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Acceptability and preferences for safer conception HIV prevention strategies: A qualitative study

Sheree Schwartz^{1,2}, Nora West³, Rebecca Phofa³, Nompumelelo Yende³, Ian Sanne^{4,5}, Jean Bassett³, and Annelies Van Rie¹

¹Department of Epidemiology, University of North Carolina at Chapel Hill, Chapel Hill, USA

²Department of Epidemiology, Johns Hopkins School of Public Health, Baltimore, USA

³Witkoppen Health and Welfare Centre, Johannesburg, South Africa

⁴Clinical HIV Research Unit, Department of Medicine, University of the Witwatersrand, Johannesburg, South Africa

⁵Right to Care, Johannesburg, South Africa

Abstract

Safer conception strategies to reduce HIV transmission risk include antiretroviral therapy (ART) for HIV-positive partners, pre-exposure prophylaxis (PrEP) for HIV-negative partners, condomless sex limited to fertile periods, and home-based self-insemination. Resistance to taking treatment or cultural concerns may limit uptake of strategies and intervention success. Understanding the acceptability and preferences between different approaches is important to optimize service delivery. Between February-July 2013, 42 adults (21 HIV-positive and 21 HIV-negative) receiving primary care at Witkoppen Health and Welfare Centre in Johannesburg, South Africa, participated in focus group discussions or in-depth interviews. Themes were analyzed using a grounded theory approach. Acceptability of antiretroviral-based (ARV) strategies varied. Concerns over side effects, ARV treatment duration, and beliefs that treatment is only for the sick were common barriers, however desperation for a child was noted as a facilitator for uptake. HIV-negative men and HIV-positive women had favorable attitudes towards self-insemination, though paternity and safety concerns were raised. Self-insemination was generally preferred over PrEP by HIV-negative men, and ARV-based strategies were preferred by couples with HIV-negative female partners, despite concerns raised about condomless sex while virally suppressed. Knowledge about the fertile window was low. A strong counselling component will be required for effective uptake and adherence to safer conception services.

Keywords

HIV-1; safer conception; discordant couples; HIV-prevention; fertility intentions

Corresponding Author: Sheree Schwartz, PhD, 615 N. Wolfe St, E7139, Baltimore, MD 21205, Tel: +1 443 983 2564, Fax: +1 410 614 8371.

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Introduction

Substantial reductions in mother-to-child HIV transmission during pregnancy have been achieved in recent years.^{1, 2} However there is growing awareness of the unmet need for services to reduce the risk of horizontal HIV transmission in discordant couples trying to conceive.^{3, 4} Intrauterine insemination or in-vitro fertilization, coupled with sperm-washing if the male partner is HIV-infected are strategies used in resource rich settings, but are rarely available in Sub-Saharan Africa.⁵⁻⁷ Low cost safer conception strategies, however, can be made available globally. These approaches focus on reducing HIV exposure by limiting condomless sex to the peri-ovulatory period, or utilizing home-based self-insemination when the male partner is HIV-uninfected (also referred to as timed vaginal insemination or manual insemination).⁸ Additionally, antiretroviral-based (ARV) strategies including early initiation of antiretroviral therapy (ART) (i.e. prior to the currently recommended CD4 count threshold) for the HIV-infected partner or pre-exposure prophylaxis (PrEP) for the uninfected partner are gaining importance and may be used separately or in conjunction with the non ARV-based strategies.⁹

Understanding the acceptability and preferences between different approaches is important to optimize service delivery. As safer conception services remain largely unavailable in the African context,^{3, 10} little is known about preferences for different strategies among HIV-affected couples in high burden settings. Previous acceptability studies have either evaluated ARV-based strategies for HIV prevention outside of the context of safer conception, or have focused on single safer conception methods without comparing the acceptability and preferences across methods. For example, manual timed self-insemination was acceptable to most Kenyan healthcare providers and patients,¹¹ and most Ugandan couples planning to conceive were willing to use condomless intercourse limited to the fertile period.¹² Many (60%) HIV-infected individuals in discordant relationships participating in a PrEP clinical trial in Kenya indicated a willingness to start ART early and 93% of HIV-negative partners were willing to use PrEP, however use of methods for safer conception was not explored.¹³

As part of the design of the safer conception service, *Sakh'umndeni*,¹⁴ we interviewed potential clients regarding their knowledge of safer conception methods and assessed the acceptability and preferences for different strategies. We also identified potential barriers and facilitators for uptake and adherence to safer conception approaches.

Methods

Study design and population

We performed 16 in-depth interviews (IDIs) and four focus group discussions (FGDs, n=42) with clients attending primary health care services at Witkoppen Health and Welfare Centre (WHWC). WHWC is a primary care clinic that provides services to residents of an informal settlement in Northern Johannesburg, South Africa.

Clients attending HIV counseling and testing services and HIV pre-ART or ART care from February-July 2013 were purposively sampled and invited to participate. Men and women were eligible to participate if they were 18 years, desired to have a child in the future, and

were either HIV-positive and in a relationship, or HIV-negative and in a relationship with someone they knew or believed to be living with HIV. Both individuals in HIV seroconcordant and serodiscordant relationships were eligible as safer conception services are likely to be taken up by both serodiscordant and seroconcordant couples concerned about reinfection and/or mother-to-child transmission. Sampling was stratified to ensure comparable representation of HIV-positive and negative women and men. FGDs were conducted separately according to sex and HIV status. Participants took part in either IDIs or FGDs, there was no overlap in participation.

Ethical approval was obtained from the Institutional Review Board at the University of North Carolina at Chapel Hill, USA, and the Human Research Ethics Committee at the University of the Witwatersrand in Johannesburg, South Africa. All participants completed written informed consent.

Data collection and analysis

FGDs and IDIs were semi-structured, using standardized guides, and were led by study team members with experience in facilitating qualitative interviews. Questions about acceptability and preferences for methods were preceded by a verbal description of what the method involves and how to apply it, followed by a discussion to ensure that the participant understood. A standardized understanding of methods was ensured through the interview guide descriptions. To gain insights on the general societal acceptability of methods and potential barriers in the community, FGDs included situational questions that were both directly relevant to participants as well as situations that were less relevant (e.g. asking HIV positive men about manual self-insemination). Notes, including verbatim quotes, were recorded by the study team member and an independent transcriber, and compared immediately following the interview to enhance accuracy and completeness. Interviews were conducted in English, Zulu or Sotho. Typed notes and transcripts were translated into English.

A grounded theory approach was used to examine patterns and emergent themes across the transcripts. Categories were identified based on interview guides, and were used to develop codes.^{15, 16} Two reviewers independently coded each transcript using an iterative process in which a codebook of descriptive and interpretive codes was developed, applied, compared, discussed, agreed upon, and then repeated iteratively until saturation of emergent themes was reached.

Results

IDI and FGD participants included 21 women (12 HIV-positive and 9 HIV-negative) and 21 men (11 HIV-positive and 10 HIV-negative).

Knowledge of safer conception methods

Participants had generally good knowledge about prevention of mother-to-child transmission (PMTCT), but limited understanding of safer conception methods to prevent horizontal transmission between partners. Initial responses about safer conception strategies were typically limited to knowledge of assisted reproductive technologies and concern about the

dangers of condomless sex (Table 1). After probing, participants expressed mixed knowledge about ARV-based prevention strategies and very limited knowledge about self-insemination or timed condomless intercourse.

Acceptability of ARV-based prevention strategies for safer conception

Acceptability of PrEP use among HIV-negative participants varied. Most participants were willing to try this method, though concerns regarding side effects were common.

“I don't like ARVs but I would take them for a short period, if they don't treat me well I would stop them.” [Female of unknown age, HIV-, 007]

“I would take it. If I didn't like it, if it doesn't suit you, you have to stop. If it causes side effects – this is a problem.” [39-year-old male, HIV-, 003]

Still, desperation for a child was perceived by many participants, especially HIV-negative women, to be more important than the potential side effects of PrEP.

“I don't mind taking ARVs, I would take them 100%. I can deal with the side effects. If you are willing to have a baby, you can have side effects.” [28-year-old female, HIV-, 013]

“I'm not afraid of being infected. I started trying for a baby last year without a condom and I was put on PEP [post-exposure prophylaxis], but I'm still negative. I'm so desperate, everything is fine with me...all I want is a baby.” [Female of unknown age, HIV-, 007, who was prescribed ARVs by a nurse for conception purposes]

Some HIV-positive participants on ART predicted lower acceptability of treatment for uninfected partners.

“I don't think HIV-negative people will take ARVs because they will say they are not sick. People taking ARVs are only doing it because they are sick. Most fear the side effects these ARVs come with. My partner and I are both taking ARVs, but if I was negative there is no way I will take ARVs.” [31-year-old female, HIV+, 005]

Participants expressed that treatment duration, lifelong or until pregnant, influences acceptability of PrEP.

“As long as it is not a lifetime thing—I could take them until I get pregnant.” [Female of unknown age, HIV-, 007]

“She must go for ARVS in the time when she tries to conceive or forever? [If just while she tries to conceive] then she could do this.” [Male of unknown age, HIV+, 016, discordant relationship]

Among the few ART-naïve HIV-positive participants interviewed, earlier ART initiation was largely acceptable.

“I only know of pills to prevent infection to the babies, but [if ARVs for the infected partner worked as a prevention strategy] I would take ARVs.” [Male of unknown age, HIV+, 016]

Acceptability of non ARV-based strategies for safer conception

Men living with HIV did not perceive home-based self-insemination with a syringe as a viable option for discordant couples in which the male partner was HIV-negative. Concerns were largely related to a lack of understanding around human reproduction. Thus even though participants understood how to perform the self-insemination method, they often demonstrated misconceptions about how conception without condomless sex alters paternity.

“The syringe is bad because if I use syringe, is this my baby or is it the syringe's baby?” [32-year-old male, HIV+, 001]

“Education before would be very important—getting everyone on the same page. Men don't want to be robbed of our manlihood. It's not going to be our baby, it is like it's someone else's.” [Male of unknown age, HIV+, FGD]

To HIV-negative men and HIV-positive women however, acceptability was much higher and cultural concerns less pronounced.

“I would use the syringe as long as I would get a baby and if I wouldn't get the virus. The most important thing is to have a baby and remain HIV-negative, how the baby is done is not important.” [40 year-old male, HIV-, 002]

“I think we would do it—my partner would. The main thing is to maintain the negative status of the other partner. They should be focusing on their safety and not on the traditional way.” [31-year-old female, HIV+, 005]

Acceptability was driven by an understanding of what self-insemination means for paternity, as well as knowledge of how to apply the method. Men commonly expressed concerns of hurting their partner but were open to having the female partner insert the syringe herself. The importance of education was highlighted by men as critical for uptake.

“For me to do it? No. Every time I look at her I'd go blind. When you step on a bottle you don't want to take it out. I wouldn't want to hurt her—putting a syringe in her I don't think I could do it, so she could do it.” [39-year-old male, HIV-, 003]

In general, condomless sex limited to the fertile period in the presence or absence of ARV-based strategies was a cause for concern. Although women noted that HIV-negative men would prefer sex without a condom or a syringe, messages of the importance of condom use had been absorbed by most participants and condomless sex was viewed with skepticism and even incorrect information.

“[Condomless sex] is not safe, even if the viral load is low, condoms only.” [Female of unknown age, HIV+, FGD]

“I heard that the chances of me getting sick are higher if we have unprotected sex, than of him getting infected.” [Female of unknown age, HIV+, FGD]

Preferences between ARV-based and non ARV strategies

Participants were split in their preferences between ARV-based and non ARV-based prevention strategies (Table 2), highlighting the diversity in views. In general, self-insemination was preferred over PrEP if the male partner was uninfected and the female

partner infected due to total elimination of HIV transmission risks and absence of side effects.

“I don't like pills because of side effects. The syringe would be easier than taking pills every day.” [24-year-old male, HIV-, 009]

“I think the syringe is better [than ARVs] because you can't get infected.” [Male of unknown age, HIV-, FGD]

“The HIV-negative person would not agree to take ARVs but will agree to use a syringe, because they are not sick. They might consider in-vitro fertilization....I don't think I would have sex with an HIV-negative man, it is risky and I wouldn't want to infect him. I would prefer to use the syringe.” [34-year-old female, HIV+, 006]

“I will choose syringe. But if my partner was positive and I was negative I would not take ARVs. I am only taking ARVs because I don't have any choice.” [31-year-old female, HIV+, 005]

However other men noted they preferred PrEP with condomless sex as it is more “natural” and easier to implement.

“Pills (ARVs) would be better. I would prefer to do it naturally.” [32-year-old male, HIV+, 001]

“[Regarding manual self-insemination] People will call it insanity. But I guess this is no problem. But just I'm afraid of hurting her. The pill is easier!” [39-year-old male, HIV- 003]

The only respondent with experience using the method preferred pills. However he had only obtained one syringe which required cleaning prior to each use and found self-insemination tedious and frustrating. Although he and his partner successfully conceived using this method, when asked if he would use the method for future conception, he indicated that he would not use self-insemination again.

Among discordant couples where the woman was uninfected, ARV-based strategies were typically preferred. Motivation to use ARV-based prevention strategies did not seem to be driven by fear of HIV acquisition, but centered around concerns of HIV transmission to the developing fetus in the event of seroconversion.

“I am not scared to be infected but I am worried about the baby. If I get infected I might also infect the baby—this is what I would worry about.” [Female of unknown age, HIV-, 007]

Barriers and facilitators to safer conception uptake and adherence to strategies

The majority of HIV-negative participants indicated that they had learned about serodiscordance, but many were not fully convinced that discordance was possible. These beliefs could reduce motivation to use and adhere to prevention strategies.

“The last time I tested negative was last week, but still I don't believe it because my partner is positive. I have tested negative six times and my partner is positive, but

sometimes there are false results. I know I am positive. I have sex with an HIV-positive woman without using a condom, it means I am also HIV-infected.” [40-year-old male, HIV-, 002]

“The child might get infected, because 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.” [Female of unknown age, HIV-, 007]

Poor knowledge around fertility and conception was another barrier, potentially reducing the efficacy of timed condomless sex and timed manual self-insemination. Women generally knew when to expect their menstrual periods but few knew when they were most fertile.

Similarly various men in the FGD demonstrated questions about the viability of conception through manual self-insemination.

“How do you make sure it [semen] will stay in without sex?”

“But how will you know how far to put it in? Is there a certain temperature that semen needs to be to live? Because it might cool down too much before I put it in.”

“Does she need to be hot or in the mood?”

Despite these barriers, several factors were identified which may facilitate success, chiefly high motivation to protect the health of a future baby.

“I would like [a safer conception clinic] to help us have babies born free from HIV. I will always feel guilty if my baby will be born HIV-positive because of me. I will think I should not have made this baby.” [31-year-old female, HIV+, 005]

Safer conception services may also serve as a mechanism to get partners to test together if HIV status has not yet been confirmed for both partners.

“Getting a positive baby is scary but what I hate to think about is the fact that my partner may be positive—maybe even knows he is positive, but wants a baby and so I am taking a huge risk.” [28-year-old female, HIV-, 013]

Furthermore, the concept of treatment as prevention was well understood in terms of pills for the mother for PMTCT as well as post-exposure prophylaxis for situations of known occupational or sexual trauma-related exposure.

“What I think is that when a woman is raped she takes post-exposure prophylaxis, ARVS, to prevent getting infected. So maybe ARVs could work to prevent infection to partner as well. I don't know.” [Female of unknown age, HIV+, FGD]

Discussion

In this study, where South African HIV-positive and negative men and women were asked to compare multiple safer conception methods, we observed high acceptability for both ARV-based and non ARV-based approaches. Preferences for specific methods varied across participants and were predominantly influenced by assessment of effectiveness at reducing or eliminating risk, concerns over ARV-related side effects, and knowledge about the method.

Despite high willingness to use ARV-based methods, these strategies were not always preferred. High motivation to protect the potential fetus and baby and familiarity with early initiation of ART for PMTCT may facilitate the uptake of ARV-based safer conception methods. Nevertheless, side effects and ARV appropriateness for those who are not sick were raised as concerns, which are themes that have also emerged outside of the context of safer conception services.^{17, 18} The perception that ARV use is not 'normal' for healthy adults may change in the future, as countries are moving in the direction of ART-based prevention strategies for a greater number of individuals, including all pregnant women and serodiscordant couples as recommended by the World Health Organization, but not currently in the South African Department of Health Treatment Guidelines.¹⁹⁻²¹ Suboptimal retention in care as experienced in PMTCT Option B+ programs²² may also occur in the context of early ART or PrEP for safer conception if side effects are perceived as too burdensome or motivation for ART wanes after peri-conception and pregnancy-related transmission risks elapse. Similarly for PrEP, side effects may limit efficacy, which is highly dependent on adherence.²³⁻²⁶ In discordant couples in the Partners PrEP study, only 71% of women who conceived had active drug detected in plasma at time of pregnancy diagnosis, and drug levels were not higher among women who conceived than those who did not conceive, though pregnancies may have been unintentional.²⁷ Qualitative data from women participating in PrEP studies highlight adherence barriers including participant confusion about ARVs for prevention versus treatment, and HIV stigma concerns around being perceived by others as HIV-positive if they are taking ARVs.¹⁸ Still the limited timeframe for PrEP for conception and motivations around PMTCT may facilitate higher adherence. Additionally previous qualitative work has cited partner support for PrEP as a facilitator for adherence and support is more likely in the context of a couples-based safer conception service.²⁸ When adherence to ARV-based safer conception strategies is difficult to achieve, other strategies may play an important role.

Preference for home-based insemination was common among HIV-positive women and HIV-negative men, but men expressed concerns regarding their manhood, fear of hurting their partner, and paternity. Qualitative work from Kenya and Cape Town, South Africa, echoed concerns related to masculinity or culture,^{29, 30} and also raised issues around whether the male or female partner should perform the insemination.¹¹ Concerns around the cultural acceptability of non-natural conception strategies were also raised in Uganda by providers and clients. In this setting awareness of non ARV-based safer conception methods was much higher than in our study, however similar themes related to limited knowledge about ovulatory periods and the implications of home-based insemination on the health of the fetus were raised.³¹ What emerged in our analysis is that the concerns around self-insemination were largely fueled by lack of knowledge and low self-efficacy, but that after further information men became overwhelmingly interested. This suggests that education rather than deep-rooted cultural opposition is a barrier and that uptake of this strategy may be high in the context of safer conception counseling and skills building.

Misconceptions around serodiscordance and fertility could also be important barriers to any safer conception strategy. Individuals in discordant couples who do not fully believe that they are HIV-negative despite testing negative have also been reported by others,^{32, 33} and this fatalism may diminish motivation to adhere to prevention strategies. Poor understanding

among women about when they are most fertile and among men about the potential for conception with self-insemination were also consistently reported. Together these issues demonstrate the need for specific counseling within safer conception services around both HIV and fertility.

While our findings may not be generalizable to other settings, emerging themes bring together many separate ideas found elsewhere. Furthermore, high uptake of self-insemination and low uptake of PrEP in our on-going safer conception service developed through this formative work support the findings of this qualitative analysis.¹⁴ Lack of audio recording may have limited participant probing and resulted in loss of some information. Another limitation of this study is that few HIV-positive participants were ART-naïve, limiting the extent of in-depth analysis around the acceptability of early ART initiation. Strengths of the study were that multiple safer conception methods were compared and patients were specifically asked to indicate their reasons behind preferences for specific approaches.

Together these findings indicate a strong education and counseling component of couples will be required for effective safer conception services. Training of providers will also be required to ensure service availability as well as uniform messaging about fertility and safer conception. Providers will need to offer multiple strategies instead of a following single algorithm, such that couples can choose a strategy based on a variety of personal and relationship-based preferences. Adherence to strategies will require monitoring and support services. Providers should also be aware that adjustment of approaches may be necessary to optimize HIV prevention and pregnancy outcomes.

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Table 1
Patient knowledge of safer conception methods (SCM)

SCM Knowledge	Summary	Illustrative Quotes
Overall knowledge	<ul style="list-style-type: none"> Generally low and primarily limited to cursory understanding of assisted reproductive technologies Concerns frequently expressed about the dangers of HIV transmission and reinfection related to condomless sex while trying to conceive 	<i>"I have not heard of ways. I have heard only of in-vitro fertilization [to reduce risks] but not sure if I know everything." [34-year-old female, HIV+, 006]</i>
		<i>"I don't know of any method. The only thing I know is that they should use condoms." [44-year-old female, HIV-, 012]</i>
		<i>"What I've heard is that you are not supposed to have sexual intercourse – unprotected – if HIV+ because it is bad for your health and your viral load will go up." [Male, HIV+, FGD]</i>
		<i>"I read from a magazine that ARVs reduce the risk but I don't have enough information on that regards. There was also information about sperm donors but I am not sure if I understood well what it was about." [31-year-old female, HIV+, 005]</i>
Knowledge of antiretroviral-based strategies for prevention or manual self-insemination	<ul style="list-style-type: none"> High knowledge of ARVs to prevent mother-to-child transmission of HIV Mixed awareness on the efficacy of ARVs to prevent horizontal transmission Majority of patients had not heard of manual self-insemination as a safer conception method 	<i>"I know that ARVs prevent transmission to the baby, but I have never heard of self-insemination or any other approach." [36-year-old female, HIV+, 004]</i>
		<i>"ARVs [for the HIV-positive partner] can't prevent transmission – there is a risk because he's not positive and he's not on ARVs [himself]." [Female, HIV+, FGD]</i>
		<i>"ARVs don't prevent HIV they are only prolonging life. It stops it a bit, but never all and only for the time being. There is no way to make a baby with this. I have never heard of self-insemination, only in-vitro fertilization." [40-year-old male, HIV-, 002]</i>
		<i>"I heard that if you're on ARVs, they reduce the risk. But I am not sure of other methods. I heard one patient talking about the syringe method here in the clinic and she explained it like she had done it before." [32-year-old male, HIV+, 011]</i>
		<i>"I don't have any information and I don't know how ARVs work as I don't take them. But I think it could be true [that ARVs reduce transmission risk] based on my experience." [Female, HIV-, 007]</i>

Table 2
Preferences of participants for ARV vs. non-ARV approaches to safer conception

In-depth interviews (n=16)							Partner's HIV status	Preference for ARV vs. non-ARV Strategies
ID	Sex	Age	HIV Status	On HAART				
001	M	32	Positive	Yes		Negative		ART
002	M	40	Negative	NA		Positive		Behavioral
003	M	39	Negative	NA		Positive		ART
004	F	36	Positive	Yes		Negative		Behavioral
005	F	31	Positive	Yes		Positive		Behavioral
006	F	34	Positive	Yes		Positive and Negative *		Behavioral
007	F	Unknown	Negative	NA		Positive		ART
008	F	31	Positive	No		Negative		Behavioral
009	M	24	Negative	NA		Positive		Behavioral
010	M	44	Positive	Yes		Positive		ART
011	M	32	Positive	Yes		Positive		ART
012	F	44	Negative	NA		Positive		ART
013	F	28	Negative	NA		Unknown **		ART
014	F	35	Negative	NA		Unknown **		Behavioral
015	M	34	Negative	NA		Positive		Behavioral
016	M	Unknown	Positive	No		Negative		ART
Focus group discussions (n=26)								
				General preferences expressed within the group ***				
FGD No.	Sex	Participants	HIV Status					
1	M	6	Negative	All but one man preferred self-insemination with a syringe. The only man who preferred ARV's had actually used the syringe method.				
2	M	7	Positive	Mixed acceptability regarding ARV's . Self-insemination was perceived as only acceptable to those with high knowledge/education about the method and/or to those who are desperate for a baby.				
3	F	5	Negative	Prefer and willing to take ARV's				
4	F	8	Positive	Overall high acceptability and preference for self-insemination rather than PrEP for male partners				

* In relationships with two partners of different HIV status.

** Confirmed HIV status of partner unknown, but believed by partner to be HIV-positive.

Perceptions about acceptability and preferences in general were explored with participants in FGDs even for situations less applicable to respondents in order to assess the perceived societal acceptability and preferences for methods.

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