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"We Weren't Using Condoms Because We Were Trying to Conceive": The Need for Reproductive Counseling for HIV-Positive Women in Clinical Care

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Abstract

Although a significant number of HIV-positive women intend to have children in the future, few work with providers to safely plan pregnancy. We conducted 20 semistructured in depth interviews with HIV-positive adolescent and adult women receiving HIV clinical care in an urban setting. Participants were purposively sampled to include diversity in age and childbearing plans. Interview transcripts were analyzed and coded independently by two study team members before reaching consensus on emergent themes. Among this sample of HIV-positive women (mean age = 27.9, 95% African American, 50% on antiretroviral therapy [ART], 65% want a biological child), only 25% reported discussing their childbearing goals with their HIV provider. Women actively trying to conceive recognized the risk to themselves and their partner, but had not talked with their provider about safer conception strategies. Data regarding provider communication about childbearing were organized by the following emergent themes: (1) confusion and concern on how to conceive safely, (2) provider characteristics or dynamics that influenced communication, and (3) provider guidance offered regarding childbearing. Even in this unique study setting in which referrals for preconception counseling are possible, women were unaware of this specialized service. Provider initiated reproductive counseling is needed to strategically avoid or plan pregnancy and reduce risk of transmission to partners and infants rather than leaving it to chance, which can have major health implications.

Introduction

Antiretroviral therapy (ART) and its associated improvements in health and lowered infant infection rates provides hope for many people living with HIV/AIDS (PLHA) who have access to treatment and want to have a biological child.[1] A growing number of studies document the intention to initiate or continue childbearing among PLHA.[1–3] These intentions result in births as demonstrated by the 150% increase in the live birth rate among HIV-positive women in the United States since ART became widely available in 1996.[4] In high resources settings, adherence to appropriate ART and avoidance of breastfeeding can successfully reduce mother-to-child transmission (MTCT) of HIV to less than 1%,[5] and quality perinatal HIV care can avoid any increase in adverse pregnancy or neonatal outcomes.[6] These findings have potential relevance for over 85% of the 1.2 million PLHA in the United States who are diagnosed during their reproductive years (15–45 years).[7] The risk of heterosexual transmission, however, remains a significant public health concern,[7] particularly among two populations at increased risk in the United States: African American women and serodiscordant couples. First, African American women in the United States have increased risk for adverse pregnancy and health outcomes in general.[8] Coupled with their increased risk for HIV infection,[7] the need for safer conception and pregnancy planning with providers among African American HIV-positive women is paramount, and should be available for all HIV-positive women and men in their reproductive years. Serodiscordant couples who intend to have biological children are also at increased risk for seroconversion (HIV-partner infection).[9] In addition to HIV, other health

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conditions (e.g., hypertension, diabetes) require appropriate intervention prior to pregnancy to avoid adverse outcomes for women and infants.

Given this context, and the frequency of serodiscordant partnerships,[3] it is critical for HIV providers to work with PLHA to carefully plan or avoid pregnancies. The recent HPTN 052 findings demonstrating a 96% reduction in HIV transmission to serodiscordant partners with the use of early ART initiation,[10] provides a feasible strategy for safer conception among serodiscordant couples. Similarly, preexposure prophylaxis (PrEP) to the uninfected partner can be used to reduce the risk of transmission during the conception period.[11,12] The opportunity to apply such research advances can only occur if communication regarding childbearing plans occurs between patients and providers prior to pregnancy. It is essential that communication occur prior to conception in a manner that encourages collaboration between providers and patients to plan or avoid future pregnancies (as determined by patient desires). The first step in this process requires a conversation, one that is often avoided due to providers' discomfort with the topic and patients' fear of disapproval or judgment.[13] Unfortunately, even in countries with greater resources for HIV care, providers fail to routinely discuss reproductive plans with patients.[14] Consequently, this lack of communication may result in missed opportunities to: (1) reduce transmission to serodiscordant partners, (2) prevent reinfection among concordant couples, (3) address health issues that lead to poor birth outcomes, and (4) meet patients' comprehensive reproductive health needs that keeps clients engaged in care.

The Department of Health and Human Services (DHHS) Panel on Treatment of HIV+ Pregnant Women and Prevention of Perinatal Transmission provide guidelines on Preconception Counseling and Care for HIV+ Women of Childbearing Age.[15] HIV provider awareness of such guidelines, however, is uncertain. When reproduction is discussed in a clinical setting, the emphasis is typically on avoiding unintended pregnancies and reducing transmission to infants. High rates of unintended pregnancies among HIV-positive women, however, suggest that current efforts are inadequate.[16] For those HIV positive patients who want to conceive, early discussions about childbearing plans and preconception counseling enable PLHA to make informed reproductive decisions, avoid teratogenic drugs, identify issues such as diabetes or hypertension that may require intervention prior to pregnancy, and discuss safer conception strategies.[17,18] Patients with such interests may need a referral for HIV preconception counseling, a skill-set that few HIV providers currently have.

Research in the United States has mostly focused on fertility desires and/or intentions of women, with minimal focus on the dynamics of provider communication regarding reproductive options. We present data from 20 qualitative interviews with HIV-positive adolescent and adult women engaged in clinical care regarding communication with their HIV provider and gynecologist regarding future childbearing.

Methods

Patient selection and data collection procedures

We conducted 20 semistructured in-depth interviews with HIV-positive adolescent and adult women receiving HIV clinical care in an urban east coast setting in the United States with a high level of both HIV infection and unplanned pregnancies.[19,20] In 2008, participants were recruited from one of two clinics: a designated HIV clinic for adults or an intensive primary care clinic serving HIV-infected youth up to age 24 years. Participants were purposively sampled to include diversity in age and childbearing plans. Exclusion criteria included: (1) current pregnancy, (2) history of hysterectomy, and (3) age outside of reproductive range (younger than 15 or older than 44 years). After providing oral informed consent, interviews were conducted in a private room within the clinic. The average interview lasted 50 min. Participants received a $20 gift card to a grocery or retail store in appreciation of their time. Nearly all (19/20) of these participants are a subset of a larger quantitative study regarding childbearing intentions and both partner and provider dynamics.[3,21]

Analytic strategy

Interviews were recorded and transcribed. Transcripts were analyzed and coded independently by two study team members before reaching consensus on emergent themes. The larger study team then reviewed and refined themes. The interview guide focused on future goals, living with HIV (disclosure, treatment issues), interest in future childbearing, and communication with their provider about reproductive desires and interests. This article focuses on data regarding the provider–patient dynamics related to reproduction communication.

Results

Demographic characteristics

A total of 20 HIV-positive women receiving clinical care participated in the interviews. The sample mean age was 27.9 years old (standard deviation [SD] = 8.2) ranging from 18 to 42 years old. One quarter (25%) of participants had at least one or more biological children (Table 1). Nearly all participants (95%) are African American and 50% currently received ART.

Sexual experience and current activity

With the exception of three perinatally infected adolescents, 17 women were sexually experienced with 14 (82.4%) of these women reporting a current sexual partner. Among these 14 currently sexually active HIV positive women, nearly 80% had partners who were either serodiscordant or of unknown HIV status and 36% reported inconsistent condom use (Table I).

Childbearing motivations, desires, and communication

A majority of participants expressed the desire to have a child in the future (n = 13, 65%). Most commonly reported motivations to have a biological child were related to one or more of the following: attachment, either to a child (e.g., "to have someone to love" [n = 13, 65%]) or to a partner (e.g., "to share a child with one's partner" [n = 4, 20%]) and/or developmental normalcy (e.g., 'having a child was a normal life experience' [n = 12, 60%]). Most common reasons not to have a child either now or in the future included advanced age or already finished childbearing (n = 4, 20%), fear of HIV transmission to infant (n = 6, 30%), and financial insecurity (n = 5, 25%). While nearly all women (n = 16, 85%) expressed a

Table 1. Participant Characteristics, Childbearing Desires, and Communication with Providers

Characteristics and practices	n = *20 (%)*
Mean age ± (SD), range	27.9 (8.2), 18–42 years
African American	19 (95)
Has ≥ 1 biological child	5 (25)
Currently on ART	10 (50)
Current sexual partner	14 (70)
Partner serodiscordant/ unknown status	11 (79)
Reports consistent condom use	9 (65)
Future childbearing desires	
Wants a child in the future	13 (65)
Provider communication about childbearing	
General communication	15 (75)
Personalized communication[a]	5 (33)
Knowledge of MTCT risk	
Accurate	3 (15)
Overestimated	10 (50)

[a]Among those reporting some communication about childbearing, 5 women reported a conversation personalized to their own situation and future goals.

SD, standard deviation; ART, antiretroviral therapy; MTCT, mother-to-child transmission.

preference for a biological child, a few women ($n=3$) preferred adoption, which would allow them to have a child and not risk transmission; two of whom had already inquired about their eligibility to adopt.

The quality and content of provider–client reproductive communication reported by participants varied. Some type of childbearing communication with a provider was reported by 75% ($n=15$) of the sample. Among those reporting communication, five participants reported a personalized discussion about future childbearing options. To put this into context, among women who want to have a biological child, only 38% (5/13) reported discussing this plan with their provider.

Primary study results

Three themes emerged that describe current provider–client communication about reproductive health for PLHA and inform recommendations for enhancement. We focus the remaining presentation of results on women's experiences that suggest (1) very few understand reproductive options to reduce the risk of transmission to partners, (2) the dynamics of provider communication influence women's comfort level in discussing this topic, and (3) guidance on childbearing varies between providers.

Confusion and concern regarding safer conception options. Several participants expressed questions and confusion regarding how safer conception is possible among serodiscordant couples. In general, respondents were uninformed and expressed disbelief that a couple could successfully become pregnant without transmitting HIV from a positive to a negative partner. The two quotes below speak to this confusion and concern and how it is expressed by both younger and older respondents.

> I mean I don't understand how you can have a child and how your partner don't get it [HIV], you understand what I'm saying? It's like it's confusing. So I don't know how that works. But even though my child might not have it, I might give it to him and I wouldn't want to do that . So that's why I say no. (ID 21, 22 years)

> I think about it because what about the sex partner? Like that's what you've got to think about too. Like if you would have a baby..I know your partner would have to know.…but he's negative, so how would that work? And like right now I think I'm undetectable, so I wonder like if I would get pregnant would all my meds change? (ID 16, 36 years)

For some women the desire to become pregnant outweighed concerns about transmission or reinfection. Given the lack of information about safer conception practices, couples pursued pregnancy goals without safer practices. The quotes below evince how some women and their partners knew they were putting themselves at risk, but did so with the goal of pregnancy. The following participant in a seroconcordant relationship describes her awareness of the risks to herself and partner.

> We don't use condoms cause we was trying to have a baby, we don't use anything. I wouldn't say that it [condom use] is not necessary, because I guess he can keep infecting me more or I can infect [him], however that may go, but like I said, we really haven't used it because we've been trying to conceive. But we also know that one of us can worsen; the other will keep giving the other the infection even more. However, we do know that. (ID 19, 40 years)

> I really started taking medicine when I met my husband because we started using unprotected sex trying to get pregnant…we was wanting to get pregnant so bad it was like he was aiming for it. You know us exchanging fluids and stuff like that it kind of like attacked my CD4 and my viral load due to us trying to get pregnant on our own instead of going getting help, assistance, and that's what made me had to start medicine…because my husband is full blown [AIDS] and I'm positive…(ID 1, 29 years)

Despite this lack of knowledge about safer conception strategies, respondents noted that they have many questions about the process of becoming pregnant and an interest in learning more about reproductive options. Some of the questions women have are presented in the quotes below. These questions range from preconception to pregnancy-specific topics.

> I have questions about what would happen if I got pregnant; would I carry full term or would I have to be on some kind of medication? What could me and my husband do to help us along to conceive? (ID 19, 40 years)

> Before I even think about getting pregnant I would like to speak to a doctor that's in that field and, you know, deal with HIV patients to explain to me like should I take medicine before I try to conceive or should I start it after, you know, should I be like as soon as I feel the first little pain, hurry up and get to the doctors, like what do I suppose to do? (ID 18, 24 years)

Provider characteristics and relationship dynamics influence comfort and quality of childbearing communication. Participants discussed how provider characteristics such as age and gender and the quality of rapport and trust influence their confidence or comfort in discussing personal topics. How participants viewed the dynamics of their relationship with their provider (e.g., saw their provider as a friend or as a mother figure) influenced communication about childbearing as did the

provider's medical specialty. One woman expressed her concern that young providers lack knowledge and experience, which may serve as communication barriers.

> My doctor is young. It's like sometimes I'll be thinking something like do she know what she talking about because she…I'm older than my doctor. (ID 1, 29 years)

Furthermore, some female respondents prefer to talk with female rather than male providers. One female respondent reported that having a male provider served as a barrier to conversations because of additional angst created.

> I got a man doctor.…. you got to ask a woman doctor. You know you feel comfortable asking a lady doctor those kind of questions like that, ..but, huh-uh, I ain't talking to a man…they feel embarrassed talking to a lady about that …… they don't like that. (ID 14, 31 years)

Qualities that promote conversations with providers are very strong rapport and a high level of trust. In particular, provider availability to talk when clients have questions is very important for building a quality provider–client relationship.

> Once we [participant and HIV provider] started having regular conversations and like I call her if I want to know something or I just call her and be like hey how you doing or she'll call me and see how I'm doing. It's like I felt close to her, I just talk to her about anything. Cause like…she's my physician, but it also felt like she was like a friend when I needed it…(ID 18, 24 years)

> We have a close relationship. I ask her questions about my virus and she answers them. I just brought it up one day [future pregnancy].…She said well if your viral load is low and if that's what you want to do then, you know, go right ahead. Just make sure you are careful. Now if my grandma was in there maybe I wouldn't have brought it up, but you know, we was in there by ourselves. (ID 2, 20 years)

For women who did not feel a need to talk about reproductive options now, there was a sense that they would feel comfortable raising this topic with their provider if and when it became relevant for them.

> I didn't really want to talk to her about it [future pregnancy] because it is just something I hold inside, I mean it's really not— if it were to get in my mind she would be the first person I would trust to get me through…(ID 9, 40 years)

Motherly relationships between providers and adolescent patients can facilitate communication for some (e.g., familiar with the provider) and hinder it for others (e.g., concern over being judged).

> I would feel comfortable [talking about childbearing], she takes care of me. I couldn't hide it if I wanted to. She's like mom, like you can talk to her, you ain't got no choice, its your mother. (ID 15, 19 years)

> She's a second mother to me. I've had the same doctor since I was 8. I love my doctor. She's a mother figure to me. And like some things I just don't want to talk to her about. Like we can talk everything else, but I refuse to talk to her about sex.…I think she'd just be judgmental. (ID 4, 21 years)

Respondents reported preferences for conversations with gynecologists compared to primary HIV providers. Participants were more likely to report supportive or provider-initiated communication with their gynecologist compared to their primary HIV provider.

> The GYN, she just told me the things that probably have to happen before I get pregnant and the facts about my tests and stuff. She wasn't trying to persuade me either way, she just, you know, let me know that…it can be an option for me. (ID 8, 35 years)

> She [primary HIV provider] talked to me about using protection, but she didn't talk about pregnancy, because she don't deal with the female, that's probably why. But if I dealt with her [brought it up] then she probably would talk about it. (ID 14, 31 years)

What is clear from these data is that provider characteristics and provider–patient dynamics influence the quality of communication regarding reproductive plans.

Many providers do care and attempt to offer guidance on reproductive decision-making. When asked to describe their communication with providers about childbearing, women who had such discussions described various scenarios in which providers offered support for informed decision making or caution regarding health and transmission risks. Providers' medical expertise appeared to influence the scope and orientation of communication about reproduction. Some providers reportedly assessed interest in discussing reproductive plans with a brief question before moving on to other concerns. Thus, opening the door for communication that women could choose to walk through or close. Below two participants describe their avoidance of the topic.

> She asked if I'm trying to get pregnant and I say no then she continue her conversation on my contraception. (ID 7, 24 years)

> Yeah [provider brought up the topic of childbearing]. But I don't like talking about it. I just skip the subject. (ID 6, 18 years)

Women also provided examples of open and nondirective communication regarding childbearing. As exemplified in the quote below, the provider reportedly takes a vested interest in the desires of the client. While expressing concern for her client's well-being, the provider gives advice about avoiding coercion from partners and making decisions about what the client wants in order to avoid ambivalence and ambiguity.

> No she just listens and tries to guide me. She doesn't try to persuade me. She just tries to guide me and she'll just remind me like, um, when he tries to pressure me to having unprotected sex and then I come in and tell her I had unprotected sex when I just had a pregnancy test two months ago, she'll be like well you know…you need to decide if you're going to have a baby or not. (ID 3, 24 years)

The following quote illustrates a provider's concern for the risk the patient is exposing herself and others to by practicing unsafe sex and an effort to emphasize the reality of what having a child would mean. The provider appears willing to spend additional time and effort to empower the patient with knowledge and information in the hopes of influencing her behavior.

> She'll say you shouldn't be doing this [unprotected sex], you know you're putting yourself at risk. You're not only putting yourself at risk, you're putting the other guy at risk. Putting yourself at risk for getting other STDs and other disease and..she'll do all that, she'll give her mother speech and then she'll give her doctor speech. Well if you do decide to become pregnant, if you are pregnant, you know this would have to happen…medicines, roles I'll have to play, things I'll have to

> do. Like she'll give me all the resources and pamphlets. Like she'll even go as far as bringing up information on the internet for me. (ID 4, 21 years)

A participant who realized her HIV positive status during her pregnancy reiterates the provider's role in facilitating informed decision-making.

> It was real stressful and questionable as far as if I wanted to a have her [daughter]. But when my healthcare provider informed me that I could take the AZT during my pregnancy and it was a good possibility that the baby wouldn't get it [HIV] and then she'd have to take medicine after her birth, you know, [I took] all those things into consideration [to continue with pregnancy]. (ID 11, 42 years)

Some providers reportedly expressed their concerns regarding their patient's health. While not ruling out childbearing, they identified health priorities that needed to happen before becoming pregnant.

> I talked about pregnancy with her and I talked about having bypass surgery and she said no. So she was like, I think that if you want to have a child you should really like lose at least you know, 50 pounds first. (ID 1, 29 years)

As mentioned in the previous section, participants perceived gynecologists as more amenable to such discussions. This may in part be due to the difference in each provider's priorities and expertise. One participant describes how communication and guidance about childbearing options with both her gynecologist and primary HIV provider elicited difference responses.

> My GYN doctor, she asked me did I ever want to have kids in the future, because there's other alternatives that could happen and I told her I would think about it…They [GYN] always say if I ever consider it to just let them know. But they really don't like to push the issue. They say if I ever think about it, just talk cause they could recommend me to somebody that will be more helpful, that know more about it, that could teach me more. (ID 16, 36 years)

> Because like when I got my abortion she [primary HIV provider]…I mean I can't say she was…I think she just wanted the best thing for me, because she had just got my HIV status down to undetectable. So feels as though if I get pregnant again, my medicines would switch…if I have to switch medicines she don't know how effective they would be. So I think that's pretty much why she was behind me with the abortion…It was hard [decision to abort]. I know I didn't want to have an abortion, but I knew how my doctor was going to feel about it. Like she always keep telling me, have protected sex. She encouraged me to get the Depo shot and stuff like that. She did ask what do you want to do? And I was like I would rather abort it than bring a baby into the world with the HIV. (ID 16, 36 years)

While the HIV provider likely felt that protecting her patient's immunologic status was the priority, it did not appear from the participant's account that the provider made efforts to educate the patient on MTCT risks or alternative treatment options. This participant's scenario illustrates how a more comprehensive assessment of HIV patients' needs, including reproductive goals, could improve provider-patient collaboration on risk-reduction and treatment strategies.

While not included in the interview guide, one participant was asked how she would suggest providers raise the topic of childbearing with their patients and she replied,

> I would just say, "In the future what do you want to do with yourself? Would you have kids or how do you feel about it?" I would talk to them [patients] first to see where they are and then go from there. I wouldn't just cast it out there because I don't know how people feel unless you get in and start talking to them about it. (ID 14, 31 years)

This woman's suggestion emphasizes again the importance of provider-initiated conversations to better understand patients' reproductive goals.

Discussion

These data from reproductive aged women receiving clinical care at dedicated HIV clinics express a diversity of feelings regarding childbearing and experiences with provider communication. While the majority of women reported some type of discussion about pregnancy with either their primary HIV provider or gynecologist, a much smaller proportion had actually discussed options and plans for future childbearing, and no one had been referred for HIV preconception counseling. Medical advances present multiple opportunities to make childbearing among PLHA safer. Benefit from these prevention opportunities can only be fully realized once open discussion regarding childbearing plans becomes systematized as part of comprehensive HIV care. HIV providers encounter these needs among their reproductive aged female patients; but without clear clinical guidance and institutional support, providers who do attempt to address these issues often do so without appropriate training or support. These data highlight the need for informed reproductive counseling and compliment previously published quantitative data about future childbearing plans and provider communication among the same priority population.[3,21] Based on the emergent themes, we offer the following recommendations to enhance HIV provider–patient communication about the reproductive health needs and desires of PLHA in an effort to minimize health risks and maximize attainment of reproductive goals.

Recommendations

1. Improve provider training on safer childbearing options and clinical practice guidelines

Nearly all participants reported good rapport with their provider, but provider characteristics and relationship dynamics served to either facilitate or constrain open communication about pregnancy or childbearing intentions. Perhaps a larger factor influencing the frequency and quality of HIV provider communication about safer childbearing is their level of training and experience with reproductive health. The provider's medical specialization and the age of patients they treat (adolescent versus adult) appeared to influence the way they approached discussion about childbearing. In general, female clients preferred to have reproductive health conversations with gynecologists over HIV providers.

Gynecologists likely feel more adequately trained to raise this topic with patients and are more likely to view contraception or childbearing as an important part of comprehensive care; whereas the primary HIV provider (most likely infectious disease specialist) generally feel that maintaining the patient's ART treatment success is of highest priority and may feel uncomfortable talking about pregnancy. It is important to specify that the gynecologists referenced in this study provide care within the designated HIV clinic, and thus

have specialized training in HIV unlike most general gynecologists. It may be this combined training of HIV and reproductive health better positions such gynecologist to address these needs. A recent exploratory study with $n=8$ HIV providers in the United States found that HIV providers emphasized the need for training and specific provider guidelines to equip them to adequately address the varied conception needs of their patients.[22] The lack of safer conception information or reproductive options relayed to female patients in our study likely reflects the uncertainty that many providers feel on how best to advise their patients. The economic insecurity that many HIV patients in the United States face, prohibit expensive assisted reproductive technology solutions. This reality likely further compounds providers' tendency to avoid this topic when clear guidelines and feasible solutions are not readily available.

2. Systematize reproductive health discussions and referrals for preconception counseling or contraceptive management as part of routine HIV clinical care

Consistent with a previous qualitative study with nine HIV-positive women in the United States,[23] a major theme of the current study is confusion regarding how to conceive while protecting one's partner. Several women expressed confusion and concern regarding conception with a serodiscordant partner and awareness that their own health and treatment success was at risk by having unprotected sex with a HIV-positive partner in order to conceive. While not specifically prompted to do so, no one mentioned safer conception strategies. From these interviews it is evident that many women are uninformed about safer conception strategies to protect themselves, their partners, and their infants and most lack adequate information about the risk of mother-to-child transmission of HIV. Several clients did articulate the relationship between medication adherence, viral load, and risk of transmission; demonstrating general HIV transmission knowledge, but not information specific to safer conception strategies. This information is important to provide to HIV-positive patients with future childbearing intentions, particularly since pregnancy desires have been associated with increased sexual risk behaviors among HIV-positive women.[24]

While the potential of a referral for preconception counseling was mentioned by one study participant, others seemed unaware such specialized services existed, even though the study site is unique in that an experienced OBFGYN-HIV specialist is available to provide HIV preconception counseling to individuals and couples wanting to safely conceive. Given the lack of use of the term "preconception counseling" or acknowledgment that this referral service is available onsite, we conclude that not only is improved communication needed between providers and patients, but also among providers and hospital administrators at these clinic sites.

Implications for practice

Many PLHA in the United States[25] and globally[26,27] feel reluctant to express interest in childbearing and fear disapproval from providers, thereby highlighting the importance of provider-initiated communication. It is also likely that few infectious disease providers feel confident to initiate fertility-related discussions as this is not their area of expertise. While it is unrealistic for all HIV providers to gain detailed proficiency in fertility-related issues and safer conception strategies, they can be trained to effectively assess patients' interest in future childbearing, to lay out existing options, and then refer them appropriately for either contraception or preconception counseling. Improving provider training and systematizing childbearing discussions and referrals to HIV preconception counseling can reduce associated stigma; just as routine opt-out counseling and testing have reduced HIV testing stigma.[28]

The guidelines on preconception counseling and care for HIV-positive women of childbearing age are available online and can provide HIV providers with a basic understanding of the importance of assessing childbearing intentions and guidance on initiating counseling, which if applicable may result in a referral for more specialized preconception counseling. While this resource is helpful, more detailed clinical guidance to evaluate individual risk and need for various safer conception strategies will likely increase providers confidence to address these issues. Increasing access to feasible referrals for HIV preconception counseling is an emerging challenge as few providers have the combined expertise in obstetrics and gynecology and HIV clinical care, and fewer yet may have training on how to conduct in depth counseling with patients and their partners. A need exists to identify and expand the national cadre of HIV preconception counseling providers to improve geographic accessibility. In the meantime, options for remote preconception counseling referrals that utilize available technology are needed.

Strengths and limitations

This study is unique in that it includes several adolescent women, those both behaviorally and perinatally infected. Including young women still receiving their HIV care at the Adolescent Health Clinic provides an interesting contrast between participants of different ages and their experiences with their providers. Many perinatally infected youth have had the same provider since childhood, while some adult participants may only see their HIV provider three times a year for immunologic monitoring. Such qualitative data describing women's communication with providers about childbearing in the United States has not yet been published, and identifies some positive efforts being made in the context of a system that does not implement routine reproductive counseling with referral to preconception counseling or for contraception management. Lastly these qualitative data serve to triangulate and further expand upon previously published quantitative data that addressed the same themes with the same study population,[3,21,29] and can generate hypotheses to pursue in future larger scale research.

Only patient perspectives of past communication are presented here and may not accurately or fully reflect exchanges that occurred. The perspectives of HIV providers are needed to better understand current practice and more importantly to identify ways to assist comprehensively coverage of reproductive needs. While still less than adequate, the provider communication described in this study likely presents a best-case scenario for what may occur nationally. These participants were receiving care at comprehensive HIV clinical care sites with integrated gynecologic care and access to a HIV preconception counseling specialist.

Future directions

A critical analysis of the neglect of comprehensive reproductive health needs, specifically childbearing, among

HIV-positive women in the United States identified the dearth of research regarding reproductive counseling or efforts to incorporate reproductive counseling as a routine part of HIV clinical care.[30] The quantitative findings that are part of this larger study, the Women Living Positively Study,[25] and a very recent survey among 93 HIV-positive male and female patients[22] are the only published data we are aware of that assess communication with HIV providers about safer childbearing options in the United States. While such research in the United States is scant from the patient perspective, it is nearly nonexistent from the provider perspective. Several questions remain; How many providers are aware that guidelines for preconception counseling exist? What do HIV providers perceive as the primary individual and structural barriers to routine reproductive counseling? How willing are male partners to participate in preconception counseling and to follow recommendations for conception? These are some of the important questions that must be explored in subsequent research.

Conclusion

These qualitative data give voice to a reality we already know: the desire to have a child and experience parenthood is not mitigated by HIV status in this era of highly active antiretroviral therapy and increasingly more options (both low and high resource) to make conception and childbearing safer. Despite the fact that many of these women intend to have children in the future or were actively trying to conceive, we found evidence of limited communication or active preconception planning. Nonetheless, some providers do try to assist their patients with their reproductive goals, despite limited training or clear guidelines. Some participants clearly describe that their desire to conceive a child results in purposeful unprotected sex even with serodiscordant partners, consistent with findings from a recent quantitative study.[24] Clearly, people know how to conceive a child. It is the role of providers and the public health community to assist people living with HIV to plan conception in the safest possible way. Without such services, patients with childbearing intentions become pregnant without medical consultation regarding the couples' health status and the safest timing and strategy for conception, resulting in missed opportunities to reduce new HIV infections, improve infant outcomes, and respond to the comprehensive needs of HIV-positive patients.

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