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"I don't know if this is right…but this is what I'm offering": Healthcare provider knowledge, practice, and attitudes towards safer conception for HIV-affected couples in the context of Southern African guidelines

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Abstract

The 2011 guidelines for safer conception for HIV-affected individuals and couples were adopted by the South African Department of Health in December 2012. We assessed implementation gaps

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and facilitators and barriers to delivering safer conception services through examining patient and healthcare provider (HCP) experiences. At Witkoppen Health and Welfare Centre, a primary care clinic in Johannesburg, we conducted in-depth interviews (IDIs) with 9 HCPs (doctors, nurses and counselors) and IDIs and focus group discussions with 42 HIV-affected men and women interested in having a child. Data were analyzed using a grounded theory approach. HCPs were supportive of fertility intentions of HIV-affected couples and demonstrated some knowledge of safer conception methods, especially ART initiation to suppress viral load in infected partners. Unfortunately, HCPs did not follow the key recommendation that HCPs initiate conversations on fertility intentions with HIV-affected men and women. Providers and clients reported that conversations about conception only occur when client-initiated, placing the onus on HIV-affected individuals. Important barriers underlying this were the misconception held by some HCPs that uninfected partners in serodiscordant partnerships are “latently” infected and the desire by most HCPs to protect or control knowledge around fertility and safer conception methods out of concern over what clients will do with this knowledge before they are virally suppressed or ready to conceive. Almost all participants who had conceived or attempted conception did so without safer conception methods knowledge. HCP concern over conception readiness, perception of what clients will do with safer conception knowledge, and gaps in safer conception knowledge prevent HCPs from initiating conversations with HIV-affected patients on the issue of childbearing. Examining these findings in the context of existing South African guidelines illuminates areas that need to be addressed to facilitate implementation of the guidelines.

Keywords

HIV-1; safer conception; HIV-serodiscordant couples; HIV-prevention; healthcare service provision

INTRODUCTION

In the era of increasing access to antiretroviral therapy (ART), people living with HIV (PLWH) are living longer and healthier lives. Many couples affected by HIV now desire to have children (Beyeza-Kashesya et al., 2010; Cooper et al., 2007; Homsy et al., 2009; Nattabi, Li, Thompson, Orach, & Earnest, 2009), with studies showing that 34 to 75% of Sub-Saharan African PLWH of reproductive age consider having children (Cooper et al., 2009; Schwartz et al., 2012; Wekesa & Coast, 2014). Although provider acceptance of PLWH having children has shifted in recent years, positive attitudes towards the reproductive rights of PLWH may not in themselves result in safer conception counseling service provision (Finocchario-Kessler et al., 2014; Goggin et al., 2014).

The Southern African HIV Clinicians Society published guidelines for safer conception for HIV-affected individuals and couples in 2011 (Bekker et al., 2011). Based on these guidelines, the South African Department of Health (DOH) adopted a new contraception and fertility planning policy and service delivery guidelines in December 2012, with a section outlining special considerations for PLWH and HIV-affected couples wanting to conceive (Department of Health, Republic of South Africa, 2012). These guidelines offer clear direction on initiating conversations with patients about pregnancy intentions, and different

counseling and strategies that can be employed in high-burden, low resource settings (Bekker et al., 2011; Department of Health, Republic of South Africa, 2012). However, little is known about the extent to which guidelines are known to healthcare providers (HCPs) and implemented in practice.

This paper reports findings from a qualitative study intended to inform the development of a safer conception service. We evaluate gaps in implementation of the South African safer conception and fertility guidelines through assessing HCPs knowledge, experiences, competencies, facilitators and barriers to provision of safer conception services. Patient experiences are incorporated to further illuminate HCPs implementation of the guidelines.

METHODS

Study Setting

Data for this study were collected between February to July 2013 at Witkoppen Health and Welfare Centre (WHWC), a nongovernmental primary care clinic located in Johannesburg, South Africa that operates in partnership with, and receives funding from, the DOH. At time of the study, no standard of care existed at WHWC for HIV-affected individuals or couples trying to conceive. HCPs had not received formal training on safer conception guidelines or methods, and no systems were in place for routinely consulting patients on their pregnancy intentions.

Ethics approval was obtained from the University of North Carolina institutional review board and the Human Research Ethics Committee at the University of the Witwatersrand. Written informed consent was obtained for all participants, and all FGDs and interviews were conducted in private spaces to ensure confidentiality.

Study Population

Nine HCPs (3 clinicians, 3 nurses and 3 lay counselors) who regularly care for PLWH were purposively selected for key informant interviews, with preference given to HCPs with some safer conception counseling experience. In addition, using convenience sampling, HIV-affected men and women 18 to 45 years of age attending the clinic who expressed interest in having a child in the future were also recruited for participation in focus group discussions (FGDs) and semi-structured in-depth interviews (IDIs). The four FGDs consisted of either HIV-infected men (n=7), HIV-uninfected men in discordant relationships (n=6), HIV-infected women (n=8), and HIV-uninfected women in discordant relationships (n=5). The 16 IDIs were conducted with equal numbers of participants represented across HIV-status and sex strata.

Procedures

Data collection was performed by experienced facilitators using an interview/discussion guide. Key informant interviews with HCPs were conducted in English with detailed notes taken by the interviewer, including verbatim statements, and a summary sheet completed following the interview. FGDs with clinic patients were conducted in English. The FGD facilitators and an additional note taker recorded detailed notes. Notes were compared,

discussed, and combined into a master copy. IDIs with clinic patients were offered in English, Zulu, or Sotho. Detailed notes were taken by the interviewer and a summary sheet was completed following the interview.

Analysis

The study used a grounded theory approach for data analysis (Glaser & Strauss, 1967; Strauss, 1998). Transcripts were reviewed and categorized under themes. Through an iterative process NW and SS discussed these themes, compared for accuracy and interpretation, and developed a codebook of descriptive and interpretive codes. Both NW and SS then independently coded again, compared for consistency, and discussed and resolved discrepancies.

RESULTS

The sample included 9 key informant interviews from HCPs (3 HIV lay counselors, 3 nurses, 3 doctors), three of whom were male, and six female. Opinions of 42 clinic patients, 21 males and 21 females, were collected through 16 IDIs, and 4 FGDs with 26 participants. The IDIs and FGDs were evenly distributed by sex.

Findings are presented in the context of the safer conception guidelines (Bekker et al., 2011; Department of Health, Republic of South Africa, 2012), with qualitative evidence and illustrative quotes organized to compare and contrast the extent of implementation in a primary care setting to the recommendations (Table 1).

Communication with individual patients and couples about fertility and childbearing intention

A key recommendation from the safer conception guidelines is that HCPs repeatedly initiate conversations on the topic of fertility intentions with HIV-affected men and women. Both PLWH and HCPs elucidated that PLWH are uncertain about whether they are able to have children. PLWH consistently expressed that the onus is on them to initiate a conversation about conception. HCPs uniformly confirmed that conversations about conception were not frequent and that these conversations were patient-initiated. None of the HCPs indicated that they screen for fertility intentions as part of routine clinic visits (Table 1, Section 1). “Mostly women ask if it is possible to have a child if they are HIV-positive. They ask “how [can I conceive] the natural way?” They are scared of infection.” [M, doctor]

Despite conveying general support for the reproductive choices of HIV-affected couples, providers frequently expressed a desire to protect or control knowledge around fertility and safer conception methods out of concern over what patients will do with this knowledge. HCPs were concerned that spreading information about safer conception would encourage premature attempted conception by patients who they perceived not to be ready to have children. The HCPs’ desire to control knowledge was also noted in the patient interviews, where patients highlighted that they did not have any information, or had been discouraged from seeking pregnancy. “During a normal visit day women will ask: ‘Sister, can’t we have children now?’ We can’t broadcast information because there is a different situation for every couple and it really depends if they are stable couples.” [F, nurse] Almost all

participants who had conceived or attempted conception did so without knowledge of safer conception methods.

> Yes I am scared of infecting him [partner], especially if one of us has a scratch – in our genital area - there is a chance of infecting him. Also looking at the previous time when we were trying for a baby with my ex-partner, we were not using any protection. I think if one comes into the clinic you can get Nevirapine pill for the baby, but I know of nothing else [to prevent HIV transmission during conception]. [F, HIV+ in serodiscordant partnership, not on ART]

A couples-based approach is recommended

Findings from the IDIs and FGDs indicate that men, regardless of HIV status, were less likely than women to have discussed fertility intentions with HCPs as part of their routine clinic visits. HCPs expressed concerns about the feasibility of a couples-based approach to safer conception because of the perceived challenges of getting male partners to test, attend clinic with their female partners, and adhere to safer conception methods. Some HIV-affected women however indicated that, “for the peril of the baby”, their male partner would attend the clinic. Similarly, men often reported they would attend the clinic with their female partner and initiate a discussion on conception with a HCP (Table 1, Section 2). “We would go the clinic to seek information because of fears for the baby. I also fear being ill, but this is not my primary concern.” [Male, HIV-, in serodiscordant partnership]

Selection of safer conception methods by healthcare providers

The safer conception guidelines outline different strategies with respect to the type of partnership (seroconcordant or serodiscordant) and the sex of the HIV-infected partner. All HCPs demonstrated some knowledge of safer conception methods, but breadth of knowledge varied by type of provider. Lay counselors primarily focused on the importance of taking ART and viral suppression, whereas nurses and doctors demonstrated broader knowledge with an understanding of how to apply methods dependent on which partner is HIV-infected in serodiscordant partnerships, as well as appropriate approaches for concordant partnerships (Table 1, Section 3). Some HCPs reported having looked for safer conception recommendations, but none mentioned existing guidelines as a resource. HCPs also highlighted that the poor economic status of most PLWH limits access to sperm washing or in-vitro fertilization and determines the recommendations they can make within a primary healthcare setting.

> If the man is positive and the woman negative, this is when I’ve used PrEP – tenofovir, 3TC [lamivudine], efavirenz. Again, sex only during ovulation, and for all approaches, condoms at all other times. I also suggest self-insemination for couples which are both infected. I don’t know if this is right, but based on all of the research that I’ve done, this is what I’m offering. I would like to do sperm-washing or IVF [in-vitro fertilization], but this is not possible. [F, nurse]

Despite some general safer conception knowledge demonstrated by HCPs, clear gaps in understanding emerged (Table 1, Section 3). Some providers expressed beliefs that serodiscordant partnerships are not possible and that the uninfected partner is latently

infected. This belief influenced provider support and inhibits counseling about risk reduction methods. HCPs may not offer safer conception strategies or referrals if they do not believe that serodiscordant couples can remain HIV negative if they have condomless sex.

> No I hadn't heard [of ARVs to reduce HIV transmission risks], but now that you ask that, that's something I've been asking myself for quite some time. Because we had sex without a condom I should have been infected by now. The counselors couldn't believe it. [Male, HIV-, in serodiscordant partnership, female partner on ART]

Provider encouragement of conception and understanding of situations in which conception should be delayed

While promotion of reproductive autonomy and rights is a key tenet of the safer conception guidelines, the guidelines also list situations when it is appropriate to encourage delays in conception or to discourage couples from conception, such as infertility or when the viral load is not suppressed (Table 1, Section 4). Indeed HCPs often expressed positive attitudes towards PLWH conceiving and encouragement of PLWH's pregnancy intentions along with the caveat that patients must be adherent to, or at least taking treatment, and worries about behavior and its impact on transmission.

> I tell them it's not a good idea to fall pregnant if they don't know their viral load. They should be undetectable [virally suppressed] for at least 6 months. I always say it's ok to have a baby; you can have a baby, but not now. [F, nurse]

PLWH understood and expressed fears about transmission, but the desire to conceive and lack of knowledge about safer conception strategies led them to attempt conception without risk reduction strategies.

> I wish just to have one more baby that will wipe away all the tears I had with miscarriages… I am negative and my partner does not always want to use condoms so we have unprotected sex. I don't like it, to sleep without a condom – I wish I could use a female condom. My husband doesn't want to take treatment and his last CD4 was 260 and he doesn't like to go to the clinic. [F, HIV- in a serodiscordant partnership]

In addition to concerns regarding transmission, HCPs also voiced social and psychosocial concerns, which influenced their willingness to encourage conception. In particular, HCPs were concerned whether HIV-affected couples could provide for children and give them proper support, and worried about PLWHs' lifespan and orphaning children. *"I know we have PMTCT but there are patients who are not too well. I am worried about their life span and orphans."* [F, doctor]

DISCUSSION

In this qualitative study of South African HCPs and people affected by HIV, we found that healthcare providers have a generally positive attitude towards the desire of HIV-affected couples to conceive and that HCPs have some knowledge on safer conception methods. HCPs unfortunately fail to initiate a discussion about safer conception with clinic patients,

limiting acquisition of safer conception knowledge to patients who are comfortable enough to ask.

Few studies have examined healthcare providers (HCPs) knowledge of and attitudes towards counseling HIV-affected individuals and couples on fertility intentions and safer conception methods. Studies from South Africa and Kenya reported a lack of standardized service provision and inconsistent counseling on safer conception methods (Crankshaw, Mindry, Munthree, Letsoalo, & Maharaj, 2014; Matthews et al., 2014; Mmeje et al., 2014). In Johannesburg clinics, only 41% of HIV-infected women reported that an ART healthcare provider had spoken with them about safer conception options (Schwartz et al., 2012).

Our findings reinforce prior evidence that the crucial first step of healthcare provider initiated counseling on safer conception is not taking place - with HCPs and patients alike reporting the onus is on the patient to raise the topic, meaning that the topic is rarely raised (Goggin et al., 2014; Kawale et al., 2014; Matthews et al., 2012). Our findings elucidate reasons why HCPs may fail to take the vital first step of initiating discussions about pregnancy and fertility with PLWH. The foremost barrier to HCPs initiating discussions around fertility desires for PLWH stems from the goal to prevent HIV transmission and relates to the concern of counseling couples perceived as not ready to conceive because they are clinically or socially not ready to have children or the HCP finds that patients' conception choices are not being driven by reasons that HCPs find acceptable. Examples are PLWH who are not virally suppressed, those in unstable partnerships, when the HIV status of the partner is unknown, when the HCP believes that the PLWH's goal is to solidify a new relationship by producing a child, or when the HCP feels that the patient does not consider the consequences of being HIV-infected and having a child. Additionally providers may have concerns about whether HIV-affected couples are financially stable enough to support a child. Abundant evidence however demonstrates that PLHIV will conceive and have children regardless of transmission risks, negating the idea that not giving patients information about safer conception strategies will deter them from attempting to conceive (Nattabi et al., 2009; Nebie et al., 2001; Schwartz et al., 2012). Indeed, patients in our study often expressed desperation to conceive, even at the risk of their own health. Not engaging in conversation with PLWH about conception goals during clinical consultation may deprive them of an opportunity to set goals to optimize their health in preparation for conception. The guidelines do state situations where it is appropriate to discourage PLWH from conceiving, including unsuppressed viral load, infertility or conditions affecting fertility, medical contra-indications, and non-disclosure of HIV-status to partner (Bekker et al., 2011; Department of Health, Republic of South Africa, 2012), but this does not imply that a conversation about childbearing is not appropriate even if conception turns out to not be recommended. Providing HIV-affected couples with the knowledge that there are methods to reduce risk of HIV transmission when attempting to conceive may motivate them to adopt safer conception strategies, including delaying conception until they are virally suppressed or ready to use the safer conception method of their choice.

While guidelines for safer conception exist in South Africa, poor availability of the guidelines at clinic level and lack of inclusion of these guidelines in training, monitoring and reporting contribute to the lack of implementation. Nevertheless, most HCPs were

knowledgeable about some of the safer conception methods recommended by the guidelines. HIV counselors primarily were aware of ART-related approaches such as achieving viral suppression before attempting conception and pre-exposure prophylaxis, while doctors and nurses were able to discuss both behavioral and biomedical methods. HCPs did however express trepidation as to whether they were counseling patients correctly as they were not aware of the existing guidelines and lacked formal training on safer conception strategies. HCPs and patients also referenced sperm-washing and in vitro fertilization, strategies that are not accessible in the low-resource primary care setting. Timed intercourse and self-insemination for discordant couples was raised by only half of HCPs. This may demonstrate lack of confidence in low-technological prevention strategies or the misconception among some HCPs that a person cannot remain HIV-uninfected when engaging in a sexual relationship with an HIV-infected partner. Previous research also suggests that HCPs may be uncomfortable with the idea of counseling serodiscordant couples on engaging in timed condomless vaginal intercourse (Crankshaw et al., 2014; Kawale et al., 2014; Matthews et al., 2014), and that both patients and HCPs may struggle to understand HIV discordance (Matthews et al., 2014).

Our findings support the conclusions by others that there is a need for training and development of models for service provision of safer conception (Crankshaw et al., 2014; Goggin et al., 2014). Whether safer conception is provided as a separate clinical service or in an integrated fashion, all primary care HCPs need formal training on the South African guidelines for safer conception to ensure consistent messaging and screening, but facility level champions or specific clinicians who are dedicated to deliver the service may be the most feasible way to structure service delivery. Our findings further indicate that training on HIV serodiscordance, seroconversion and health behavior are necessary to remove barriers that may inhibit providers from raising conversations with PLWH and HIV-affected couples about the issue of childbearing. Messaging campaigns within the primary healthcare setting may help to challenge common misconceptions about HIV serodiscordance held by both patients and HCPs (Spino, Aldo, Clark, and Stash, 2010). Additionally, employing participatory training has shown to be an acceptable and useful tool for both healthcare providers and patients, and may help raise self-awareness of the barriers to open communication on conception for PLWH, promote positive attitudes, as well as enhance skills (Fonn & Xaba, 2001).

While our findings support the limited evidence regarding HCPs' knowledge and use of safer conception strategies (Crankshaw et al., 2014; Matthews et al., 2014), they add crucial dimensions by examining the results through the lens of implementation of existing guidelines and including the patient perspective. This study was however not without limitations. First, data were drawn from a qualitative study at a single primary care clinic, possibly limiting the generalizability of the findings. Nonetheless, a study from 6 clinics in Durban, South Africa also showed low awareness of safer conception methods among healthcare providers, suggesting that our findings may not be unique to our study site (Matthews et al., 2014). Second, we deliberately sought out HCPs with some experience in or potential knowledge of safer conception practices. The HCPs interviewed may thus not represent the broader healthcare provider population within or outside WHWC. This

suggests that our findings are likely best-case scenarios in terms of routine implementation of the guidelines.

In conclusion, healthcare provider concern over readiness for conception, perception over what patients will do with safer conception knowledge, disbelief in HIV serodiscordance, and gaps in safer conception knowledge prevent HCPs from initiating conversations with PLWH and HIV-affected couples on the issue of childbearing. Development of tools for routine screening of contraceptive use and fertility intentions, assessment of partners' status, and safer conception counseling, as well as training and education campaigns to correct common misconceptions about HIV discordance are needed to overcome challenges in implementing safer conception guidelines and giving HIV-affected couples a chance to conceive safely.

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Table 1

Safer conception guideline recommendations and qualitative findings

Key Guideline recommendation	Summary of qualitative evidence	Illustrative quotes
1. Healthcare providers must raise the topic of fertility and childbearing intention or interest with HIV-infected women and men. The topic should be brought up recurrently.	• Patients and healthcare providers both reported that conversations regarding fertility planning are nearly always patient-initiated. • Because conversations regarding fertility planning are predominantly patient-initiated, these conversations do not occur with regularity.	• "Usually they [the patients] initiate the conversation – although often it is a question that they have about the future and they are trying to learn to understand what is possible now that they are HIV+." [F, nurse] • *Have you discussed having a baby with a doctor or a nurse?* "NO." (Unanimous). *Could you discuss having a baby with a doctor or a nurse?* "Yes, but the patient would have to bring it up." (Others unanimously agreed). [FGD, HIV+ women]
2. Issues about fertility and childbearing intention should be discussed with both men and women, and a couples based approach is strongly recommended	• Healthcare providers viewed challenges with partner involvement as a barrier to counseling couples on safer conception strategies. • Patients highlighted desire for both information about transmission risk reduction options, and generally felt that partners would be willing to attend as a couple for conception consultation, though work was a noted barrier to attendance.	• "What if the man doesn't want treatment? It happens. If you can bring him in – we write letters to partners to invite them, but we are losing a fighting battle to them. In that case we cannot approve conception because even if she is undetectable and having sex every day without a condom, she will be detectable [*from the unprotected sex with the viremic partner].*" [F, nurse] • "Yes he will come if it is on weekends. He is not the type to come in general, but just for the peril of the baby." [F, HIV-, in serodiscordant partnership]
3. Use of safer conception strategies should account for HIV seroconcordant or discordant relationships, resources available, and risk. In the low resource setting: • Male+/Female-: preconception highly active antiretroviral therapy (HAART) for male partner, periovulatory condomless sex, pre-exposure prophylaxis (PrEP)*for female partner • Male-/Female+: preconception HAART for female partner, self-insemination, PrEP for male partner • Male+/Female+: preconception HAART, periovulatory condomless sex, or self-insemination. *PrEP is not listed under optimal methods in the South African Department of Health guideline, but noted as strategy that may be considered for serodiscordant couples.	• Healthcare providers demonstrated knowledge of a variety of methods, and highlighted awareness of need for low-resource setting appropriate strategies for safer conception. • Despite knowledge, provider experiences exposed gaps in application of appropriate safer conception strategies in counseling patients, and disbelief that safer conception strategies will be utilized by patients. • Patients' lack of experience with and knowledge of safer conception methods also supported that use of safer conception strategies was limited in medical consultations.	• "If one [partner] is infected, get the other partner tested and kept in HIV care. Women keep a calendar of menses cycle to learn their fertile periods so as to do self-insemination with syringe. If both [partners] are infected, still keep a calendar, and use timed unprotected sex plus self-insemination." [F, doctor] • "We tell them to go take bloods and check their CD4 count and viral load – because when she is going to conceive she won't use condoms and the CD4 will drop and the viral load go up and when she delivers it [CD4] will go down more and the high viral load is a risk for the baby." [F, nurse] • "Patients don't know that [ARVs can reduce risk of transmission] – they know that it reduces the virus for themselves, but not transmission. Because we don't highlight this because we don't want them to stop using condoms." [F, nurse] • "I only know about in-vitro fertilization. And adoption, which I am also considering." [F, HIV+, in serodiscordant partnership] • "With patients, they don't plan babies, they just come. I don't think they worry about re-infection, they're still not using condoms – I don't think they are worried if one is negative and one is positive." [F, nurse]

Key Guideline recommendation	Summary of qualitative evidence	Illustrative quotes
		• "I try to explain discordance. That they are carriers and can transmit." [F, nurse] • "Even though I'm negative, I don't think I'm 100% negative, if I sleep with someone who is negative I might infect that person." [F, HIV-, in serodiscordant partnership]
4. Situations or circumstances where it may be appropriate to discourage attempting conception: viral load can't be suppressed; non-disclosure of HIV status to partner; documented infertility; conditions affecting fertility; medical contraindications	• Viral suppression was a concern for health care providers in patients with conception desires, and considered a reason to discourage patients from attempting conception. • Health care providers expressed a desire to control information about fertility and safer conception, and only encourage conception in couples they perceived to be ready.	• "Deal with your health first – then worry about having a baby. If the viral load is high we can't have this conversation. We focus on these conversations with patients who don't miss visits and take their medication." [F, nurse] • "Doctors have been telling me to forget about having children as I'm HIV positive." [F, HIV+, in seroconcordant partnership]