted the importance of considering existing children in reproductive counseling.[47] Researchers in the mid-1990s examined factors associated with reproductive choices (pregnancy, abortion, or sterilization) among a sample of HIV-positive women in New Orleans, Louisiana (n = 403).[48] They found that young age and history of sexual assault were associated with becoming pregnant after HIV diagnosis, but did not include fertility desires and intentions as predictors of reproductive decision-making although the authors did call for culturally sensitive, noncoercive counseling messages.[48]

In several studies assessing reproductive intentions of HIV-infected women, Sowell et al. also called for providers to address childbearing desires.[49–52] A qualitative study of 20 HIV-positive women, however, reported that participants believed that health care providers viewed them as women who should not reproduce under any circumstances.[53] In 2004 Thornton et al. published a literature review examining reproductive decision-making for serodiscordant and seroconcordant couples with the aim of identifying useful information for counseling these couples.[54] This is one of the few articles to also include men and consider the issue in the context of couples.[3,6,28,54]

Current Context

Desire for biological children among persons living with HIV. Since 2007 there has been a relatively dramatic increase in the number of peer-reviewed publications related to fertility desires among HIV-positive individuals, when one takes into account the historical lack of literature on this topic. We identified 18 publications that explored fertility desires and intentions among HIV-positive women and, albeit to a lesser extent, HIV-positive men (see appendix available as a supplement to the online version of this article at http://www.ajph.org). Nattabi et al. conducted a systematic literature review of peer-reviewed empirical studies published between 1990 and 2008 that specifically addressed factors influencing fertility desires among people living with HIV.[11] They identified 29 studies published globally, including 12 from the United States,[3,49–52,55–61] and concluded that fertility desires were influenced by myriad factors, including demographics, health, stigma, and culture.[11]

Many of the studies identified in that review as well as others continue to provide evidence of the basic fact that makes the unmet need for reproductive planning critical to address: people living with HIV in the United States desire to and will have children.[11,62–66] Data suggest that between 28% and 59% of people living with HIV of reproductive age desire to have children.[3,4] The most recent study identified, which examined fertility desires among both HIV-infected women and men in Los Angeles County, California (n = 93), found that 39% reported a desire to have children (there was no significant difference between women and men).[6] Evidence from a sample of HIV-positive women in the Midwest (n = 74) also indicated that women aged 30 years and younger are more likely to choose to become pregnant than women aged older than 30 years (39.5% vs 11.1%, respectively).[61]

Because of the importance of age as a determinant of fertility intentions, which is demonstrated by a number of other studies,[11] there are notably few studies focusing explicitly on the reproductive desires among young people living with HIV. The majority of studies have included adult women with the mean age often in the mid-30s.[11] One recently published study focused specifically on young women by comparing a clinic-based sample of HIV-positive female youths (n = 46; age 15–24 years) in Baltimore with a community-based sample of at-risk non–HIV-infected female youths in Baltimore (n = 355; age 15–24 years) and found no significant differences in childbearing motivations or desire for a future pregnancy; indicating that one's HIV status did not diminish childbearing plans.[67] Qualitative interviews that included both perinatally and behaviorally infected female youths in addition to adult women suggested that the role of effective treatment has redefined the question of childbearing among people living with HIV. When asked "Do you think it's okay for HIV+ women to become pregnant if they want to have a child," a young participant responded

> I can't believe that is really a question . . . . The bottom line is everyone deserves to have kids. Yes, I have HIV. No, I didn't want [HIV], but I still want a family, I still want a life . . . everyone deserves that right. (24-year-old female)[68]

Lack of attention to patient–provider communication about reproduction. Despite increasing recognition of the desire of people living with HIV for biological children, only 5 studies explicitly considered patient–provider communication about reproduction and all pointed to a lack of provider-initiated conversations in the United States.[5–7,68,69] In the Women Living Positively survey, a cross-sectional survey of 700 HIV-positive women, approximately 30% had been pregnant before the survey or would consider pregnancy, and of these women, 48% were not asked by their HIV provider if they wanted to have a child either now or in the future.[7] Although several young women living with HIV from the Baltimore-based qualitative study reported at least some brief discussion related to childbearing with their provider, no one was familiar with the term "preconception counseling."[68] These findings are consistent with the high unmet need for reproductive counseling (56%)

that Finocchario-Kessler et al. identified among a sample of HIV-positive women receiving care in Baltimore.[5]

Even with this best-case scenario, because the study was conducted in dedicated HIV care clinics committed to a comprehensive care model, the authors found that the majority of conversations with providers that did take place were patient-initiated.[5] The most recent study on this topic, from Los Angeles County, also pointed to the need for provider-initiated counseling. More than two thirds of the clients reporting a desire to have a child had not discussed their fertility desires or methods of safe conception with providers although 64% said that they would like to discuss this topic with their provider. Providers surveyed in this study noted the need for specific training in reproductive health services for people living with HIV as well as county, state, and national guidelines related to biological childbearing for this population.[6]

Making conception safer. The importance of providers in ensuring safer childbearing for HIV-positive women—in terms of the woman's own health, the health of the baby, and the health of the partner—is also well-established, and communication is central to their role. Specifically, preconception counseling has been identified as a provider-initiated strategy promoting safer conception, pregnancy, and delivery for HIV-positive women.[70–73] The concept of preconception counseling was introduced more than 60 years ago as a way to improve maternal and infant outcomes generally.[74] Recently, this strategy has been adapted to address the particular risks associated with pregnancy among HIV-positive women, and a US Department of Health and Human Services panel has released guidelines specifically for HIV preconception counseling.[75] The CDC also plans to include preconception counseling as part of forthcoming recommendations on prevention with persons with HIV.[76]

Essentially, preconception counseling offers a standardized way to (1) impart information about the risks of transmission to infants and sexual partners and strategies for minimizing those risks, and (2) ensure patients receive services that minimize risk of transmission, including provision of ART, management of sexually transmitted infections, and referrals for assisted reproduction.[72] Frequent concerns that can be addressed during these consultations may include the need to initiate or change ART regimen, to optimize treatment for other health concerns such as diabetes or hypertension, to identify any medications that are contraindicated in pregnancy (i.e., efavirenz), and to discuss optimal strategy for safer conception with serodiscordant couples. Two key features are inherent in this fundamental strategy for reducing transmission of HIV during conception and pregnancy: (1) effective patient–provider communication that occurs before conception and (2) a collaborative effort between providers and patients to apply risk reduction strategies to minimize risk and maximize healthy outcomes.

Although few, there are clinical settings nationally where a trained clinician is available to provide HIV preconception counseling to couples interested in conception. One such example is at the Johns Hopkins Moore Clinic for HIV Care. Data from a chart review of 81 preconception counseling sessions for HIV-positive patients interested in childbearing revealed that the majority (65%) of couples were serodiscordant and 49% of patients had no living children. Approximately half (51%) of female patients had at least 1 medical comorbidity—the most common of which were psychiatric conditions (16%), hepatitis C (11%), and hypertension (9%), highlighting the need for strategic planning before conception.[77] Furthermore, 28% of female patients on ART were on a regimen including efavirenz, and one third or more of all couples reported no or inconsistent condom use.[77] These findings demonstrate a number of issues such as unsafe sexual practices, prudent regimen considerations, and other common medical problems to be addressed in the context of preconception care.

DISCUSSION

The public health implications of this lack of understanding about patient–provider communication as well as low reported levels of communication from the few studies available cannot be ignored. Lack of communication is associated with a lack of accurate knowledge of perinatal transmission risk. For example, only 15% of women living with HIV and receiving clinical care in the Baltimore-based study were aware that the risk could be reduced to less than 2% with ART and avoidance of breastfeeding.[4] Qualitative findings also suggest that few had accurate knowledge of safer conception strategies, as several expressed confusion regarding how it was possible to reduce risk during conception with serodiscordant or seroconcordant partners.[68]

The need to maximize and apply available risk-reduction strategies and technologies becomes even more critical in the context of HIV treatment as prevention. Findings from the HPTN-052 trial show that risk for infection among serodiscordant couples is reduced by 96% with the early initiation of ART for the infected partner.[78] The Partners PrEP and the TDF2 studies with serodiscordant heterosexual partners found a reduction in HIV acquisition by negative partners via preexposure prophylaxis.[79,80] The recent US Food and Drug Administration approval of Truvada for use as preexposure prophylaxis with non–HIV-infected adults at high risk of HIV infection,[81] along with the release of CDC interim guidelines on use of preexposure prophylaxis in heterosexual discordant couples,[82] make this strategy feasible in the United States.

As several authors have already pointed out, the implications of treatment as prevention for childbearing among people living with HIV must be considered[83,84] and the role of the provider and provider-initiated communication will continue to be paramount. Use of ART is already a key component of strategies to reduce vertical transmission. Now data show the effectiveness of this approach to prevent horizontal transmission. This development thus has the potential to help reduce some of the persistent stigma related to risks associated with childbearing. The application of ART for PMTCT was not sufficiently leveraged to address stigma that emerged during the pre-ART era, and it is important that providers understand and communicate the possibility of safer conception to people living with HIV. Because of the identified importance of early ART initiation and viral suppression to achieve the maximum prevention benefits, providers must also appropriately communicate with their patients to ensure that they are retained in care and support adherence to prescribed regimens. Finally, as large-scale efforts are made to get more people living with HIV on treatment earlier, more patients may want and have biological children (if one considers the dramatic increase in live births observed when ART was first rolled out). Even without changes in reproductive desires and behaviors, the basic imperative remains—it is essential that providers ask patients about their reproductive plans.

A Persistent Legacy of Stigma

The stigma against childbearing among people living with HIV persists among the general public and medical providers today. A 2008 Foundation for AIDS Research–sponsored national survey of public perceptions of women living with HIV found that only 14% of the respondents (~5000 total) reported that HIV-infected women should have children.[85] The Women Living Positively survey found that HIV-positive women perceive this stigma; 59% reported that society strongly urges them not to have biological children.[7] The majority of the Baltimore-based sample of HIV-positive women felt that it was okay to have a child,[4] and supporting qualitative data illustrated caveats that some women described (e.g., it is okay as long as the mom is taking her medications faithfully).[68] Stigma and discrimination surrounding HIV pose a severe challenge to the delivery of adequate sexual and reproductive interventions generally.[86] Stigma appears to be one important factor contributing to the missed opportunities to strategically and safely plan pregnancies with patients and thus preventing full application of the science and knowledge available to prevent new infections while maximizing autonomy and respect for human rights.

Throughout the evolution of the HIV epidemic, stigma has been a recurrent theme. Because of the limitation of pediatric formulations to treat HIV and the limited life span afforded to adults before the availability of ART, the context for providers' initial resistance to childbearing among women living with HIV was understandable. Significant advances in treatment and prevention, however, have mitigated many of the initial justifications for resistance. This stigma—societal and medical—continues to discourage pregnancy among HIV-positive women and men even as medical and behavioral developments have increased the ability of people living with HIV to have biological children with minimal transmission. This stigma against people living with HIV having biological children is likely conflated by stigmas associated with racism and poverty, especially given the overrepresentation of HIV among Black women and men and persons of low socioeconomic status. It is important to remember that people living with HIV are people, first and foremost, with sexual and childbearing desires and intentions similar to those of people living without HIV.

Implicit in the current lack of patient–provider communication is this long-standing legacy of stigma around childbearing for people living with HIV. The discouragement of childbearing among people living with HIV and deprioritization in the medical field most likely contributed to a lack of education and training in effective communication among medical providers and patients around family planning and childbearing. Other more general challenges to communication are also worth noting. The most relevant study regarding patient–provider communication proposed 5 reasons why providers are inconsistent in applying effective prevention strategies for poor pregnancy outcomes: (1) lack of knowledge regarding the incidence of unintended pregnancy, (2) inadequate provider education, (3) lack of confidence in the value of preconception counseling, (4) a belief that women will know to seek appropriate care, and (5) concerns over lack of reimbursement coverage for preconception visits.[87] The identified lack of knowledge and competence to communicate effectively with patients offers clear opportunities for intervention.

Recommendations for Moving Forward

Incorporating preconception counseling opportunities and information for all HIV-positive women and men into routine HIV care is one major area for future work. We recommend preconception counseling as a universal discussion among providers and patients of reproductive age with any chronic transmittable or genetic condition. HIV is only one of many such conditions. Inherent in this effort, researchers, policymakers, and clinicians must prioritize improving patient–provider communication about fertility desires, intentions, and practices. Because of the scope of this article, we will focus our recommendations on people living with HIV in the United States, but recognize that they apply to many other medical conditions and settings.

We recommend the following as a starting point: (1) address research gaps related to HIV provider attitudes about childbearing among people living with HIV and barriers to recommending and implementing preconception counseling, including provider assessment of patient–provider communication; (2) improve provider training on HIV preconception counseling; (3) systematize HIV providers' assessment of reproductive desires and intentions to identify those individuals and their partners needing preconception care; and (4) make concerted efforts to attend to the reproductive desires and needs of men who are HIV-positive or who have HIV-positive sexual partners.

Currently, research is lacking on the extent to which and how providers attend to HIV-positive patients' reproductive desires or the reproductive desires of HIV-negative women and men with HIV-positive partners if one considers that only 1 of the identified studies included provider perspectives.[6] Although low levels of provider-initiated communication have been documented, this information is based largely on patient reports. Future research needs to examine, from providers' perspectives, attitudes and communication related to pregnancy and childbearing among people living with HIV. Our understanding would be greatly enhanced by directly surveying provider attitudes about childbearing among people living with HIV, as well as provider and patient dyadic reports of communication about childbearing. Providers may think they are addressing the issue when they really are not. Patients may perceive that providers have negative opinions about people living with HIV bearing children when in fact providers may not have knowledge about preconception counseling. Or, providers may assume that if patients are interested in bearing children, patients will initiate the conversation. Greater research attention to younger patients and the providers who care for them is also needed.

A better understanding of the potential ambivalence providers may face as they weigh individual rights and concern for new infections should be explored. Such ambivalence may be at the core of avoiding direct communication about childbearing. Gender inequality, relationship dynamics, and a diverse range of normative beliefs about sexual behavior heighten the complexity of reproductive counseling,[88] which is further complicated by HIV and its associated stigma. As has been demonstrated by health behavior change efforts in other contexts, the style and manner of how providers communicate this information is often just as important as the content.[89,90] Therefore, research that assesses how (as well as what) providers communicate regarding reproductive and conception risk reduction options is important. Furthermore, investigation of structural barriers to routine reproductive counseling as part of HIV clinical care in the United States is needed. Time constraints and large provider–patient ratios are always a realistic consideration when one is aiming to improve comprehensive consultations. Discussions regarding who is the individual best suited to provide reproductive counseling (or other lifestyle and behavioral risk counseling) in the health care context are emerging. Lastly, it is important to recognize that the ideal implementation strategy may likely vary on the basis of clinic resources, geographic patterns of HIV prevalence, and physical distance to HIV preconception counseling specialists.

On the basis of the existing literature describing barriers to patient–provider communication and the single identified study on provider perspectives with regard to fertility intentions of HIV-infected clients, we recommend improving training on communication skills generally and HIV preconception counseling skills specifically in medical curricula for HIV care providers. Research has shown that provider communication skills can be successfully taught and acquired.[91] Equally important, physicians have expressed interest in such training.[6,92] Beyond medical and nursing academic programs, follow-up training should also be offered at the facility level to orient providers to the preconception health services available for HIV-positive patients. This can be facilitated by online resources such as the guidelines from Department of Health and Human Services panel[75] and the forthcoming CDC recommendations on prevention with persons with HIV.[76]

Providers may be more willing to initiate discussions with patients about their reproductive intentions if they know how to connect patients to services that they need. A referral model may be the most feasible to consider in the United States, in which HIV providers initiate the conversation and assess patients' goals, and then appropriately refer them for either contraception or HIV preconception counseling. Given the current dearth of HIV preconception counseling specialists, efforts to identify and train such specialists are needed. Gynecologists in HIV care settings may also be perceived as preconception experts and thus should be offered specialized training. In the meantime, innovative distance referral options should be considered.

Moving toward systematizing providers' assessment of reproductive desires and intentions to link them to preconception services is an essential next step. A short, efficient checklist offers one potential mechanism for helping providers systematically determine if their patients desire children (or are unsure) and could benefit from preconception counseling. The effectiveness of tools designed to improve communication with patients has been demonstrated previously. In the context of family planning, brief decision-making tools have resulted in delivery of information that was better tailored to patients' needs and increased patient involvement.[93,94] Similar tools also have increased providers' confidence in discussing sexuality with patients.[95] In busy clinics a checklist could act as a tool to remind providers to discuss reproductive issues while simultaneously expressing their openness to conversations about how to plan future safe pregnancies. It is also hoped that making childbearing discussions routine will reduce stigma, just as routine opt-out HIV counseling and testing have been identified as a potential way to reduce stigma.[96]

Such a tool also offers an opportunity to assess HIV-positive men's and partners' reproductive desires, which have largely been neglected and are important to address in both research and practice going forward. Whereas some women may discuss childbearing during gynecological appointments, men do not have a similar opportunity. An intervention that could assist HIV providers to quickly assess reproductive needs and make appropriate referrals may provide the first chance for HIV-infected men to discuss childbearing with a health care professional. In addition, questions about HIV-positive patients' perceived partner desires for children should also be asked to help providers better understand relationship dynamics and offer couples-based preconception counseling. Finally, greater understanding is needed about HIV-negative women in partnership with HIV-positive men. Although these women are not at risk for perinatal transmission, preventing horizontal transmission during conception must be addressed in clinical care.

Conclusions

Through effective patient–provider communication, medical professionals can identify HIV-positive women and men desiring children and connect them to further preconception counseling and services to ensure safer childbearing. For these conversations to be incorporated as standard practice in HIV care, however, we must first confront the reasons underlying the current neglect of patients' reproductive desires in clinical services. With this literature review, we have attempted to do just that.

The challenge we currently face is rooted in a history of neglecting HIV-positive individuals' fertility intentions. With the early focus on MSM, the impact of the epidemic on reproductive health generally and reproductive desires specifically were not considered. Even as women became increasingly infected through heterosexual intercourse, the public health response to very legitimate concerns about vertical transmission to infants and horizontal transmission to uninfected male partners ignored or outright discouraged reproduction in a directive manner that sidelined reproductive desires and rights and stigmatized childbearing. This stigma persisted even as changes in the epidemic made childbearing more feasible and provider attention to childbearing desires even more critical. The consequences of this history cannot be ignored. HIV-positive patients, like HIV-negative patients, desire and will have children and require appropriate medical services to support their own health as well as the health of their infant and sexual partners.

More generally, promoting open discourse about sexual and reproductive health strategies offers an opportunity to challenge stigma head on and strengthen the public health response to HIV in a manner that supports the rights of individuals living with HIV. Stigma continues to operate as an underlying driver of the epidemic that needs to be addressed.[97] Tackling stigma at the provider level as it relates to sexual and reproductive health care for people living with HIV offers one promising strategy that has been largely untried.

At this point in the epidemic, supporting HIV-positive patients' reproductive desires and maximizing public health go hand in hand. The unfortunate legacy of ostensibly prioritizing public health at the expense of reproductive intentions needs to be addressed. The time has come to engage providers in conversations with their reproductive-age patients about fertility desires and intentions. ■

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Contributors

R. J. Steiner led the conceptualization, research, and writing of this article. S. Finocchario-Kessler and J. K. Dariotis contributed to the framing, research, and revisions of the article, and J. K. Dariotis oversaw the entire process. All authors reviewed and approved the final version.

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