

# Lost Opportunities to Reduce Periconception HIV Transmission: Safer Conception Counseling By South African Providers Addresses Perinatal but not Sexual HIV Transmission

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**Introduction:** Safer conception strategies create opportunities for HIV-serodiscordant couples to realize fertility goals and minimize periconception HIV transmission. Patient-provider communication about fertility goals is the first step in safer conception counseling.

**Methods:** We explored provider practices of assessing fertility intentions among HIV-infected men and women, attitudes toward people living with HIV (PLWH) having children, and knowledge and provision of safer conception advice. We conducted in-depth interviews (9 counselors, 15 nurses, 5 doctors) and focus group discussions (6 counselors, 7 professional nurses) in eThekweni District, South Africa. Data were translated, transcribed, and analyzed using content analysis with NVivo10 software.

**Results:** Among 42 participants, median age was 41 (range, 28–60) years, 93% (39) were women, and median years worked in the clinic was 7 (range, 1–27). Some providers assessed women's, not men's, plans for having children at antiretroviral therapy initiation, to avoid fetal exposure to efavirenz. When conducted, reproductive counseling included CD4 cell count and HIV viral load assessment, advising mutual HIV status disclosure, and referral to another provider. Barriers to safer conception counseling included provider assumptions of HIV seroconcordance, low knowledge of safer conception strategies, personal feelings toward PLWH having children, and challenges to tailoring safer sex messages.

**Conclusions:** Providers need information about HIV serodiscordance and safer conception strategies to move beyond discussing only perinatal transmission and maternal health for PLWH who choose to conceive. Safer conception counseling may be more feasible if the message is distilled to delaying conception attempts until the infected partner is on antiretroviral therapy. Designated and motivated nurse providers may be required to provide comprehensive safer conception counseling.

**Key Words:** safer conception, client-provider communication, HIV prevention, South Africa

(*J Acquir Immune Defic Syndr* 2014;67:S210–S217)

## INTRODUCTION

Stable serodiscordant partnerships account for up to 60% of new HIV infections,<sup>1</sup> and 20%–50% of men and women living with HIV desire children.<sup>2–7</sup> As many as 30% of stable heterosexual couples in South Africa are HIV-1 serodiscordant.<sup>8,9</sup> Safer conception strategies, including home artificial insemination, unprotected sex limited to peak fertility, male circumcision, antiretroviral therapy (ART), and pre-exposure antiretroviral prophylaxis, create opportunities for HIV-serodiscordant couples to realize fertility goals while minimizing periconception HIV transmission risks.<sup>10–12</sup>

Safer conception recommendations have evolved; yet, implementation has not kept pace. Before effective HIV treatment, the prevailing professional recommendation was

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Supported by the NICHD (R03-HD072602) and the Canada-Sub-Saharan Africa HIV/AIDS Network (CANSSA). The analysis was also supported by NIH grants K23 MH095655, K24MH87227, K24MH094214, K23MH096651, and the Harvard CFAR (P30 AI060354).

The content is the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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for people living with HIV (PLWH) to avoid pregnancy.<sup>13</sup> South Africa's constitution protects reproductive rights for PLWH, and recent guidelines from the Southern African HIV Clinicians Society and South Africa's Department of Health offer strategies for those who choose to conceive.<sup>11,14,15</sup> The World Health Organization (WHO) recommends treatment for the infected partner in serodiscordant relationships, particularly if the couple plans to conceive.<sup>1</sup>

However, HIV-infected men and women rarely discuss fertility desires or plans with health-care providers, a critical first step to safer conception counseling. In Cape Town, over 30% of HIV-infected women and 65% of HIV-infected men attending public sector clinics were interested in having additional children; yet, only 19% and 6%, respectively, had discussed this with a health-care provider.<sup>16</sup> Among HIV-infected women in Johannesburg with plans to conceive in the next year, 40% had a conversation about fertility plans with a provider.<sup>17</sup> Conversations with providers about conception plans were also infrequent in Uganda,<sup>18</sup> Argentina,<sup>19</sup> Brazil,<sup>20</sup> Canada,<sup>21</sup> and the United States.<sup>22,23</sup>

Thus, many HIV-uninfected partners of PLWH are exposed to more periconception risks than necessary given the efficacy of pharmacobehavioral prevention for HIV-serodiscordant couples. For uninfected women, HIV acquisition during periconception or pregnancy periods harms her health and increases the risk of perinatal transmission. We used qualitative methods to understand whether fertility assessments were taking place in eThekweni District, South Africa, an HIV-endemic setting. We explored barriers to patient-provider communication about fertility intentions and providers' safer conception knowledge and clinical practices among health-care providers, including doctors, nurses, and counselors. The goal of this research is to inform interventions to limit transmission among HIV-serodiscordant partners who choose to conceive.

## METHODS

### Setting

We conducted in-depth interviews (IDI) and focus group discussions (FGD) with providers from 6 public sector clinics in April and May 2012. These clinics are located in a township outside of Durban, South Africa, part of the eThekweni District where antenatal clinic HIV prevalence is estimated at 42%.<sup>24</sup>

### Sampling and Recruitment

Lists of providers were generated for each clinic. Six doctors were working across the selected clinics; thus, we attempted to conduct interviews with all available doctors. For nurses and counselors, the lists were randomized and stratified by site and provider type and selected providers were invited to participate. If a selected provider refused to participate ( $n = 2$ ) or was unavailable (several providers at each site were on leave or working night shifts during recruitment), we approached the next provider on the list. Interviews were conducted with counselors, nurses, and doctors. Two FGDs were conducted, one with counselors and one with professional nurses. In public

sector clinics in South Africa, professional nurses are responsible for most patient consultations, including initiation of and management of ART, antenatal care (ANC), and preventing mother-to-child transmission programs (PMTCT).<sup>25</sup> Doctors are available in the clinics on a sessional basis to see patients referred for more complex problems and often to initiate ART. Most counseling activities are the responsibility of lay counselors.<sup>26,27</sup>

### Ethics

Ethics approvals were obtained from the University of the Witwatersrand Human Research Ethics Committee (Johannesburg, South Africa) and Partners Healthcare (Boston, MA).

### Data Collection

The research focus was to explore whether and how providers assess fertility intentions among their HIV-infected male and female patients. This required open-ended questions through IDIs and FGDs and an inductive approach to data collection and analysis.<sup>28,29</sup> Interview guides were developed by the authors with input from local providers. Guides explored provider practices of assessing fertility intentions among HIV-infected men and women, attitudes toward PLWH having children, knowledge of safer conception practices, and provision of safer conception advice. Interviews explored individual-level practices and attitudes, whereas focus groups explored commonly held views and accepted practices. Interviews and focus groups were conducted by research assistants fluent in English and isiZulu; sessions were audio recorded and lasted approximately an hour.

### Data Preparation

Research assistants produced a complete transcript in English from either English or isiZulu language digital recordings. Each transcript was reviewed for quality by another member of the study team, and corrections were made where indicated.

### Data Analysis

Content analysis was used to assess whether providers assessed the fertility goals of HIV-infected men and women in their clinic, what advice was offered, and knowledge of different safer conception strategies. Themes related to why providers do not assess fertility goals among PLWH were uncovered and explored. This iterative process was performed by the authors (L.T.M., C.M., and R.G.) using techniques described by Miles and Huberman.<sup>30</sup>

The coding team first identified major themes through independent review of a subset of transcripts. Coding was then performed to structure data into categories and create groups. Themes were then reexamined, and major and minor themes within each content area were identified. To ensure validity of the emergent data, themes were discussed with additional study team members, including the research assistants who

conducted interviews and focus groups. To ensure reliability, 3 coders analyzed the data independently. Results from each phase of analyses were compared and discrepancies discussed until a resolution was reached. To check reliability of coding in the final phase, 9 interviews were coded by 2 coders each and then reviewed to resolve discrepancies before proceeding with coding the remaining data. NVivo10 software (QSR International, Melbourne, Australia) was used to organize the analysis.

## RESULTS

Forty-two providers participated in the study, including 29 IDIs with nurses (22), counselors (15), and doctors (5) and 2 FGDs with professional nurses (7) and counselors (6), respectively. Most participants were women (93%) who had worked in the clinic for a median of 5 (range, 1–27) years and saw a median of 11 (range, 2–60) HIV-infected patients in their last full workday (Table 1).

### Overview

The data are presented first as a description of providers' practices around assessing fertility desires among HIV-infected patients followed by an exploration of barriers to assessing fertility desires. Some of the categories were identified before the research (*a priori*) and some emerged from the data (emergent). We first describe (1) whether providers assess fertility goals (*a priori*) followed by a description of barriers to fertility goal assessment, including (2) assumptions of HIV seroconcordance (emergent), (3) low knowledge of safer conception strategies (*a priori*), (4) tension between a rights-based approach and personal feelings toward PLWH having children (emergent), and (5) challenges to delivering individualized safer sex messages in a busy clinic (emergent).

### Providers Do Not Routinely Assess Fertility Goals

Most providers did not routinely assess fertility goals for women living with HIV and almost never assessed fertility goals for men living with HIV. Many providers spontaneously

reported that patients ask about their options for having children (Table 2, quote A). Some providers assessed fertility goals for women at ART initiation to avoid efavirenz because of teratogenicity concerns (Table 2, quote B).

### Assumptions of HIV-Seroconcordance Limit Recognition of the Risks of Periconception HIV Transmission

Providers working as counselors, nurses, and doctors demonstrated skepticism about HIV serodiscordance—or how an HIV-infected individual could be sexually active with a partner who remained HIV uninfected. In the FGDs with counselors, who conduct couple-based HIV counseling and testing, challenges to understanding and explaining serodiscordance were a major conversation topic raised by the participants (Table 2, quote C).

Accordingly, providers did not know how to respond to patient descriptions of a serodiscordant relationship (Table 2, quote D) and underestimated the prevalence of serodiscordance (Table 2, quote E), which is about 20% among stable couples in the province of KwaZulu-Natal.<sup>8,9</sup> When asked about the risks they worried about for PLWH who wanted to have children, most providers assumed the woman was infected and focused on issues related to the well-being of the child: the mother's health, perinatal transmission, and social issues such as the ability of the couple to support the child. During IDIs, only 7 providers (24%) listed sexual transmission to an uninfected partner as a risk they worried about.

### Low Knowledge of Safer Conception Strategies Leads to Referral as Deferral

All providers were familiar with strategies to prevent mother to child transmission (PMTCT) and recommended practices, such as waiting to conceive until the CD4 count is high, initiating the woman on ART during pregnancy, encouraging adherence to ART during pregnancy, the importance of attending ANC appointments, and breastfeeding practices.

Many providers suggested that if PLWH want a child, they should come to the clinic, plan pregnancy, check CD4

**TABLE 1.** Characteristics of Participating Providers

	Total Providers	Nurses	Counselors	Doctors
Sample size	42	22	15	5
In-depth interview (IDI) participants	29	15	9	5
Focus group discussion (FGD) participants	13	7	6	0
Proportion women (%)	93	96	94	83
Median age (range), yrs	41 (28–60)	42 (28–60)	41 (30–57)	34 (29–53)
Median time worked in clinic (range), yrs	5 (1–27)	7 (1–27)	8 (1–13)	2 (1–9)
Median no. patients seen in work day (range)	27 (5–140)	45 (8–140)	15 (5–50)	21 (17–98)
Median no. HIV-infected patients seen in work day (range)	11 (2–60)	13 (2–50)	5 (2–50)	21 (17–60)
Median minutes spent in typical patient encounter in last workday (range)	16 (3–52)	10 (2–60)	38 (5–60)	10 (5–40)

**TABLE 2.** Representative Quotes in Support of Themes

Theme	Quote ID	Quote	Provider Type
Providers do not routinely assess fertility goals	A	I don't ask them at all...if they want children. Because they come for CD4 count. And then, after taking this treatment [ART], let's say for 6 months or a yr, they just come and say, "oh sister, now I want to have a child." They come, yeah, they come on their own and say that. ... No, ... let's say you come in for the CD4 count, I don't ask if you ... want to have children.	Enrolled nurse
	B	Interviewer: Do you ask HIV positive individuals about their plans for having children?  Women more than the men. Simply because when deciding on the regimens...at initiation. Beyond initiation, is there a discussion about family planning or intentions to have children? Not really because I would not really see them, it would be the nurses that would be mainly involved with the follow up ... of the client, I would only come in when there was an issue.  Do you think it is followed-up by the nurses? Uhm ... no I don't think so	Doctor
Assumptions of HIV-seroconcordance limit recognition of the risks of periconception HIV transmission	C	We are not well informed as to what is happening [with HIV-serodiscordance]. As my colleagues say, it is this issue I am talking about: [Let's say] I am negative, she is positive but we have been ... getting children. Maybe you find out that [the] children have been negative. Now when getting here ... we have to test and they still desire to get other children. That is why there has to be clarity that what is going on here, when it is positive and negative. ... we have this problem of knowing nothing at all.	Counselor in focus group discussion
	D	We are not sure of it, you see that? Because the man says "I'm negative" out of the blue, no nothing, no improvement, no not even the results or the paper that shows us. You see? So now we cannot just rely on that thing, and then we cannot even trust. You see? Because now, they sleep together, you see that? They don't even use protection... they don't even use condoms, but the man just say that "I'm negative," and the woman said "yes, I'm positive." They do come, but we don't believe. They do come.	Professional nurse
Low knowledge of safer conception strategies leads to referral as deferral	E	I haven't [seen] that case really [HIV-serodiscordant couples]. ... We had a case once where the one partner was uninfected but it was sort of a window period, they'd just had one test. So we said we'd see them after 3 months ... I remember because that's very rare.	Doctor
	F	First you come to the clinic. And check your CD4 count and your viral load.  Interviewer: So what if I come to the clinic and my CD4 count, I have checked and it is 350, and my viral load is suppressed, they can't see it. I don't know. I would send her to the counselor.	Enrolled nurse
	G	In the class there are people who need to get children, and then a lot of questions come up. ... We do not have much information. We used to just say if a person needs to have a child, she needs to come and see the doctor.... What we know is that it is the doctors' field because we do not know anything.	Counselor in focus group discussion
	H	Interviewer: So if someone asks you about having children, you would give them some advice and then send them?  No, I give them advice and then send them that side [ANC]. But the problem, I've never checked whether they are trained in that facility.	Doctor
PLWH have a right to have children	I	Interviewer: What if a positive woman came back? At initiation she said "yes I want to have a child", you told her what to do, she comes back 6 months later and she says, "ok, my viral load is suppressed, my CD4 count is up. I've disclosed to my partner, my partner tested HIV-negative." What would you recommend for them?  It's never really happened. And I've never really thought about that. I have to phone a friend I think.	Doctor
	J	I respect that she wants to have a child and I know she is a human being. Just because they have a virus, it does not change anything, they are still human and they need to live, just like anybody else.	Counselor

(continued on next page)

**TABLE 2.** (Continued) Representative Quotes in Support of Themes

Theme	Quote ID	Quote	Provider Type
Tension between rights-based approach and personal attitudes towards PLWH having children	K	I think they do have a right to have a child because I think when they, most of them, when they are diagnosed with HIV they feel like something has been stripped out of them. It's like there are some missing parts from them. So maybe if they are told they can't have kids at all it adds on to the burden that they already have. So I think they should have [children if they want to].	Doctor
	L	So I feel bad for them, for me inside, but I cannot decide for the other people. For me, if somebody maybe is positive, she must just, stop all that ... she must just even like do the litigation, and stop getting the children. For me, but I cannot decide for other people, you see that?	Professional nurse
	M	I don't want them to bear children. ... Others become really sick after [pregnancy], yes. Yes, but as I meant, they said you must check your HIV, your CD4 count first and the viral load so you can bear children. It's not a problem. ... Yeah they can have, they have the right to have children.	Enrolled nurse
Challenges to delivering individualized safer sex messages	N	I feel so sorry. Because it's not easy for them to continue going [without having children] and it is not easy even for me to encourage them to do unsafe sex so that they can get children.	Counselor
	O	Participant #5: And at the same time it [safer conception counseling] will make them want to have children. Participant #3: It will make them want to have children. Participant #1: Ja, that is so, and remember that we will be counseling them and giving them the education that is right and them, they will take it and tell the neighbor, and the neighbor [will understand it differently], because she will have not been here...	Focus group discussion, professional nurses
Time limits	P	So in this encounter with this woman who was interested in having children but didn't know her partner's [HIV] status, were there topics you wanted to talk about or discuss with her but didn't have time to address? To be honest I didn't have time because I've already there for four hours and I'm going to go back to work [in private clinic]. So I just try to cover the basics when I'm there. So what things would you talk about if you had more time? Uhm, STI's. Looking at the history of STI's, ... sitting and talking about her reproductive health to look and see how her periods were like, to look and see you know uhm, just in terms of, is her current partner the same partner is the one she had before. Had she had any miscarriages or anything else that we would be concerned about uh, just something that would make me think that there might be a problem with, with infertility. ... Or if we know your partner's status if he is positive these are the options, if he is negative these are options.	Doctor
	Q	At times you know, the time does not allow [to provide individual counseling to clients]. ... Because the clients, when you stay with one client for a long time inside, they start shouting and say "oh she is wasting time, you know this something has been inside for a long time" and they forget that their problems are not the same.	Professional nurse

cell count and HIV viral load (principally to reduce perinatal transmission risk), and disclose HIV status to partner. Because so many providers listed these tasks, interviewers probed for what providers would recommend if the individual returned to clinic having completed these assignments. Most providers then recommended referral—counselors referred to nurses, nurses referred to doctors, and doctors referred to another doctor (specialist or tertiary facility) or counselor. No provider described follow-up with a client who had successfully followed through on their recommendations and/or successfully sought care at a referral site (Table 2, quotes F–I).

Only 2 providers (doctors) had ever offered safer conception counseling. When asked what they would offer, most providers were not familiar with the range of safer

conception options and tended to focus on resource-intensive, largely unavailable strategies, such as sperm washing and in vitro fertilization (Table 3).

### Tension Between Rights-Based Approach and Personal Attitudes Toward PLWH Having Children

Almost all providers stated that PLWH have a right to have children (Table 2, quotes J–K). This was consistent across all clinics and provider types.

Although some providers reported positive attitudes toward PLWH having children, many expressed concerns that risks to the mother and the child are too high to justify intentional conception (Table 2, quote L).

**TABLE 3.** Safer conception Strategies Mentioned by Providers

Strategy*	Counselor IDIs, n = 15	Nurses IDIs, n = 22	Doctors IDIs, n = 5	Counselors FGD	Nurses FGD†
Sex limited to peak fertility	2	1	4		‡
Male circumcision	1			‡	‡
Manual insemination	2		1		‡
ART for positive partner (not for PMTCT only)	1	1	2		
Microbicide	1		1		
PrEP	0	0	0		
Sperm washing	3	1	3		‡
In vitro fertilization	3	5	3	‡	‡
Number who listed any strategy	6 (40%)	5 (22%)	4 (80%)		

\*These are strategies mentioned. Often, the provider could not explain how or why the strategy would work but had heard of it. Some strategies such as crural sex (for a male-positive couple) or delayed ejaculation until the woman climaxes (for a female-positive couple) were offered as possible safer conception strategies and are not listed here as these are unlikely to lead to pregnancy (crural sex) or reduce transmission risk (delayed ejaculation).

†One provider in the professional nurses focus group discussion was very familiar with this topic.

‡Strategy mentioned in the focus group discussion.

IDI, In-depth interviews; FGD, Focus group discussion.

### Challenges to Delivering Individualized Safer Sex Messages

Providers were uncomfortable recommending unprotected sex. This was linked to personal discomfort offering harm reduction advice and concerns that couples would increase risk behavior if given information about the relative risks of sex without condoms (Table 2, quotes N–O). The challenge of offering a message that deviates from standard condoms as prevention was linked to time constraints: nurses and doctors spend 5–10 minutes with each client (Tables 1 and 2, quotes P and Q). Deviating from standard messages in a public sector clinic may not be feasible for providers carrying out routine care.

### DISCUSSION

Addressing periconception HIV transmission may reduce HIV incidence among women, men, and their children in HIV-endemic settings. Our data suggest that despite evolving guidelines, providers do not routinely ask patients about their plans for having children. When they do, the advice is for women and focuses on protecting the future fetus (avoid efavirenz, wait to conceive until the woman is healthy, come to the clinic for ANC, adhere to ART once pregnant). Now that efavirenz is offered to women regardless of pregnancy plans (based on WHO guidance and data suggesting that the risks of efavirenz teratogenicity are relatively low),<sup>31</sup> the primary trigger for these conversations no longer exists.<sup>32</sup> Safer conception counseling that addresses sexual transmission risk is hindered by misunderstandings of HIV serodiscordance, a lack of information about safer conception strategies, providers’ discomfort with PLWH having children, and time constraints that limit capacity to deliver tailored prevention messages. Empowering providers to effectively counsel men and women living with HIV who want to conceive will require more than improving providers’ technical knowledge of safer conception strategies.

Prevention for HIV-serodiscordant couples is a priority for policy makers and researchers.<sup>1,33–35</sup> Our data suggest that counselors, nurses, and doctors responsible for implementation do not understand the principles underlying prevention for this high-risk group. Providers assumed HIV seroconcordance in stable partners and thus rarely identified sexual transmission as a concern for PLWH who want to have children. Underestimation of the prevalence of serodiscordant couples reduces safer conception counseling and any prevention for serodiscordant couples. Almost a decade ago, confusion about serodiscordance among clients and counselors in Uganda was highlighted as a public health concern.<sup>36</sup> We reported that South African men and women in HIV-serodiscordant relationships were confused by HIV serodiscordance, but this is the first data we are aware of suggesting that providers also struggle with this concept.<sup>37</sup> Our data suggest an urgent need for education and training about HIV serodiscordance, especially as WHO guidelines such as ART for the infected partner in a serodiscordant relationship are implemented.<sup>1</sup>

Protocol-driven patient care allows providers to manage a large number of clients but limits capacity to deliver tailored messages. Providers are overwhelmed addressing the immediate needs of clients presenting for care and do not have time or energy to solicit additional patient issues (such as plans for pregnancy) requiring non-protocol-based responses. Safer conception guidelines exist for South Africa, but providers were not aware of these. Many providers in our sample had heard something about safer conception but focused on costly methods, such as sperm washing and in vitro fertilization. As work progresses to implement safer conception protocols, the most important message within safer conception counseling may be to delay conception attempts until the infected partner is on ART with suppressed viral load. Adding this distilled message to existing protocols for ART initiation, family planning, and HIV counseling may promote safer conception behavior without overwhelming providers. In addition, efforts to disseminate safer conception guidelines may empower providers to address this topic as part of the guideline-based care.

Additional safer conception methods (preexposure antiretroviral prophylaxis for the uninfected partner, limiting unprotected sex to peak fertility, male circumcision, and manual insemination for female infected partners) could be explained by a provider with supplemental training. Our data suggest that PLWH would most benefit from a reliable provider with the information, motivation, and time to address safer conception at each clinic site. Steiner et al<sup>38</sup> considered who should provide preconception care for PLWH from the US perspective and suggested a medical home model, call centers, and/or web-based consultation. At present, these are not viable solutions for public sector clinics in South Africa. The Southern African HIV Clinicians guidelines and the Department of Health guidelines do not specify who should provide preconception counseling. It is clear from our data that specific responsibility needs to be assigned to limit referral as deferral. Safer conception training for nurses in family planning and HIV clinics may be a good starting point because doctors are rarely available and nurses can prescribe antiretrovirals for prevention.

Many providers in our sample were conflicted between reproductive rights policies and personal feelings about PLWH having children, with opinions nearly identical to those expressed a decade ago.<sup>14</sup> Providers' personal feelings about PLWH having children may hinder their capacity to provide quality counseling and care, no matter how simple the message. Data suggest that PMTCT successes have made providers more comfortable with women having children<sup>18</sup> (this dataset, data not shown); increased information about safer conception may similarly influence providers to support conception among PLWH. The first pillar of PMTCT is to prevent infection among women of reproductive age.<sup>39</sup>

Thus, uptake of safer conception counseling may be increased by framing it as an important part of PMTCT—a strategy to prevent transmission before the woman is infected, which clearly benefits the woman's health and that of her child. This framing also provides an opening for engaging male partners in prevention, through their desire to father uninfected children and the role they play in conception.<sup>40–43</sup>

Limitations to these data are those inherent to qualitative research. Although these data are rich and revealed unanticipated themes, few providers were sampled and the findings may not be generalizable: these findings should be explored in a larger sample. Because of the nature of qualitative interview and FGD techniques, there is a risk of social desirability bias. Strengths of these data include opinions from a range of providers working in the public sector in an area with high HIV prevalence after publication of safer conception guidelines.

In conclusion, our data suggest that providers need information about HIV serodiscordance and efficacy of safer conception strategies to move beyond discussing perinatal transmission and maternal health for PLWH considering conception. Distilling the basic safer conception message to delaying conception attempts until the infected partner is on ART with viral load suppression may make it feasible for providers to offer useful advice within current protocols. Designated nurse providers with knowledge and motivation may be required to provide comprehensive safer conception counseling.

## ACKNOWLEDGMENTS

The authors thank the providers who participated in this study and the Maternal, Adolescent, and Child Health Research team that participated in data collection and preparation.

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