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Perspectives on safer conception practices and pre-conception counseling among women living with HIV

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Abstract

Pregnancies are frequently unplanned and higher rates of unplanned pregnancies occur among HIV-infected women. Reviewers examined reproductive decision-making, conception practices, and patient-provider communication among women living with HIV. Qualitative interviews were conducted with 19 HIV-infected sexually active women aged 18–45 in Southern Florida, USA. Using thematic analysis, we found decisions to conceive were influenced by women and partners; knowledge and use of safer conception practices were low. Discussion and support from partners, family and providers was limited and diminished by stigma and nondisclosure. Preconception counseling discussions in HIV care should be comprehensive and initiated frequently by all healthcare providers.

Acquisition of HIV neither reduces the desire to have children nor the likelihood of having children (e.g., Ethiopia: Melaku, Zeleke, Kinsman & Abraha, 2014; USA: Finocchario-Kessler et al., 2010, 2012; Rahangdale et al., 2014; Sutton et al., 2014; Zimbabawe: Clouse et al., 2014). Women of reproductive age (15–45 years) constitute a significant portion of newly and previously diagnosed cases of HIV, and as such, the number of children born to HIV-infected mothers continue to rise globally (Ethiopia: Melaku et al., 2014; USA: CDC, 2013; Hoyt et al., 2012; Rahangdale et al., 2014; Steiner, Finocchario-Kessler, & Dariotis, 2013; Sutton et al., 2014; Zimbabwe: Clouse et al., 2014). Prevention of Mother to Child Transmission (PMTCT) strategies, e.g., adherence to prescribed antiretroviral therapy and post-partum regimens, has been associated with less than 1% risk of mother-to-child-transmission of HIV, making pregnancy a viable option for HIV-infected women (e.g., Italy: Marazzi et al., 2011; USA: Finocchario-Kessler et al., 2010, 2012; Hoyt et al. 2012; Loutfy et al., 2013; Rahangdale et al., 2014; Zambia: Chibwesha et al., 2011;). Computer modeling estimates indicate that 90–95% participation in PMTCT plus effective antiretroviral therapy (Torpey et al., 2012) would reduce infant HIV incidence to the WHO (2008) goal of < 5% (Ciaranello, Perez, Keatinge, Park, Engelsmann, & Maruva, 2012), drastically decreasing vertical and sexual transmission of the virus (e.g., Italy: Monforte et al., 2014; USA: Hoyt et al., 2012; Sutton et al., 2014; Squires et al., 2011). Yet, despite PMTCT availability,

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however, not all pregnant women are tested (Van Lettow et al., 2011; Larsson et al., 2012; Peltzer, Mlambo, & Phaweni, 2010), not all women receive treatment (Goga et al., 2012), not all mothers provided with medication take it themselves or provide it to their newborns (WHO, 2012; Laher et al., 2012; Global meta-analyses: Nachega et al., 2012) and not all newborns are tested (SA DOH, 2010; WHO 2012). Preconception counseling and safer conception methods, strategies to conceive that reduce the likelihood of sexual transmission of HIV to partners (Matthews et al., 2012), receive little attention in HIV care (e.g., South Africa: Matthews et al., 2013; USA: Finocchario-Kessler et al., 2012; Squires et al., 2011). Thus, though conception and pregnancy among HIV-infected women can be safely accomplished, women may not pursue this desire safely.

Many women become pregnant subsequent to an HIV diagnosis and most pregnancies are unplanned and the result of unprotected sex (e.g., Uganda: Muyindike et al., 2012). In general, women’s fertility desires are influenced by biological imperatives, partners and social and cultural mores; children may be perceived to strengthen or solidify a relationship and extended families may pressure couples to reproduce (e.g., Matthews et al., 2013). Among women living with HIV, additional factors may influence reproductive decision-making, including current health status, partner HIV status, HIV disclosure, HIV knowledge, financial limitations, health care providers and health care access (Delvaux & Nöstlinger, 2007). Women’s knowledge of safer conception practices appears limited and discussions about pregnancy desires and safer conception methods with providers are rare and seldom comprehensive (South Africa: Matthews et al., 2013; USA: Finocchario-Kessler et al., 2012; Loufty, 2013; McDonald, 2011; Rahangdale et al., 2014; Steiner et al., 2013; Sutton et al. 2014; Squires, 2011). In order to understand how pregnancy among HIV-infected women can be safer for women, partners and neonates, it is necessary to understand how women consider, articulate and pursue their desires to have children.

Ecological models of human development (Bronfenbrenner, 1979) posit that researchers should interpret the multifaceted aspects of human development within the lens of both the individual and his or her environment, including factors such as socioeconomic status (SES), family, and marital status (Grzywacz & Fuqua, 2000). As such, the reciprocal relationships between the diverse conditions of women’s sociocultural and physical environments are reflected in their experience and decision making (Kurtz et al., 2005). Within this framework, individual well-being may vary as a function of the environment and should be understood within these different contexts (Grzywacz & Fuqua, 2000). For instance, inadequate discussions about pregnancy with healthcare providers may not be inherently detrimental to women with a broad access to varied resources about pregnancy and HIV infection, but among women living in marginalized communities with little access to information on preconception counseling beyond their healthcare providers, these discussions become imperative (USA: Finocchario-Kessler et al., 2012; Ward, 1993).

The purpose of this study was to address reproductive decision-making, conception practices, and patient-provider communication among women living with HIV and their healthcare providers. Investigators explored how women consider and decide to become pregnant, examining the intersection of their attitudes, knowledge and practices with regard to pregnancy, fertility, and safer conception methods. Although all women do not exercise their reproductive agency with the same resources and constraints, by acknowledging their agency regardless of their constraints, we hoped to have a more in depth understanding of how women reconcile pregnancy and HIV serostatus. We theorized that gaining a clearer understanding of how these decisions are made may enable protocols to be tailored to increase the uptake of safer conception practices, to empower women to play active roles in their reproductive practices and ultimately to reduce vertical and sexual transmissions of HIV.

METHOD

IRB approval was obtained prior to study onset. Participants ($n = 19$) were recruited from public and private hospitals in urban Southern Florida, USA. Eligible participants were HIV seropositive women aged 18–45, sexually active within the past 6 months, non-pregnant, and capable of conception (no history of tubal ligation or hysterectomy). Study candidates were screened via telephone or in person to assess eligibility, and if eligible asked to provide consent and participate in an interview. Quantitative assessments of participants were conducted in a private office using an audio computer assisted self-interview (ACASI) computer system in which women listened with headphones to survey questions presented in writing and selected their responses using a touch screen. All women enrolled were provided $30 as compensation for time and travel to the site.

Interviews

Prior to interviews, rapport was established through informal communication between the assessor and the participant, which took place in the interview room in the study offices. Women's discussion centered on neutral topics, e.g., the weather, transportation, food. Interviews consisted of open-ended stem questions and were up to one hour in duration, with an average time of 31 minutes. Interviews were held in a private room in the study offices and were digitally recorded; each recording was coded by participant number to maintain confidentiality. One interview could not be transcribed due to the poor quality of the recording. Interviews assessed knowledge, attitudes and beliefs regarding (a) fertility intention and planning (b) knowledge and attitudes about safer conception practices (SCP), (c) SCP counseling practices with healthcare providers, (d) perceptions and interpretations of the counseling received with providers, (e) experiences with negotiation of reproductive goals, contraception, and safer conception practices with partners, (f) HIV disclosure, partner status, and intimate partner violence (IPV), (g) stigma, and (h) influences of other persons in the women's social networks (e.g., family, mother-in-laws, close relatives, friends).

Transcription and analyses

Question stems were created using an iterative, collaborative process and included topics associated with reproductive decision making, preconception counseling, and patient-provider communication among HIV-seropositive female patients. The interview framework of open-ended questions was developed collaboratively by the team, which included healthcare providers in psychology, obstetrics/gynecology and infectious diseases, and was supplemented by information derived from informal groups and discussions conducted with relevant hospital staff. Proposed focal topics were reviewed and refined by the entire team; stems were presented as open-ended questions and time was available during interviews to address additional topics as topics arose.

Digital audio recordings of interviews were transcribed and coded line-by-line using QRS Nvivo9 qualitative data analysis software. The coding process consisted of standardized reviews by three team members for dominant themes; information in which coders disagreed on coding were discussed and resolved among team members. Coded themes were primarily categorized around women's pregnancy and safer conception knowledge, attitudes, and practices (SCKAP), perceived provider attitudes and practices regarding SCKAP among patients, and issues associated with living with HIV. Information that fell outside these primary themes was coded as arising themes until saturation was reached and no more themes emerged. Primary themes that emerged were pregnancy desires and practices, safer conception knowledge and practices, and communication and support, sub-categories included family and friends, partners and providers, and within these categories, issues related to barriers to care, stigma, violence and disclosure.

RESULTS

Participant characteristics

Participants (*n* = 19) were African American, Hispanic and from the Caribbean region (see Table 1). The majority of participants had children, wanted more children, and had discussed their desires with a provider and partner. Most women were unmarried and had a partner, were unemployed and on disability and had not completed high school. Most women had an HIV seronegative partner, and though almost all women were on antiretroviral therapy, almost half (42%) had not achieved viral suppression and had a CD4 count below 500 copies.

Summary of themes

Arising themes included pregnancy planning and strategies, support for pregnancy and family planning, and barriers to retention in care; subthemes were identified under all of the major themes as needed. Subthemes for pregnancy planning and strategies included women's pregnancy desires and preconception knowledge, discussions with partners and other women, pregnancy planning, and strategies for conception. Within support for pregnancy and family planning, several subthemes arose, including support from family and other women, partner support, partner support in the healthcare setting, and healthcare provider support. Lastly, within barriers to retention in care, disclosure was identified as a subtheme. Participant responses illustrating these themes is provided below.

Pregnancy planning and strategies

Women's pregnancy desires—The majority of women expressed a desire to have children and many already had children; only a few had no desire for any or additional children. Women described numerous factors influencing decisions to conceive, including both personal and partner factors. Personal factors included HIV status, personal viral load, fear of HIV transmission to infant and/or partner, seeing other HIV-infected women have

HIV-infected babies, lack of information regarding conception, pregnancy and postpartum, previous complications associated with conception, pregnancy, and/or birth. Partner factors included having a partner, wanting an HIV-infected partner while having an HIV-negative partner, partner not wanting children, finding someone that will care for the child in case of death, and concerns that safer conception methods make the partner feel "left out." Simply stated,

> I just want one. I don't want a whole house full… I just want one baby, something that's me, a part of me. That's something that I can develop and it's still great too.
>
> (*Latoya, African American, age 39*)

Women aged 38–44 expressed concerned about their age and felt an urgency to conceive before they were unable to become pregnant, one commenting,

> Because I'm 38 and I don't have any kids, I feel like that now, like ooh by the time I'm 40 it's like I'm putting a time limit on it. You know like oh I better hurry up and do something if I'm going to do something but then you got to meet a nice guy, you got to possibly know that's the guy because you don't want to get a deadbeat and you know so that's important too.
>
> *(Keisha, African American, age 38*)

Despite these concerns, for a variety of reasons, most women desired pregnancy or had been pregnant. These desires included, the desire to experience pregnancy and child bearing, to have their name carried on, to obtain government assistance, to experience love they did not receive in their own families, and to correct a "wrong"--- such as having lost custody of a child due to substance use.

Preconception Knowledge—Many women had no knowledge of safer conception methods or strategies to conceive safely other than simply engaging in unprotected sex. Knowledge of safer conception methods ranged from absolutely no knowledge to very limited and/or erroneous knowledge about certain methods, including fairly detailed knowledge of both safer conception methods and behavioral practices that aid in safer conception and pregnancy. Most women were aware of the risks to their partners but perceived them as minimal. Some emphasized the importance of achieving optimal medication adherence and viral suppression before engaging in unprotected sex with their partners. Some women had general knowledge of the existence of artificial insemination through a fertility clinic, use of a turkey baster or condom to insert sperm. Women's knowledge about conception methods varied, as illustrated below,

> To me there is no safe way to have a baby and be HIV positive without infecting your partner and infecting your child. No known medicine that can prevent the baby or partner from becoming infect[ed] with HIV.
>
> (*Sandra, Hispanic, age 38*)

> You can have artificial insemination. You can use his sperm and shoot it up in you. They got that but that cost money. Who got that kind of money? If you got HIV you ain't got that kind of money.

(*Latoya, African American, age 39*)

> Yes I know that they say you're supposed to have him ejaculate in a cup and then use a syringe but that's weird.

(*Miriam, African American, age 18*)

> As far as I know, protection of my partner if I want to get pregnant, I would have to have a turkey baster, intravenous.

(*June, African American, age 34*)

Discussions with partners and other women—Many women observed they knew other HIV-infected women who wanted children. Some commented that desires to conceive were not often discussed with other women living with HIV, which they attributed to shame or distrust of other women. Although most women reported having discussed their desires to conceive with their partners, a few stated these types of discussions had not occurred. One woman commented that couples living with HIV did not discuss childbearing because they believed that HIV stops the "ticking of their [biological] clock" or reduces their sperm count. In this sense, these misconceptions regarding the effect of HIV on the body limited their discourse. Women felt that disclosure of HIV status, trust in the relationship, and the stability of both partners contribute to communication. Some women said they spoke openly about their desires to get pregnant but others described their conversations as roundabout, avoiding stating their desires outright. Conversations with partners varied in depth, as below,

> I talk to mine [partner]. I let him know especially when I see people with their babies or when I go in the store and see the cute little shoes, it makes me want to have a baby…and then I see them as they start growing up…If they could just stay babies I would be just fine. It's off and on with me. Yeah, I want it and come on let's try to do it and then it's like don't touch me …We talk about having kids, but that's the furthest it goes, we don't go into detail about it.

(*Ryana, African American, age 34*)

While some women had discussions with both partners and providers about the risk of infection to their partner, they asserted they could not discuss safer conception because it could never be safe. Thus, knowledge of safer conception methods dictated the type of discussions that occurred. For instance,

> I mean they keep saying safe way to get pregnant, being positive and having unprotected sex there's no safe way to get pregnant. There is a risk so it's not safe. So once the risk is there it's no longer safe. There's no safety. I have to make him aware, the doctor has to educate him and he has to be willing to take that risk so it's basically his choice.

(*Latoya, African American, age 39*)

Pregnancy planning—A few women emphasized planning as an important step in conception for women living with HIV, including being on a non-teratogenic ART regimen. However, for most women, the meaning of the term "planning" differed. For some, planning included going to appointments with their partner, consideration of their health status or

ART regimen and how pregnancy would impact it, and sharing the desire to conceive with a partner. Others described planning as including discussions with providers and ensuring that partners were aware of the risk of transmission during conception. Planning sometimes also included ensuring the health of women and partners before attempting to conceive. For example,

> I know I have a lot of medical problems and before I was willing to consider becoming pregnant I wanted to make sure everything was in place. I can't afford to get pregnant and something goes wrong with my heart when I know I have an enlarged heart…I can't go and say let's get pregnant and my arthritis is going to aggravate every joint in my body during pregnancy. I can't say let's get pregnant if my levels [viral load] for HIV are all over the place, I can't do that. But you have some people that don't even look at it. I rather take every precaution.
>
> (*Sasha, African American, age 32*)

> Everything has to be planned. You got to talk to your doctor. You have to let your partner know their risk. If he's aware of them and he's willing to do what he has to do.
>
> (*Latoya, African American, age 39*)

> [You] plan it, because…being HIV positive you can't tell which way your body is going to be, when you wake up in the morning, you can't really tell how you feel until you start the day. Your body could feel good, and it could feel bad.
>
> (*Tracy, African American, age 41*)

Women framed their planning as both passive and active. Some stated "it's not really a planning thing, they just talk about it if they want to have a baby, and if it happens then it happens" (*Ladasha, African American, age 34*), such that the stated desire to have a child is a passive plan. Most women viewed their pregnancies as accidental and not actively planned. However, as one woman noted,

> Most pregnancies are "accidental" in our group of positive women; it's more likely accidental. When you say accidental I found that a lot of my peers are not using protection because the man doesn't want it and that's not accidental. That to me is willful, but technically you would say it was accidental because you didn't plan it.
>
> (*Aysha, African American, age 43*)

Strategies for conception—Most of women stated that it was very common for the women they knew, regardless of HIV serostatus, to stop using contraception or switch contraceptive methods in order to conceive. However, they also noted that most women did not use protection or contraception regardless of whether they were trying to conceive. Having unprotected sex was the most common "method" for becoming or trying to become pregnant. Women asserted that this method was their only real option for conception as it was the only method they knew, could afford, or felt comfortable engaging in,

> Unprotected sex is the way I know most of my friends do it. Even for me I probably would think of having unprotected sex once or twice a month just to give myself a

> chance but …my partner is positive too so our doctor talks to us about that all the time. He don't take the same pills I take so that's a problem and I can get adjusted to my meds, he can get adjusted to his meds and it's not much you can take after that. I have been down pretty much all the pills out there in my lifetime…so I have to be careful about having unprotected sex because I don't want his strain so it's difficult but …I will work with the doctor.
>
> (*Keisha, African American, age 38*)

Many women stated they felt comfortable engaging in unprotected sex to conceive because both they and their partners had achieved viral suppression. For some women, having an HIV-infected partner made practicing safer sex more challenging,

> I think what it is, because I have done it in the past…when you find a guy and you feel comfortable with them and they accept what is going on with you, you cannot use condoms, even though you know you can get re-infected…when you are blinded by that person you take risks, I take risks, and say ain't nothing going to happen to me, ain't nothing happened to me so far so what the hell.
>
> (*Ryana, African American, age 34*)

Almost all women rarely or never addressed or used safer conception methods, though a few, one of whom conceived using a syringe provided by her physician, had done so. Some women had male partners who wanted to bring about pregnancy without their partners' consent. Most women cited examples of damaged condoms, switched pills or forced or coerced unprotected sex; one woman described a partner that pulled off the condom during sex. Her provider had previously counseled her partner about the risk of infection to himself and a baby, and when their baby was diagnosed as HIV-infected and became ill, her partner abandoned her and disclosed her status to other community members. Women also commented, some men "wanted sex, they didn't give a damn if you got pregnant" (*Latoya, African American, age 39*). Another said:

> I did not choose a safe method. With my oldest daughter, I wasn't trying to get pregnant. I gave the dad condoms [and] he poked holes in the condoms. Lo and behold I have a 12 year old because of a condom. My youngest one I didn't use any condoms, I was on birth control trying not to get pregnant, and her dad was playing with my birth control and I didn't know it…when I went to go take…what I thought was my birth control it was candy. And he regretted it, not because I am a bad mom or …a bad person, because he didn't know what was behind it…the your family versus my family, or your tradition versus my tradition, or who is going to take her to the doctor and watch her while she gets a needle in her arm.
>
> (*Sasha, African American, age 32*)

Support for pregnancy and family planning

Support from family and other women—Responses regarding familial support of pregnancy included familial support regardless of HIV status, familial support as conditional, and lack of familial support because of HIV status. About a quarter (22%, 4/18) of participants stated that families would be supportive regardless of a woman's HIV status, while others (11%, 2/18) participants asserted that familial support was conditional. Conditions for familial support included adherence to ARTs, the woman's happiness (and happiness with her current partner), and the sense that pregnancy was what she wanted. It was also asserted that obtaining support from a partner's family was not always possible after serostatus disclosure. Half (50%, 9/18) reported their own families would not be supportive of pregnancy, for reasons related to HIV status, HIV stigma, the presence of other non-HIV linked health issues, and the absence of social, economic, and/or personal structure needed to raise a child. For some women, lack of support for the desire to conceive was associated with other health issues and fear of these health issues being exacerbated by the combination of pregnancy and HIV. Some women felt the lack of familial support reflected extreme HIV-related stigma, as some reported being told that having a child while knowing their status was "stupid," "immoral," or "careless."

Other factors underlying the lack of familial support include social, economic, or personal infrastructure. Some women felt the lack of familial support and excitement surrounding a potential pregnancy was associated with the family's desire for them to be married before having a child, concerns existing economy would create difficulties in raising children, or the absence of a committed partner's assistance. One woman offered tangible evidence of a lack in potential future support based on a prank,

> … I played a joke on them. When they told me how big the fibroids were I called my mom and was like "Mom, guess what? I'm 20 weeks pregnant"…you could hear a pin drop, she was like, silence. I said "Hello?" she said "What?" I just said "Wow, at least I'll know how you feel…I was like, "Mom, dang, that how you feel if I'm pregnant?" She's like "Baby, I'm just in shock." She said "I'm in shock" and I said "No, Mom, that's a joke. I said the fibroids are 20 weeks, like I'm 20 weeks". She said "Oh God, oh." So I don't think they'll be too excited just on the way they acted… but I don't know maybe if I had a man because they know I'm not really serious with nobody on dating…so maybe that's why…I don't think they'll be too excited if I was to tell them I was pregnant.
>
> (*Keisha, African American, age 38*)

However, women were not deterred from desiring children by family members, as one noted,

> I didn't need to tell anybody, I am grown. The only person I need to talk to is my husband and if he didn't authorize it, I was going to get it one way or another so. I really don't care for…what family has to say, because …as a grown individual you have to be grown enough… to make your own decisions.
>
> (*Wanda, African American, age 33*)

Others tried to have discussions about pregnancy but were met with disapproval, which prevented future discussions. One woman became pregnant and told her mother, who replied, "Why are you getting pregnant? You know you have HIV." When the woman subsequently miscarried, her mother was relieved and said she "didn't want to hear any more about it [pregnancy]." Consequently, the woman no longer talked about these issues with her mother (*Rita, African American, age 42*).

The influence of culture and religion on pregnancy and family planning supported marriage before sex and conception. Other objectives to achieve before pregnancy included completing school, financial stability, responsibility for the care of the child, having a home, and being of an age, mentally and physically, to properly raise a child. Despite understanding these cultural and religious messages, all women viewed these expectations as unrealistic.

Women's support networks were comprised primarily of partners and family members, though a few also included support group members and friends. The majority of women asserted they had few or no female friends, and attributing this distance from other women to an inability to trust other women, particularly HIV-negative women, due to experiences of losing friends following disclosure of their HIV status. Despite this distrust, the majority of women yearned for opportunities to engage in in-depth discussions about pregnancy with HIV and emphasized the benefit of sharing their status with others as a means of learning to accept their diagnosis and gain a new normal,

> I'm comfortable telling what is going on with me, see because my Mom died in 1998 from the virus and I watched her deteriorate and at the time I was using drugs so I thought that's the way that I was going to die, until I got myself together and said I am going to the doctor, started getting medication and getting educated, asking questions and reading pamphlets, and realized this is no different from cancer, lupus or anything else; as long as I take care of myself… See the biggest thing is being afraid of being rejected…you got people that are coming off of the streets [in drug recovery meetings] that are trying to get their life together and then you have somebody that's been around and they talk so open and freely about it, it makes them think "I got what I got and it's nothing to be ashamed of, all I need to be concerned about is taking my medication, going to my doctor appointments, doing my lab work, not getting high and not drinking and I'll be okay"---I give them hope.
>
> (*Ryana, African American age 34*)

Partner Support—Many women felt their male partners want to have children, regardless of the partner's serostatus. A few women noted that some partners believed "a woman's body is her body and don't understand what a woman's body goes through when they are pregnant", and as such, they did not feel the need to be actively involved in the pregnancy beyond conception. Women noted that some male partners were ashamed for others to know they were in intimate relationships with HIV-infected women, but that most men were unconcerned if they were infected with HIV during conception. This lack of concern regarding infection was interpreted by women as symbolizing acceptance and love, acceptance of women as being more than their HIV status,

> He's [partner] with me, he's got my back 110%. So anything I decide I want to do he supports me -- there's not a lot of men that do that. When I met and let him know what my status was, he told me "and what?" He didn't see my status he saw that person that I was, that I am, he knows that I am a good person and that's what

> he saw. There are people who are ashamed to be with you if they are not positive and are about what other people are going to think.
>
> (*Ryana, African American, age 34*)

For many women, the framework of understanding and articulating men's lack of concern for safer conception practices was a dichotomy of shame or acceptance. Few women viewed this lack of concern outside of this dichotomy, though one woman stated,

> For a person to actually be in that mindset and say "I love you and I don't care if I get it, we just need a baby." I think that's borderline insanity and I don't think I would want to be with a person like that.
>
> (*Aysha, African American, age 43*)

The fear of intimate partner violence was a factor limiting both disclosure and communication regarding pregnancy. Women asserted that violence was more likely to occur if couples had engaged in unprotected sex prior to disclosure or the partners were in a long-term relationship. Anticipated violence ranged from beatings to murder. One woman noted,

> Oh…I know [of women who experienced IPV upon disclosure]. I've seen women say that they're positive and next thing you see is their brains on the floor…I know for a fact it has happened.
>
> (*Wanda, African American, age 33*)

Partner support in the healthcare setting—Women reported most male partners accompanied them to their healthcare appointments prior to, during, and/or after pregnancy, and lack of serostatus disclosure to partners was not noted as a reason to restrict men from accompanying women to their appointments. Men's attendance at clinic appointments during pregnancy depended on a variety of issues, including (a) whether or not the pregnancy was wanted, (b) level of commitment to the woman and/or baby, (c) interest in staying informed about the health of the baby and mother, (d) desire to monitor personal HIV status, (e) level of excitement for pregnancy (i.e., whether this was their first child), and/or (f) perception of clinic space. Women remarked regarding their partners' participation,

> My husband did [participate], all nine months he was there.
>
> (*Tracy, African American, age 41*)

> A lot of guys [think]… "she got pregnant"…if it's something that is a careless thing, "she got pregnant and it wasn't planned," usually the guy will leave it up to lady, to do whatever they have to do, because they were the one that was supposed to be on a pill or something.
>
> (*Neeta, Hispanic age 45*)

Many women experienced partners' support as participating in the clinical visit; ranging from (a) active engagement, to (b) passive engagement, to (c) no engagement, as illustrated below,

> That man goes above and beyond. He goes to the appointments, he delivers the kids, he babies them, does the whole. He even goes and asks, "Can I be examined with her?" He go to all my appointments and I go to his. We're like Bonnie and Clyde…no [he will not participate in discussions], he'll sit down and listen. He's someone who will try to learn so he'll sit down and try and listen everything he can to learn more.
>
> (*Ashley, Bahamian, age 34*)

> He was just there just as the furniture sitting in the lobby waiting. I think he was just there hoping "ok if she go in labor, I'm here"….he was just there for support.
>
> (*Wanda, African American, age 33*)

For those men who were present but not actively engaged, one woman felt it was the nature of the visit and the clinic structure that reduced men's engagement,

> They [male partners] don't feel comfortable because they [providers and women] are mainly talking about vaginas and things like that. They don't give any input, but they come and listen. They don't share their feelings or anything about it.
>
> (*Tracy, African American, age 41*)

> I'd like to push the issue [of the] male partner going with the female because the male is left out. Whenever the female has something [they] have to wait in the waiting room but I think they should come in some they could get a better understanding of what is going on too. When the female comes out and they [are] discussing it, she can't explain exactly everything they were just discussing so he's left in the dark.
>
> (*Lakisha, African American, age 39*)

Healthcare Provider Support—Most (53%, 8/15) women felt providers were supportive of their desires to get pregnant. Most provider support took the form of excitement and assistance prior to, during, and after pregnancy. One woman commented,

> My doctor was very hands-on and had a lot of knowledge on everything. She gave me some information that I thought was wonderful, as far as taking care of myself when I have the baby, and things to do with the baby, as far as preventing her from being HIV positive …they were very helpful explaining that to me.
>
> (*Tracy, African American, age 41*)

The importance given to providers' attitudes varied. Some women failed to find adequate support, e.g., one reported her provider was excited for her, wished her luck and said to let her know if she became pregnant (Lakisha, African American age 39). Some (40%, 6/15) women felt little or no support, and interpreted this as either indifference or disapproval, as illustrated below,

> Honestly I don't think they [providers] have a problem with it. Because everything is just about money; if you have a woman that's pregnant, and you're seeing her, and every time she comes to see you Medicaid bills you and you get paid. Now you

> got a child that she's had and has the virus and needs medication and needs to be seen after Medicaid pays you. So everything revolves around a dollar.
>
> (*Ryana, African American, age 34*)

> I've seen doctors that gave you that look "why you want to have a baby?" "Why would you want to bring a baby into this world?" You have doctors that actually tell you, encourage you, not to get pregnant because you are positive.
>
> (*Wanda, African American, age 33*)

For a few, provider support was contingent on following providers' guidelines for protecting the baby or the woman's physical and mental health.

Communication with providers about safer conception and pregnancy

Women reported having discussions about pregnancy, though some did not. Less than half of the women felt providers enquire about their desires to have children; for most, discussions about pregnancy and desires to conceive did not occur.

> I don't think that's a conversation that actually just pops up. I don't think doctors are just open. My doctor talks about HIV and how to stay healthy, never the fact: "Are you thinking about becoming pregnant?" He doesn't ask that unless I come out with it.
>
> (*Michalda, African American, age 44*)

> If you don't come in the office pregnant and you're HIV they're not going to [discuss pregnancy and pregnancy desires]…if I'm not pregnant they tell me I shouldn't (laughs) and she [MD] preaches that.
>
> (*Latoya, African American, age 39*)

> They don't really ask [if I want to have a baby] and you know I used to get so offended by that because I used to feel like because I was positive y'all didn't want me to procreate. …They were trying to give me a hysterectomy and I didn't want that because I don't have kids and I felt that because I was positive y'all don't want me to have kids and I was very pissed off and I talked to a different doctor and that's the [response] I got. I don't know if it's [how] they meant it but that's how I felt. And I went and complained to my doctor, she said "Oh, no, I'm not sending anybody else there because you have rights. Every woman deserves to be a mother." So my doctor she's one of those. My GYN, it was a GYN asking me if I've been protecting myself…they don't really say do you want a baby? How do you feel about that? They don't really.
>
> (*Keisha, African American, age 38*)

> I have been positive since 2002, they [providers] never asked me "Do you want to have a baby?" They never asked me or had any concern about do I want to have a baby or my status with baby, or how would I feel.
>
> (*Tracy, African American, age 41*)

Women felt that discussions on pregnancy occurred with OB/GYNs and Primary Care Providers (PCPs) or HIV specialists. Although many reported that their providers were not engaging with them in ways that showed an interest in their desires to conceive, many felt they had a good rapport with their providers.

> My GYN she tells me you're not supposed to have sex without condoms, you know you can get a different strain, you know you can get other STDs, so she does try to enlighten me about stuff, but my doctors they don't tell me anything.
>
> (*Ryana, African American, age 34*)

Most women felt providers focused solely, or heavily, on health risks and the prevention of pregnancy rather than on methods to safely conceive. Many felt their providers did not want them to conceive, and some asserted that providers asked about their desires to get pregnant and then told them why they should not have children. Though most women felt their providers' attitudes reflected a stigma against HIV-infected women having children, a few felt their providers' attitudes showed concern and awareness of the stress of living with HIV. Some women observed that many providers simply might not feel comfortable talking about pregnancy and women's desires for pregnancy. Most felt their conversations with providers about pregnancy were self-initiated and if they needed information about HIV and pregnancy they must speak up.

> My doctor doesn't ask me about desires for children. This is all he does, sit on the table, check the stomach, check the knees, are you still smoking, yes, how many a day, about 5–7 cigarettes, okay, here's your prescription, I sent it to the pharmacy, make sure you make an appointment to come and see me and that's it. No education. No nothing. Not even just the babies or the virus, no disease. No education for nothing…and I have had him over two years…
>
> (*Ryana, African American, age 34*)

Visits with healthcare providers that did address pregnancy included suggestions to use protection, to avoid becoming pregnant, to "get undetectable, stay undetectable, keep it undetectable" (*Wanda, African American, age 33*), to be aware of the high risk of having an HIV-infected infant, and to plan for a "romantic evening" for conception. However, most did not address safer conception methods, even when prompted by the women,

> My doctor constantly asks me do I want any kids and I'm like yeah, eventually, I do want kids, before my biological clock stops; and we talked about it but we didn't get into details…not yet, because I haven't really told her that I am trying to have kids; I tell her, "I don't use protection all the time." And [she said] "Well, that's not safe." Well how are you supposed to get pregnant if you have to protect yourself all the time? She told me when we decide to have kids, to come back and talk to her about it…she just told me keep protecting myself, because he (partner) is HIV positive, and we could infect and reinfect each other; but he takes the same medication I take.
>
> (*Mooriah, African American, age 40*)

Few women reported their providers talked to them about safer conception strategies; the method most frequently proposed was in vitro fertilization, a method relatively unattainable for most women. Some visits also included women's partners, but these discussions centered around clarifying for the male partner the risk of being (re)infected when engaging in unprotected sex. Barriers to retention in care

Women emphasized the importance of being informed about HIV and pregnancy, care during pregnancy, ensuring undetectable viral loads and the health of themselves and their baby. Though a few women were not retained in care post-partum, the majority felt that women stay in care. Many observed that once a woman has a child, dropping out of care is not an option,

> They are very strict on that. After you have the baby you must come back. At least for the 6 months, if not they are going to send somebody to your house because they are very concerned about the baby and your well being. Because it takes maybe 5–6 months for the baby's immune system to develop so they could really test it…If they take the mediation they still could become HIV positive. If the mom is doing the right thing on her medication and she gets pregnant the baby has a slim chance [of being HIV-infected]. But if the mom is not taking her medication and she is doing the wrong thing the baby could be positive. It's all up to the mom. They follow-up because they want to know that baby's status up to 6 months because they don't want the baby going to school HIV positive and nobody knows. It's mandatory.
>
> (*Tracy, African American, age 41*)

While a number of the respondents included post-partum care with infant as part of their continuing care, many did not. Only a few women mentioned initiating or continuing practices to prevent HIV infection to the newborn post pregnancy. Almost all women felt that they did not experience any barriers to accessing care before, during, or post pregnancy. However, the factors identified as preventing other women from accessing or continuing care were institutional, individual, and community-level barriers. Institutional barriers included difficulty obtaining appointments, clinic wait time, overcrowded clinics, provider personalities, insurance status, illegal immigration status, length of Medicaid (public insurance) coverage, and lack of clinic resources, such as translators. Some observed that changes in the structure of public insurance has forced them to use new clinics with new providers that they do not feel comfortable with,

> When you have certain insurances it doesn't cover the places you want to go where you feel comfortable. You have to go outside and go to another person you don't even have a background on. With my oldest all my prenatal care was at Hospital X; with my youngest I had a private doctor. It's not always easy.
>
> (*Sasha, African American, age 32*)

Thus, although they had access to care, changes in the current system could prevent engagement and retention in care.

Individual barriers included lack of partner participation, lack of support, limited transportation, concerns about disclosure, inadequate childcare, stigma, absence of agency, and the physical toll of living with HIV. According to one woman,

> Sometimes, when you have babies and you are HIV-positive, that makes us feel weaker, and it feels like it took so much out of our bodies, so that might be one of the problems [with follow-up care]. Sometimes it's a mind thing, if you just get up and force yourself to do, you'll be okay, but some of them [women] just don't want to do it.
>
> (*Jda, African American, age 33*)

A number of women stressed the need to be self-reliant and persistent, as access to resources was not only tied to their availability but also to whether or not women were able to advocate for themselves,

> Sometimes you have to tell them a little lie to get a little more [WIC milk] -- sometimes you have tell them you aren't breastfeeding even though you are so that they give you the right amount of formula. So you have to know how to get those resources.
>
> (*Sasha, African American age 32)*

> There is no reason you shouldn't be going to therapy, they have free therapy… there is no excuse for not getting the help you need for whatever it is. It's knowing, asking questions, and following through.
>
> (*Aysha, African American, age 43*)

Stigma was both a personal and community barrier to accessing and maintaining care. Some women failed to access care because they were ashamed of being pregnant and HIV-infected or afraid of seeing others from their communities at clinics and involuntarily having their serostatus made public. Stigma against HIV and HIV-infected women was attributed to an absence of knowledge about the virus. All women believed stigma towards those living with HIV was present in varying degrees in interactions with families, the community, providers, and partners. The effect of stigma on women's attitudes and practices varied; some asserted stigma had no effect on their discussions about desires to conceive, but they attributed this to only having these discussions with people they could trust, e.g., partners, supportive family members. However, one woman commented,

> Stigma …makes that person not want to talk about it [pregnancy]. So you have already labeled me, you already said how you feel about it. If we are talking, and you already said something bad about someone who has the virus -- why would I open up to you? You're going to talk about me. And see my feelings are going to get hurt.
>
> (*Ryana, African American, age 34*)

Disclosure—Most women expressed a fear of rejection and reluctance to disclose their HIV status to partners or others. Many women delayed or avoided disclosure and experienced emotional turmoil and feelings of guilt. One woman commented,

> It's like us women we beat ourselves up about our status. We hide, we don't want to go out. I suffer from depression too about it so I didn't want to go out, I don't hangout…I don't do that what I used to do; go out, have fun. Now it's no, no, I

> wonder who's going to see me. Somebody know me, I'm positive, they'll see me, they're going to look at me.
>
> (*Keisha, African American, age 38*)

For some, clinic visits were an opportunity to disclose; having a provider present felt safer for women and encouraged them to be completely honest, while providers acted as educators for partners on HIV information and clarified confusion.

DISCUSSION

This study was designed to explore pregnancy desires, knowledge and practices among women living with HIV. Women's desires and practices were examined to gain an in-depth understanding of how women pursue their desires to conceive. HIV-infected women had virtually no knowledge of safer conception methods but were aware of methods to prevent pregnancy. Desires and plans to conceive were common, and many women engaged in risky conception practices without having discussions with their providers about their desires for pregnancy. Providers focused on contraception, rather than conception, and partners and family were seldom consulted.

Consistent with prior researchers and theory regarding ecological models of human development (e.g., Bronfenbrenner, 1979; Grzywacz & Fuqua, 2000), the importance of understanding reproductive decision making within the individual-environment context was supported. Financial stability, for instance, was noted as playing a role in deciding whether to raise as a child, as found by previous investigators (Delvaux & Nöstlinger, 2007). As has been suggested, health status may be better understood by providers when they consider the SES appropriate of the context (Grzywacz & Fuqua, 2000). Similarly, the communities where women live had an important role in the management of an HIV diagnosis, the articulation of desires for pregnancy, and the methods women undertook to conceive. HIV-related stigma was pervasive and, within communities, represented a topic in which discussions of HIV and pregnancy occurred only in the context of shaming. HIV stigma has also been associated with intimate partner violence (IPV) in many settings (e.g., Nigeria: Hyginus, Chukwuemeka, Lawrence & Sunday, 2012; Shamu, 2012). Not only did community members inhibit purposeful discussions, they fostered a sense of helplessness in which women had little agency to determine the trajectory of their disease and lives. Educating themselves on HIV and its management, women regained a sense of ownership in their ability to take care of themselves. This suggests that interventions aimed at increasing the uptake of safer conception practices must give women the knowledge needed to exercise agency to actively plan and implement how they will conceive.

Results arising from this study supported previous literature suggesting that most providers do not initiate discussions about pregnancy with HIV-infected women and that the discussions that do occur rarely address safer conception methods (South Africa: Matthews et al., 2012; Wettstein et al., 2012; Uganda: Wanyenze et al., 2013; Finocchario-Kessler, 2010; Steiner et al, 2013; Squires et al., 2011). The expectation that women will initiate conversations about pregnancy if they want to conceive assumes that all HIV-infected women have agency, the ability to act on their desires. While it is not possible to completely deprive women of their reproductive and sexual agency, women's ability to exercise such agency appears linked to having some previous knowledge about HIV. The practices undertaken by women in this study mirrored the knowledge they held about pregnancy and safer conception methods.

Protocols aimed at increasing HIV-infected women's uptake of safer conception practices must not include the assumption that all women feel empowered enough to know how to speak about their pregnancy desires and plans, particularly when they are living in environments that do not nurture such skills. While results from this study did not explicitly explore how the socioeconomic class and racial realities of HIV-infected women shaped their articulation of desires to conceive and associated practices, we cannot dismiss the impact of living within marginalized communities, e.g., marginalized medically, racially and/or economically (Tangenberg, 2000). In this study, women described stigma as being against HIV-infected women becoming pregnant, meaning that these women should no longer exercise their reproductive rights. While HIV-associated stigma had an important role in women's discussions of their desires to get pregnant, it is possible that the absence of provider initiated discussions on pregnancy, pregnancy planning, and safer conception methods may all also the product of class or race-based stigma. As such, protocols designed only to educate providers on more comprehensive ways to talk to HIV-infected women about their pregnancy desires and safer conception methods may not necessarily lead to an increase in the incidence of these discussions if the providers do not believe that women, regardless of HIV status, among certain classes or races should conceive. Understanding the true source of stigma is also important because women's experiences affected their medical narratives to providers during consultations. Many women experienced consultations as encouraging contraception rather than conception and promoting sterilization. Whether or not this sense of being forced into sterilization is true, it is important because it has entered these women's personal narratives, which becomes part of their future discourses in their own communities.

Limitations and Strengths

The narratives presented in the study were drawn from women living in an urban environment who were primarily African American; responses from women in other countries, regions and from other ethnic backgrounds may differ. Investigators should continue to explore the unique experiences of women living with HIV in the USA and internationally. In addition, topics of narratives may address only negative, rather than positive, experiences, and as such, reporting may have been biased towards more painful experiences. Further, although the investigators made every effort to establish rapport with the participants through informal communication, the cross-sectional design of this study may have limited rapport-building. Finally, despite the small sample, the interviews provided a rich and diverse perspective on individual experiences.

Conclusion

Interventions designed to help increase safer conception practices among HIV-infected women must expand the scope for women to learn about all aspects of pregnancy planning in the context of HIV and facilitate women in voicing their desires for conception. Women living with HIV want to have children and will continue to do so with or without the knowledge of how they can do so safely; therefore it is imperative that comprehensive preconception counseling is initiated by providers. Comprehensive discussions must address pregnancy risks while imparting knowledge about safe and accessible ways of conceiving. Selective discussions about pregnancy do not empower women; they only close down the opportunity for discussions to evolve. While not all women may be open to having comprehensive discussions with providers about their desires for pregnancy, or may not always see themselves as needing to address issues of pregnancy and safer sex practices, these discussions should always take place because these messages will likely be relevant at a later time. Interventions aimed at increasing the use of safer conception methods may also introduce these discussions into informal settings where women can connect and build communities of trust.

Pluralizing the ways HIV-infected women are being engaged regarding their pregnancy intentions will allow them to address their desires in a holistic manner in which different aspects of their desires and intentions can be articulated. The use of multiple resources to increase the uptake of safer conception practices is particularly important for women who feel marginalized and might have developed coping strategies that minimize their reliance on formal institutions for care, education, and/or support (Amnesty International, 2008; Tangenberg, 2000).

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Table 1

Demographic, pregnancy, and HIV-related characteristics of N = 19 female Pathways qualitative interview participants

Characteristic	**n(%) range, mean(sd)**
Age	18–45, 36(7)
Ethnicity	
African-American	14(74%)
Hispanic	3(16%)
Non-Hispanic White	1(5%)
Haitian	1(5%)
Religion	
Catholic	5(26%)
Other	13(68%)
Not religious	1(5%)
Employment	
Working full-time	2(11%)
Working part-time	3(16%)
Not working/Volunteering	14(73%)
Receiving SSI/SSDI	
Yes	11(58%)
No	8(42%)
Monthly income	
<$300	3(16%)
$300-$700	7(37%)
>$700	9(47%)
Education	
High school degree or higher	8(42%)
Did not finish high school	11(58%)
Marital status	
Married	5(26%)
Not married, but have a partner	10(53%)
Not married, do not have a partner	4(21%)
Have children	
Yes	11(58%)
No	8(42%)
Want (more) children	
Yes	14(74%)
No	5(26%)
Discussed pregnancy with a partner	
Yes	16(84%)

Characteristic	**n(%) range, mean(sd)**
No	3(16%)
Discussed pregnancy with family	
Yes	3(16%)
No	16(84%)
Discussed pregnancy with provider	
Yes	16(84%)
No	3(16%)
Discussed contraception with provider	
Yes	17(89%)
No	2(11%)
Years since HIV diagnosis	1–29, 16(7)
On ART	
Yes	18(95%)
No	1(5%)
Self-reported viral load	
Undetectable	8(42%)
Detectable, but less than 5,000	6(32%)
More than 5,000	4(21%)
Don’t know/never had a viral load test	1(5%)
Self-reported CD4	
>500	11(58%)
300–500	3(16%)
50–300	3(16%)
Don’t know/never had a CD4 test	2(10%)
Partner HIV positive (n = 15 with a current partner)	
Yes	7(47%)
No	8(53%)