

## Clinical Research in HIV/ AIDS

### **Case Report**

# Pregnancy Planning among HIV Discordant Couples: What do Couples do and know about HIV Prevention and Risk of Transmission during Conception

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### Abstract

**Objective:** HIV serodiscordant couples are interested in having children but little is known regarding safer conception knowledge, attitudes and practices among women living with HIV infection and the knowledge and attitudes held by their HIV negative male partners. This study sought to explore knowledge, beliefs and practices regarding reproductive decision making, safer conception methods and HIV transmission risk among HIV serodiscordant couples. It was hypothesized that insight into patients' perspectives could support the development of effective strategies to enable HIV serodiscordant couples to make more informed decisions about safer conception and reduce the risk of HIV transmission to partners.

Methods: A qualitative descriptive design was used as the study design. Qualitative interview topics were developed from informal discussions with healthcare providers and HIV-infected women of reproductive age. Digital audio recordings of interviews were transcribed and coded to identify common themes, trends, and patterns. Content analysis was used to analyze data.

Results: The primary themes emerging included pregnancy planning and reproductive decision making, experiences and perceptions of HIV disclosure, knowledge, attitudes and practices regarding fertility and safer conception practices, and support attitudes from providers and family concerning pregnancy. Results provided insight into reproductive practices and communication between couples on disclosure and pregnancy. Due to a lack of important information on fertility or safer conception methods, few men had knowledge regarding PrEP or perceived themselves as having access to supportive healthcare.

Conclusion: Study outcomes highlight the important role that can be played by healthcare providers during regularly occurring health care visits.

### **ABBREVIATIONS**

HIV: Human Immunodeficiency Virus; TasP: Treatment as Prevention; PrEP: Pre-Exposure Prophylaxis; IPV: Intimate Partner Violence; ACASI: Audio Computer Assisted Self-Interview; WLHIV: Women Living with HIV

### **INTRODUCTION**

It has been estimated that there are approximately 140,000 serodiscordant couples in the United States—and approximately half express a desire to conceive1. An increasing number of HIV serodiscordant couples are interested in having children but little is known regarding safer conception knowledge, attitudes and practices among women living with HIV infection and the knowledge and attitudes held by their HIV negative male partners [1,2]. Preliminary studies have identified that despite pre-conception counseling, many pregnancies are unplanned,

often involve short term partners, and/or partners of unknown HIV status3. Informal information and past research on patients attending clinic visits suggest that women may avoid discussing their desire for pregnancy with their health care providers due to embarrassment, providers not approving of their decision to have a child, or anticipating a negative reaction from providers [4,5]. Yet, attempting to conceive without risking HIV transmission to sexual partners requires planning, engagement in treatment and consultation with health care providers.

Although some reproductive technologies, such as sperm washing, may not be affordable or available for many couples, methods such as antiretroviral therapy for HIV infected partners (treatment as prevention, TasP), pre-exposure prophylaxis (PrEP) for HIV negative partners, and timed intercourse may provide viable and acceptable options [6-8]. However, those engaged in HIV care may hesitate to share fertility desires,

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plans or practices during routine visits with their providers. In addition, providers may fail to discuss conception with their patients living with HIV, or when discussions that do occur, these discussions may be inadequate or infrequent [3,5,9,10]. Health care provider reports knowing multiple methods of safer conception and strategies to reduce the risk of HIV transmission. However, health care providers may not routinely discuss such methods with their patients [11].

HIV-infected women's knowledge about becoming pregnant with minimal risk of transmission to partner and off-spring may be limited [12], and their sexual partners may rely on this second-hand knowledge or their own beliefs [13] to inform their sexual practices and attempts to conceive. Serodiscordant couples' motivation to conceive may also influence the level of sexual risk they are willing to accept in order to conceive [14]. As in the general population, the motivation to conceive may be driven by desire rather than by a conscious choice or intention requiring the exercise of personal agency [15,16]. Thus, understanding the motivations, beliefs and intentions underlying plans to conceive is critical to creating strategies to enhance safer conception practices among HIV serodiscordant couples.

This study sought to explore knowledge, beliefs and practices regarding reproductive decision making, safer conception methods and HIV transmission risk among HIV serodiscordant couples. It was hypothesized that insight into patients' perspectives could support the development of effective strategies to enable HIV serodiscordant couples to make more informed decisions about safer conception, reducing the risk of HIV transmission to partners and children.

### **Purpose**

This study was designed to collect information on knowledge, attitudes and practices regarding fertility and reproductive decision making among HIV infected women and their sero negative male partners, and to use this information to develop a patient-centered intervention to enhance the uptake of safer conception practices.

### **METHODS**

### Design

A qualitative descriptive design was used as the study design. This design is a qualitative method of inquiry that focuses on providing a summary of the phenomenon under investigation as reported by the participation [17]. As one of the most common qualitative research design used by nurses [18], qualitative description allows a representation of data without requiring abstraction of the data [17]. Therefore, data are presented in common terms as reported by the participants, which makes the results easily understandable by others [17].

### Participants and procedures

Institutional review board approval was obtained prior to study onset. Convenience sampling facilitated recruitment, which was conducted using flyers describing the study by word of mouth at an urban public hospital and urban community health centers in Southern Florida. Recruitment and enrollment was conducted from January 16, 2014 to February 23, 2015.

Interested participants or couples were screened by telephone for potential eligibility and scheduled for an interview; women were the index case for recruitment.

Participants (n=16 couples) were heterosexual, HIV serodiscordant couples (HIV-infected women and HIV negative men), reproductive age (18-45), sexually active within the last 6 months with at least one partner, and capable of conception (no history of tubal ligation or hysterectomy). In order to participate, couples had to confirm previous mutual disclosure of HIV status; women currently pregnant were also eligible.

After providing informed consent, each participant individually completed an audio computer assisted self-interview (ACASI) questionnaire. The automated questionnaire assessed demographic information, knowledge on pregnancy, safer conception, risk reduction, pregnancy plans and clinical markers of HIV including viral load and CD4 count. Following completion of the automated interview, the couples were interviewed together as a couple. All interviews were conducted in a private room and each interview was tape recorded. Each participant was provided with \$50 as compensation for time and travel to the site.

### Qualitative interviews

Qualitative interview topics were developed from informal discussions with healthcare providers and HIV-infected women of reproductive age. The interview framework of "stem" questions was developed by a collaborative team including health care providers in psychology, obstetrics, gynecology and infectious diseases. Stems were developed using an iterative, collaborative process, and included reproductive decision making, preconception counseling, and patientprovider communication. The responses were used to develop stems that were utilized in the interviews and to establish the content of the quantitative questionnaires. The ensuing set of questions therefore included those related to safer conception and general conception practices among women and men, fertility intentions, use of contraception and attitudes toward family planning, involvement of patient partners in reproductive decision making, intimate partner violence (IPV) and coerced reproduction, involvement of family and social networks in reproductive decisions, perceived religious and cultural mores regarding childbearing and reproductive decision making, and opportunities for fertility counseling.

Prior to interviews, rapport was established through informal interactions and communication between the assessors and the participants. Couple interviews were conducted by doctoral-and master-level nurses and counselors familiar with the topics discussed. Interviewers practiced reflexivity by continuously questioning everything that was said during the interviews and was used to elicit the responses from the couples.

### Qualitative analyses

Digital audio recordings of interviews were transcribed verbatim and coded using QRS N vivo9 in order to identify common themes, trends, and patterns. Qualitative content analysis techniques were used to analyze the data 19. Qualitative content analysis is a technique for the analysis of written text data, such as interviews, that allow qualitative inferences to be made

about the data19. The use of qualitative content analysis as the method of data analysis is congruent with the study's qualitative descriptive design17. Each transcript was read in its entirety, and a list of phrase, sentences, and words were generated from the transcripts. These were condensed into categories that described how HIV discordant couples make decisions about reproduction in the context of HIV infection. When reading each transcript, manifest and latent content was identified. Manifest content involves the identification of obvious meanings without placing the data into categories or themes. Latent content allows grouping of data into categories so that data can be interpreted [19,20]. Both manifest and latent content were included in this analysis.

Information that fell outside the primary themes was coded as arising themes until saturation was reached and no new themes emerged. The primary themes emerging were categorized as follows: 1) pregnancy planning and reproductive decision making; 2) experiences and perceptions of HIV disclosure; 3) knowledge, attitudes and practices regarding fertility and safer conception practices; and 4) support and attitudes from providers and family concerning pregnancy. These four broad categories were given titles that summarized the meaning of the participants' statements. These categories, in the form of latent content, are presented to report the study's findings.

### Rigor

Qualitative research has procedures to ensure reliability and validity of qualitative research findings. In qualitative research, the terms "rigor" or "trustworthiness" are used to describe methods that a researcher may employ to ensure that the study's findings are trustworthy. These methods include credibility, dependability, and transferability [20].

Credibility and transferability were the two methods that were used to ensure rigor in this study. To ensure credibility, the researchers used representative quotes from the participants to illustrate data analysis. In addition to those collecting the data from participants, data were analyzed by other members of the research team with clinical experience with the population f pregnant women with HIV infection. After all data were analyzed, a researcher outside the clinical area, but with qualitative data analysis expertise reviewed and verified the study's findings.

Transferability was the second method used to ensure rigor. Transferability refers to the ability to which the study's findings could be transferred to other members not enrolled in the study. To ensure transferability, participants were recruited with diverse characteristics and cultures so that a complete description of the phenomena could be known. Also, Rigor was achieved through an audit trail, and by eliciting information from both the male and the female as sources of data, rather than obtaining the perspective of just one either the woman or her male partner.

### Statistical analyses

Descriptive statistics were used for demographic information, knowledge of pregnancy planning, safer conception, risk reduction strategies and clinical markers of HIV.

### RESULTS AND DISCUSSION

Participants in this study were HIV seropositive women and their seronegative male partners recruited from urban Southern Florida. A total of 16 couples were enrolled in this study; however, the demographic data from 1 male partner was lost although the qualitative interview. Data from this participant was retained and included in qualitative analyses. As shown in Table (1), women averaged 32 years of age and male partners were slightly older (mean age = 41). Most participants were African American (69% of women and 60% of men). All men reported being HIV-negative (male HIV negative status was part of the inclusion criteria), although only 47% had an HIV test in the year preceding enrollment in the study. Although all women reported that they were on antiretroviral therapy, only 19% self-reported that their viral load level was undetectable, and 75% reported a CD4 count below 500 copies (Table 2).

# Pregnancy planning and reproductive decision making

Most of the couples expressed a desire for children, and expressed the belief that most HIV infected women also desire children. Four out of the 16 participants (25%) were pregnant at the time of the interview. Those women not yet pregnant asserted that they had discussed pregnancy and their desire for children with their partners. Seven of the 12 women not currently pregnant said they were ready to become pregnant (Table 3).

Couples were asked to discuss concerns related to their decisions to become pregnant. The most frequently mentioned topics were finances and employment, school status, and age, while others discussed more personal, internal desires and thought processes regarding pregnancy. For instance, one of the women reported that having a child simply represented her personal choice to become a mother, as illustrated below, (Pregnancy planning) in order to have kids? I just wanted a son. It was me. That was just the reason. I was getting older and once I get past a certain age, I didn't want to have any more children, so it was now or never (Female, African American).

Participants also emphasized personal decision making and practices regarding pregnancy. One woman felt that personal health should be a factor that all women should take into consideration through the process of planning for pregnancy and making reproductive decisions. She shared that her priority when considering pregnancy was her personal health and that it was one of the primary factors she considered when planning her pregnancy to ensure the health of her baby and her partner. Personal health was one the primary concerns for women, particularly for women living with HIV/AIDS (WLHIV), as stated by one participant below, So I like suggest that any woman-I don't care if they're having a baby or not—to just take care of yourself. You know, always stay healthy. Get rest. Medicine every day, and you know, to protect their self. Because you have think about yourself first, so that if that does come up later, at least you know your baby will be fine and your partner will be fine also (Female, African American).

None of the women had difficulties accessing health care during pregnancy, either obstetric or HIV-related, and about



ble 1: Demographic Information CH								
Characteristic				Wome		Men		
Age			20-45 (Mean = 32)			24-57 (Mean = 41)		
Race/Eth	nicity							
African-American				11	(69%)	9	(60%)	
Hispanic				2	(13%)	5	(33%)	
Other				3	(18%)	1	(7%)	
Religio	on							
Protestant				1	(6%)	2	(13%)	
Catholic				2	(13%)		0	
Not Religious				3	(19%)	2	(13%)	
Other				10	(62%)	11	(74%)	
Employmen	it status							
Working full-time				1	(6%)	3	(20%)	
Working part-time				2	(13%)	2	(13%)	
Not working				13	(81%)	10	(67%)	
Receiving Social Security	disability insurance	:						
Yes				12	(75%)	6	(40%)	
Monthly in	ncome							
Less than \$300				4	(25%)	9	(60%)	
Between \$300 and \$600			4		(25%)	3	(20%)	
More than \$600	8	(50%)	3	3 (20%)				
Education								
High school degree or higher	9	(59%)	10 (67%)					
Did not finish high school	7	(44%)	5 (33%)					
Marital status								
Unmarried	12	(75%)	12 (80%)					

<b>Table 2:</b> HIV Status ( $N = 16$ women, 15 men <sup>a</sup> ).				
	Women		Men	
			N/A	
Years since HIV diagnosis	2-31 (Mean = 15)	2-31 (Mean = 15)		
(n = 12 provided a date of diagnosis)				
Had a HIV test in the year preceding enrollment		N/A	8 (47%)	
Last test date unknown or never had a HIV test			7 (53%)	
Have an HIV doctor				
Yes	16 (100%)		N/A	
On ART				
Yes	16 (100%)		N/A	
Last VL within the past 6 months				
Yes	16 (100%)	16 (100%)		
Self-reported HIV viral load			N/A	
Undetectable	3	(19%)		
<5,000	4	(25%)		

<sup>a</sup>N = 16 couples were enrolled in the study; however, 1 man's demographic data was lost (N.B. qualitative interview data from this participant was not

lost, and is included in qualitative analyses)



Between 5,000 and 100,000				(12%)		
Oon't know		7		(44%)		
Self-reported CD4 cell count					N/A	
>500				(25%)		
300-500		3		(19%)		
50-300			1			
Less than 50		2		(12%)		
Don't know	6 (38%)					
Taking ART reduces transmission risk to partners						
True	13		(81%)	(81%)		(67%)
False/Don't know	3		(19%)		5	(33%)
Taking ART reduces transmission risk to infants						
True	14		(87%)	(87%)		(80%)
False/Don't know	2		(13%)		3	(20%)

<sup>a</sup>N = 16 couples were enrolled in the study; however, 1 man's demographic data was lost (N.B. qualitative interview data from this participant was not lost, and is included in qualitative analyses)
ART: Antiretroviral Therapy; VL: Viral Load

	W	Women		Men	
Have children					
Yes	11	(69%)	10	(67%	
Desire for more children					
Yes	12	(75%)	10	(67%	
Currently pregnant					
Yes	4	(25%)		N/A	
Trying to become pregnant (n = 12 not currently pregnant)					
Yes	7	(58%)		N/A	
Discussed becoming pregnant with partner					
Yes	14	(87%)	11	(73%	
Discussed becoming pregnant with family					
Yes	8	(50%)	3	(20%	
Has a primary care provider or gynecologist					
Yes	14	(87%)	5	(33%	
Discussed becoming pregnant with a provider					
Yes	11	(69%)	6	(40%	
Discussed contraception with a provider					
Yes	14	(87%)		N/A	
Use contraception					
Yes, condoms	5	(31%)	4	(27%	
Yes, pill/shots/something else	5	(31%)	1	(7%	
Yes, withdrawal/pulling out	1	(7%)			
No	5	(31%)	10	(66%	
Are women more fertile at certain times during their cycle?					
Yes	12	(75%)	9	(60%	
No	3	(19%)	2	(13%	
Don't know	1	(6%)	4	(27%	
Tried/trying to get pregnant "safely"					
No	14	(87%)	15 (	(100%)	
Heard of methods of safer conception					
Yes	9	(56%)	6	(40%	
No	7	(44%)	9	(60%	

<sup>&</sup>lt;sup>a</sup>N = 16 couples were enrolled in the study; however, 1 man's demographic data was lost (N.B. qualitative interview data from this participant was not lost, and is included in qualitative analyses)



half (54%) stated they would continue HIV-related care after pregnancy. Reasons given for not continuing care after pregnancy included lack of time and unsupportive physicians. One woman stated that the lack of continuity in care after pregnancy was related to the health of the baby, which served as a strong motivator to be adherent during pregnancy, but stopped being a motivator post-partum when the baby appeared to be safe: Because when they pregnant, like "Ooo, I'm pregnant." They (women) wanna take the medicine, so the baby won't get it. But once the baby out, 'oh, don't care about my medication as long as the baby is clean, as long as the baby is not living with the virus' (Female, African American).

HIV-uninfected male partners observed that they had little or no access to health care. Only two (13%) men reported having health insurance, while the others denied receiving regular primary care or care for HIV-related services, such as preconception counseling. Men reported that information on their own HIV risk came primarily from their female partners.

### Experiences and perceptions of HIV disclosure

All female participants had disclosed their HIV status to their partners prior to the interview. The majority of the women who were currently pregnant had disclosed their HIV status prior to conception (80%) although two women said they had disclosed after becoming pregnant. Most couples asserted that women would often disclose their status to their partners, while over half of the participants (54%) believed that HIV-infected men would not.

The women who reported an undetectable viral load did not express concern about transmission to their partner. Several couples, in particular among male partners, denied worry about HIV transmission, attributing this lack of concern to the strength of their relationships, believing that love was enough to overcome the fear of becoming infected by their partner: I mean, as far as the people that do have it, the females who have HIV, and the men that doesn't have it, they should, if they are afraid to have sex or commit to the female if she has HIV, just draw closer if you love that person. If you have feelings for that person, you know, don't listen to what anybody else say and run off and things like that, you know. But, just keep a good mind that that person has feelings too; that person has a heart too. Just cause the disease; that disease not nothing (Male, African American).

However, several women recounted that the decision to share their status with their partner had been difficult, and some partners expressed concern about potential transmission. Men asserted that becoming infected with HIV became an everyday concern, to the extent that it began to bother his female partner, as described below.

I was concerned (about being infected). Unfortunately... I was getting on her nerves... It was an everyday thing. Like, "what if I do [have the virus]?" and "what should I do?" and things like that (Male, African American).

Another man shared concern about possible infection by his partner, thinking of it often, being conscious of the risk of transmission, and attempting to minimize it. This participant described 'safety' as a deterrent to conception ...Yes it (HIV infection) does concern me. It does. That's why I try not to... I don't like to wear the condom, but I know it's there for me to do... that entire time we interact, and that we are conscious about what is supposed to about to happen. But we try our best to help make it safe. But as far as with everything going on, we've been trying to have, trying to be pregnant and trying to have (a) child, but still...We try to go back to that number one thing that we got a do it safer (Male, African American).

Women reported that the primary reason for avoiding disclosure was fear of rejection or abandonment; deciding whether to disclose became an internal debate. For one woman, the decision to disclose arose from having discussions with her mother and consideration of her longtime partner. For her, time was an important determinant for the decision; [Disclosure] was very hard; it was very. I was talking to my mom and it was like, "should I, or should I not?" But I've known him for a long time, so it's like I might as well open up. And it's 'you either stay with me or you leave,'...And he chose to stay (Female, African American).

Stigma was an influential factor in deciding whether to disclose, and many women feared the stigma associated with HIV. One woman felt ostracized after disclosure in a professional setting. This sentiment was also shared by the men. It was common for the participants to report also feeling excluded by their circle of friends: But as far as women, I've known a lot of (HIV positive) women. I've worked at the hospital as well as being up here. It's still a lot of stigma. It's still a lot of stereotypes, and you basically get ostracized, professionally or not. It's still a reality out there.

You gotta understand that it only takes one person to know you have HIV because then they gonna say something and then they don't talk to me no more, don't wanna be my friend, and don't wanna hang out with me no more because of it, and I just don't want to deal with it (Male, African American).

Another woman reported that after disclosing, HIV infected women may not be able to discuss their pregnancy desires because such an action may be interpreted as wanting to transmit HIV to their partner or their unborn child. This was not only reported to apply to her circle of friends, but also to their partner. In this sense, anticipating negative reactions from their circle of friends and their partner due to stigma posed another barrier to participants in the process of deciding 1) whether to disclose and 2) upon disclosure, whether to discuss pregnancy desires with close others. However, it was also the perception of this participant that this barrier may only be broken by love between the couple, because people are afraid to even say that they want to get pregnant because of their status. Because automatically, you are saying you wanna give this person a virus. If you wanna have unprotected sex, you wanna pass it. If you wanna have a baby, you want your baby to be sick. It's still a huge stigma. But only love can break that barrier, you know (Female, African American).

Beyond fear of being ostracized, women feared intimate partner violence upon disclosure. A few reported knowing women who had experienced violence, often fatal, upon sharing their HIV status with their partners. One woman shared her personal experience following her HIV status disclosure:



He had pulled out a gun on me. I disclosed my status, and I wasn't even like having sex with this person... I know you and I'm trying to tell you my HIV status, and like you telling me that I'm lying to you. And the truth is out here. He pulled out a gun on me. So that was a scary experience...And it was like wow I would never find anyone who's gonna love me, or just be with me and have a family with me because when you tell 'I'm HIV-positive;' automatically they leave (Female, African American).

# Knowledge, attitudes and practices regarding fertility and safer conception practices

Knowledge of fertility and the menstrual cycle was limited and often inaccurate. The majority of women (85%) knew that there was a specific time during the menstrual cycle during which they were more likely to get pregnant, and four (36%) explicitly mentioned ovulation. However, of these women, fewer than half (45%) identified the correct timing of ovulation; others identified menstruation or just before or after menstruation as the time they were most fertile. Men either did not comment on this topic or, when asked directly, had no knowledge on fertility.

Nearly all the couples indicated using condoms (92%) and maintaining a low viral load (62%) were methods to prevent HIV transmission. Only one couple mentioned the use of pre-exposure prophylaxis (PrEP) as a method of preventing transmission; for this couple, PrEP was not an option due to the perceived side effects. None of the men were using PrEP.

There are too many symptoms (associated with PrEP), I can't deal with it. I mean for other people, I recommend for them to take it cause everything that's going on. But, you know, me, I can't deal with that (Male, Hispanic).

A major conflict arose between the use of contraception and conception, with many expressing the desire to become pregnant but not having information about safer conception. It was apparent that some of the women were not aware of other methods to reduce the risk of HIV transmission during conception:

We use condoms, and we practice safe sex. So I know now from having a baby, he'd have to not use a condom. So I don't want to risk giving him what I have, from trying, you know, to make a baby. And so that's one of my concerns about contracting the virus from me to him (Female, African American).

Couples were not well aware of the use of assisted reproductive technologies. Of the methods couples mentioned, manual insemination, or the use of a "turkey baster," was mentioned most often (54%), followed by sperm washing (31%) and *in vitro* fertilization (23%). All couples agreed they lacked access to reproductive technologies, and only four couples (25%) asserted that they had considered or would consider the use of these technologies. Despite this, the majority of couples (69%) agreed that these methods could prevent transmission to their negative partners, though only 31% believed that the use of reproductive technologies would reduce the risk of spreading HIV to their babies. For these couples, being compliant with medications and maintaining a low viral load was considered the best method for preventing transmission to their babies:

If a woman takes care of herself real good, you know chances that the baby can be fine. But if the woman will hardly take her medication sometimes, you know, and you skip, then the baby can come out positive (Female, African American).

Although few couples were aware of reproductive technologies, barriers to access among those who knew of these strategies were apparent. One of such barriers was the financial costs associated with these methods. Also, even if participants were willing to try these methods, the costs alone of reproductive services were a major factor prohibiting couples from utilizing these methods:

They say it's very expensive. I think that if it's expensive like that, I wouldn't try it, because I don't have the money for that. I could use that for something else with my kids around (Female, Hispanic).

Religious and cultural beliefs also played an essential role in helping couples decide whether to utilize other methods. Some of participants mentioned that the process associated with reproductive services was "not natural", and because of this, they would not consider reproductive technologies an option as a safer conception practice. As one man suggested, "It's like someone else having the baby" (Male, Hispanic). For others, religion or cultural norms played a role in shaping their opinions on these methods: I don't believe in in-vitro fertilization or artificial insemination. Because, like I said, God must agree. That's the only way you know that it's not your plan, it's His plan...I want my baby to have a soul (Female, African American).

According to one participant, HIV infected women in general lack access to fertility services because these women are primarily concerned with visiting doctors that will address their issues related to their pregnancy, baby, and HIV infection, not about fertility, as suggested below [HIV infected women], always look towards the special immunology doctors. They don't look for fertility doctors because they want to protect their baby. So everything's about the baby. It's not about you (Female, African American).

# Support and attitudes from providers and family concerning pregnancy

Opinions were mixed regarding health care provider attitudes toward pregnancy for HIV infected women. Eight women (50%) believed that at least one of their health care providers was supportive of their decision to have children, while five (31%) stated that one of their providers was neutral or did not discuss pregnancy planning with them. The physicians that were considered the most supportive were women's health providers (mentioned by 31% of participants) and primary care providers (23%). Three women (19%) stated that at least one of their physicians was explicitly unsupportive of HIV-infected women becoming pregnant. These women reported that medical personnel encouraged contraception, and in one case, abortion. Although this participant spoke on the matter of abortion as an issue of the past, consciousness that HIV infected women were once expected to abort still lingered, we have some doctors that just go by what they are taught. They don't go by sight or intuition. They just go by facts and logic. Some don't tell you never have



unprotected sex, never—always use a condom. But when you are pregnant- abortion, those were the options in my days. It was just something they were against. So when I got pregnant, they said 'we gonna do abortion.' I mean they encouraged abortion. Those were the options in my days and they don't encourage or support any type of natural intimacy.

Some participants believed that their health care provider did not support them in their decision to have a baby because of the woman's HIV status. Another woman said her health care providers were not supportive of her having children because the health care provider feared HIV transmission to her baby. One woman felt that her doctor would rather not see a woman who wants to have children when she is HIV infected, as stated below, they are negative, because they want, they would rather not see, you know, a woman who wants to have kids when they are HIV-positive (Female, African American).

The majority of couples (62%) reported receiving adequate support from their family and friends. These couples said that their families were supportive of them having children, and women who mentioned having other family members who were HIV infected reported increased support and understanding from their families. One participant stated that her family was very supportive, to the extent that they were 'waiting' on her to have a child; her family's support did not appear to be different than the support her sisters received:

They'll be supportive because they want me to have a child. My sister, that's younger than me, they have had kids. One of my sisters thought she would never have kids, and she had a little girl. Now they say, they're waiting on me [Laughter] (Female, African American).

Couples whose families were not supportive believed that family members were concerned about HIV transmission to the baby. One woman felt that it was a necessary to have a child to feel "normal", her family tried to discourage her from having children. She perceived herself and her partner as not being 'regular people', I have family, you know, it's like "Oh no, you shouldn't have more kids. No, don't do that. The kid could come out with something wrong, with HIV virus or whatever." But, you know, a lot people they don't want to hear that. Because, you know, we feel like if we can't have kids, we don't feel normal—like regular people when nothing's wrong (Female, African American).

... At one point, my family was telling me that "don't get pregnant because the child is going to get sick. Why bring a sick kid into this world?"

Just as religious and cultural beliefs appeared to be a deterrent for couples to considering using assisted reproductive technologies, religion and culture also played an important role in other types of reproductive decisions, such as deciding when it was the appropriate time to conceive. Most (77%) stated that their religion indicated marriage was a step that must occur before having children, although a few specifically mentioned disagreeing or not abiding by this belief. Although one woman believed that couples should be married before having a child, she did not feel that having a child before marriage was "bad thing" but rather, that such an action would not be socially accepted by other churchgoers and church leaders, We were going to try and

wait until we get married, but we don't, I don't want to go through the menopause now, before I have a baby. So that's why we're trying our best to get one now (Female, African American).

And the fact that we skipped the marriage card and went straight to having kids, it is kind of frowned upon, but you know people in the Church are very supportive. Because you know I have talked with my Pastor and she has talked with some of the deacons of the church and it is their call to keep in contact with both of us actually, so it is really not so much as a bad thing as it is as much frowned upon (Male, African American).

This qualitative study of urban HIV serodiscordant couples  $examined \, knowledge, beliefs \, and \, practices \, regarding \, reproductive$ decision making, safer conception methods and HIV transmission risk. The primary themes emerging included pregnancy planning and reproductive decision making, experiences and perceptions of HIV disclosure, knowledge, attitudes and practices regarding fertility and safer conception practices, and support and attitudes from providers and family concerning pregnancy. By engaging both members of the couple, results provide insight into reproductive practices, and communication between couples on disclosure and pregnancy planning provide a foundation for development of strategies to enable HIV serodiscordant couples to make more informed decisions about safer conception. As noted in previous research [10,21-23], couples desired children but most acknowledged concern about HIV transmission within the relationship or to their babies, and lacked knowledge of methods to become pregnant safely. Most also voiced concerns about HIV disclosure and had experienced negative reactions to pregnancy intentions from health care providers and family members. Though some couples perceived healthcare providers as supportive, as previously reported [9,24] others perceived them as unreceptive to discussions on pregnancy planning.

Due to a lack of important information on fertility or safer conception methods, few men had knowledge regarding PrEP or perceived themselves as having access to supportive healthcare. Study outcomes point to the important role that can be played by healthcare providers during regularly occurring health care visits. Future initiatives should consider the opportunity is to mobilize nursing and medical staff to provide simple educational/informational interventions to women in waiting rooms, clinic open spaces or examination rooms. It may also be worthwhile to encourage men's involvement in the antenatal and postnatal process25 to engage and provide education to male partners on fertility evaluation and strategies for safer conception. Studies should address strategies to encourage men's involvement in future research.

Because serodiscordant couples desire to become pregnant but may not know how to safely do so, health education by providers is an essential strategy for reducing the risk of transmitting HIV infection between partners, and between mother and child during conception and pregnancy. Although couples reported that the majority of providers were supportive of women's reproductive decisions, most couples reported receiving little information from their providers about how to safely become pregnant or how to use artificial reproductive technology. As the majority of those who were currently pregnant identified their pregnancies as planned, and all women reported



the desire to become pregnant, it is clear that providers should offer more information to women about how to safely become pregnant so that they can consider these options when planning their families. It is only in opening the dialogue between patients and providers regarding reproductive decisions that providers can identify those partners in need of PrEP, while emphasizing to HIV-infected patients the importance of treatment adherence and viral suppression to achieve healthy pregnancy outcomes.

This study has a few limitations. The majority of participants were African American, and a more ethnically and racially diverse sample may have yielded different results. Additionally, because the interviews were conducted with the participants as a couple, it is possible that different results may have been obtained had interviews been conducted separately with the woman, the man, and then together as a couple.

Results of this study support previous research on couples' perspectives regarding fertility desires, planning or practices8, 22 and highlight the need for interventions to address gaps in knowledge and care. Interventions are needed to guide HIV serodiscordant couples to make informed decisions about safer conception methods and reduce the risk of HIV transmission to partners and infants. If, as was found in the current study, couples' desires for children influence the level of risk they are willing to accept to conceive, it is critical to develop effective strategies to assist them in safer conception practices and improve access and follow-up care for HIV negative partners.

### **CONCLUSION**

Results support increasing public health initiatives to disseminate knowledge on fertility and safer conception practices for HIV discordant couples, as well as to implement access to PrEP. Safe, supportive methods to facilitate disclosure of HIV status to partners should be available for pregnant HIV discordant couples. Dialogue between couples and providers on planning pregnancy, safer conception strategies and increased access to PrEP for discordant couples must be implemented in the public health setting.

Heterosexual HIV discordant couples have limited information on how to conceive safely.

Heterosexual HIV discordant couples risk HIV transmission because of their desire for children and limited access to effective prevention strategies.

HIV negative men in a discordant relationship have limited access to HIV prevention information and would benefit from safer conception education including access to PrEP.

Healthcare providers should engage reproductive age discordant couples in pregnancy planning education and counseling.

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