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Providers' perspectives on preconception counseling and safer conception for HIV-infected women[†]

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Abstract

Introduction—Unplanned pregnancy among HIV-infected women can have negative health consequences for women, partners, and neonates. Despite recommendations, preconception counseling (PCC) appears to be infrequently addressed in HIV care. This study explored knowledge, attitudes, and practices among health-care providers regarding PCC, safer conception and pregnancy among HIV-infected women.

Methods—Physicians, physician assistants, and nurse practitioners (n = 14) providing obstetric/gynecological and HIV care in urban south Florida public and private hospitals completed structured qualitative interviews. Dominant themes arising included provider perceptions of patient knowledge and practices, provider knowledge and attitudes regarding safer conception, and provider practices regarding reproductive health.

Results—Providers perceived patients to have limited reproductive knowledge. Patients' internalized HIV stigma was a barrier to patient initiation of conception-focused discussions. Provider knowledge and utilization of PCC protocols were limited. PCC barriers included competing medical priorities, failure to address fertility desires, limited knowledge, time limitations, and unclear standard of care. Providers routinely used condom-based HIV prevention as a proxy for addressing reproductive intentions.

Discussion—Provider, patient, and structural factors prevented implementation of PCC and provision of information on safer conception; neither were routinely discussed during consultations. Both providers and patients may benefit from interventions to enhance communication on conception.

Keywords

Preconception counseling; HIV; safer conception methods; unplanned pregnancy; qualitative

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Introduction

It is estimated that as many as half of all pregnancies in the USA are unplanned or unintended (Finer & Zolna, 2011); however, this rate may be substantially higher among the approximately 280,000 women living with HIV (as high as 85%) (Hoyt, Storm, Aaron, & Anderson, 2012; Sutton, Patel, & Frazier, 2014). Pregnancy rates among women living with HIV have tripled in the era of antiretroviral therapy (ART) (Sharma et al., 2007); and numerous studies have found that many HIV-infected women maintain desires for childbearing (Hoyt et al., 2012; Squires et al., 2011; Yudin, Money, Cheung, & Loutfy, 2012). However, among HIV-infected women who were either thinking about becoming pregnant, pregnant at the time surveyed, or pregnant in the past, 57% had not received preconception counseling (PCC; Squires et al., 2011). In a recent study of pregnant women living with HIV, 33% had not prepared for pregnancy by seeking medical advice, taking prenatal vitamins, or decreasing substance use (Rahangdale et al., 2014). Although unplanned pregnancy is common in the general population (Finer & Zolna, 2011), with HIV infection, the potential for negative health consequences for women, partners, and neonates is high.

PCC by health-care providers has been associated with a reduced risk of unplanned pregnancy (Rahangdale et al., 2014). PCC for women living with HIV offers the opportunity to reduce the risk of unintended pregnancy, perinatal and sexual HIV transmission, fetal loss, pre-term delivery, low birth weight and birth defects, as well as adverse health outcomes for the woman and her partner by optimizing health and knowledge before conceiving (Hoyt et al., 2012; Panel on Treatment, 2014). PCC is recommended for all HIV-infected women of childbearing age, but may be especially important when a woman expresses desire for future pregnancy, is uncertain about her plans, or is not trying to conceive but is not using effective and consistent birth control. PCC is also recommended when there is a change in a woman's relationship status, or she is taking medications with potential reproductive toxicity or interaction with hormonal contraceptives (Panel on Treatment, 2014). Despite recommendations, protocols, and brochures to guide PCC in HIV care, counseling appears to be infrequently or cursorily addressed by health-care providers (Nattabi, Li, Thompson, Orach, & Earnest, 2009; Steiner, Dariotisa, Anderson, & Finocchario-Kessler, 2013). As few as 31% of HIV-infected women may receive a personalized discussion with their HIV provider regarding their own fertility desires and intentions, the majority of whom (64%) may have to initiate the conversation themselves (Finocchario-Kessler et al., 2010).

A variety of barriers (e.g., time limitations, competing medical priorities, stigma, attitudes, and lack of clearly defined roles and practice standards for HIV care providers, primary care providers, and obstetric/gynecological (OB/GYN) providers) contribute to the neglect of PCC provision in the clinical setting (Hoyt et al., 2012). Yet, the potential for complicated pregnancy, the need for medication regimen changes, medication adherence, viral load suppression, vitamin supplements, and the risk associated with HIV sexual transmission underscore the importance of PCC (Panel on Treatment, 2014). This study explored knowledge, attitudes, and practices among physicians and health-care providers regarding safer conception practices, PCC, and pregnancy among HIV-infected women. It was hypothesized that provider, patient, and structural factors would impact provision of information on PCC and safer conception.

Methods

Eligibility and selection

The information presented is part of a larger study, PATHWAYS, a mixed-methods pilot study conducted from March 2013 to March 2014, addressing reproductive decision-making, PCC, and patient–provider communication among HIV-infected female patients and health-care providers. Prior to the initiation of study procedures, ethical approval was obtained from the University of Miami Miller School of Medicine Institutional Review Board. Participants ($n = 14$) were HIV providers recruited from public and private hospitals located in urban South Florida. Potential study candidates were identified as key informants based on practice specialty, level of experience, training level, and patient population being served. Candidates were contacted via email, and invited to participate in the study. All providers who responded and indicated interest in participation were contacted by study staff and provided with an appointment to be interviewed in a private office. Prior to being interviewed, all participants provided informed consent. Participants consisted of four OB/GYN medical doctors, four infectious disease medical doctors, three OB/GYN nurse practitioners, two infectious disease nurse practitioner, and one infectious disease physician assistant. Medical doctors were both male and female, aged mid-30s to mid-40s; nurse practitioners and physician assistants were female, aged mid-30s to mid-50s. No compensation or incentives were provided for participation.

Qualitative interviews

Fourteen key informant interviews were conducted with health-care providers serving HIV-positive patients by one trained staff person. Interviews consisted of open-ended questions and ranged from 10 to 55 minutes in duration, with an average time of approximately 25 minutes. Interviews were held in private locations within hospital and PATHWAYS offices. Interviews were digitally recorded, and each participant recording was downloaded and identified by number using standard confidentiality procedures.

The interview was designed to assess knowledge, attitudes, and beliefs; items are presented in Table 1. Stem items and topics addressing reproductive decision-making, PCC, and patient–provider communication among HIV-seropositive female patients and health-care providers were created using an iterative, collaborative process. The interview framework was developed by the PATHWAYS collaborative team, which included health-care 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 themes were then reviewed and refined by the entire team; stem items were presented as open-ended questions and time was available in interviews to address additional topics as they arose.

Coding of transcripts

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 coding by three PATHWAYS team members for dominant themes until saturation was achieved; information in which coders disagreed on coding were discussed and resolved by team members. Themes emerging were primarily (1) provider perceptions of patients' knowledge, attitudes, and practices regarding safer conception and pregnancy; (2) providers' own knowledge and attitudes regarding safer conception and pregnancy among HIV-infected women; and (3) provider practices regarding reproductive health issues among their patients. Information that fell outside these primary themes was coded as an arising theme, barriers; no additional themes were identified.

Results

Perceived patient knowledge, attitudes, and practices

Most providers felt their patients had little understanding of the role of viral suppression in preventing transmission to a sexual partner and safer methods of conception. While the notion of a decreased or undetectable viral load is understood by the patient as indicative of good health, providers were unsure if patients knew this signified a minimized risk of viral transmission. Providers observed that the patients who were best aware of issues surrounding transmission to infants were those women who had previously become pregnant post-HIV infection and had personally confronted with the issues during their own pregnancy. In the view of providers, for many women living with HIV, the idea that there are strategies to enhance safer conception is novel and even surprising, highlighting the degree to which women may be uninformed.

Provider knowledge and attitudes

The majority of providers were knowledgeable regarding specific aspects of safer conception, that is, the importance of having an undetectable viral load and the use of a "turkey baster" or syringe as a means of inserting the semen into the vagina. Less frequently mentioned methods included unprotected timed intercourse when a woman is most fertile, pre- or post-exposure prophylaxis, in vitro fertilization (IVF) or intrauterine insemination, and application of tenofovir cream to the vagina, techniques intended to reduce transmission of HIV to the male partner. In the case of an HIV-infected male with an HIV-negative female, providers mentioned sperm washing and antiretroviral treatment as prevention and pre-exposure prophylaxis as a means of safer conception. Providers who suggested IVF or sperm washing as methods of conception suggested that these techniques were only viable options for patients without financial constraints, as these procedures are not likely to be covered by health insurance.

While the majority of providers maintained a limited yet functional knowledge base, the perceived standard of care for educating patients on safer conception provoked diverse responses. Four providers did not think there was a standard of care, or they did not know if one existed. Two providers stated that they did not generally offer education on safer conception. For example:

- "I would say, in general, I see that it's not common that providers give counseling to patients about the conception."
- I think we are not familiar with it [addressing safer conception for HIV-positive patients] and it is not something that we really hear a lot about. It is not a main discussion with HIV patients because we discuss trying to protect the partner.

One provider reported they ask all patients entering the GYN clinic if they have any desires for children, and another in the field of OB/GYN said the standard of care was to offer the available options for safer conception. The remainder of providers emphasized the importance of controlling comorbidities, understanding the risks of horizontal and vertical transmission, and contraception. Most providers agreed that the health-care professionals responsible for discussing preconception desires for children among women with HIV included OB/GYNs, primary care providers, and HIV specialists. However, as one OB/GYN commented:

- Unfortunately, from what I see in practice patterns, patients who are HIV positive who become pregnant don't really receive much counseling on it before they are pregnant. They get plenty of counseling and education once they become pregnant about how to avoid vertical transmission and how to deliver a healthy baby and keep themselves healthy. The counseling they get before pregnancy, I would say, is small or nonexistent.

Barriers

In routine consultation, providers consistently addressed the importance of contraception with HIV-infected women, specifically condom use, as condoms provide barrier protection from the transmission of HIV while preventing pregnancy to an acceptable degree of effectiveness. However, conversations regarding reproductive planning or desires for children were not explicitly initiated by the provider on a routine basis. While some providers said 20–60% of patients volunteer their desires for children during a routine consultation, other providers expressed that only 1–10%, or a "handful", of patients will bring up the topic. Whether or not the patient initiated a discussion of her personal desires for a child was not dependent on the providers' specialty – infectious disease or OB/GYN – as there were a variety of responses within each provider specialty cohort. A repeated theme among providers' responses was a perception that certain stigmas surround HIV-infected women's desires for children, which prevents women from raising the issue in a clinical context. For example:

- I think women internalize stigma in the sense that they feel that they are not able, or that people are always going to tell them not to have children. They expect they will get a bad response from others regarding having children.
- Maybe that is part of why women are not bringing it up, because they feel like providers judge them for wanting to get pregnant. I know there are staff in our hospital system who are not supportive of women getting pregnant. I think it is up to providers to let the patients know that we are not judging them.

From a provider perspective, these comments reveal an obstacle perceived as stigma that may underlie for why some women may not initiate conversations on fertility desires with their health-care providers. Although providers almost unanimously reported that they felt the majority of their patients' pregnancies were "unplanned" or "accidental", PCC was infrequently prioritized on the consultation agenda. Time constraints were cited as a barrier to initiating PCC. Other barriers identified by providers included a lack of provider understanding of preconception issues or a lack of provider resources for PCC for HIV-infected women.

Of the infectious disease providers, two of six reported addressing PCC as a part of a routine consultation. Two additional providers said they discuss PCC if the patient brings up the topic. The structure within the institution was such that if a patient expressed desires for children, the patient would likely be referred to OB/GYN for an appointment. Physicians, nurse practitioners, and physician assistants within the infectious disease subspecialty commonly serve as primary care providers, as well as gatekeepers for OB/GYN referrals. However, referrals to an OB/GYN may constitute a differently focused visit. For example:

- "These visits tend to be focused on subspecialty type things [i.e., pap smears] or things that may not directly relate to conception. If anything, the conversation involves contraception."

While few providers felt there were no barriers to addressing PCC, this did not imply that the health-care professional was in fact providing PCC.

Discussion

This study builds on the previous evidence (e.g., Squires et al., 2011) that PCC protocols are not routinely distributed or carried out among health-care professionals with HIV-infected female patients. As hypothesized, provider, patient, and structural factors acted as barriers to the provision of information on PCC and safer conception strategies were not a routine component of care for HIV-infected reproductive age women.

Discussions regarding pregnancy between providers and patients were framed in a context emphasizing contraception through condom use, as opposed to exploring the patient's reproductive desires or plans. If patients failed to initiate a conversation regarding fertility intentions during the consultation and reported regular condom use, PCC was only cursorily addressed. Providers emphasized limited knowledge, time constraints, and specialization as barriers to provision of information on safer conception methods. Protocols for PCC are present within the fields of infectious diseases, primary care, and OB/GYN (e.g., Panel on Treatment, 2014). However, results of this study suggest that dissemination of these PCC protocols among health-care professionals has been inadequate, limiting the knowledge and understanding health-care providers require in order to effectively conduct PCC. Furthermore, practitioners reported that they do not universally employ these recommendations due to time constraints and the belief that the conversation is best had with a professional of a different specialty. Diffusion of responsibility associated with providing PCC may limit patients' ability to become pregnant safely, as patients appeared to have limited knowledge regarding safer conception and were unlikely to educate themselves on the topic.

This study's primary limitation is the lack of generalizability, as the qualitative data obtained reflect the opinions of only 14 health-care providers in South Florida. However, South Florida, the site of this study, has the second highest number of HIV cases among women in the country. Study outcomes reflect important opportunities to address gaps in the provision of care among this vulnerable population.

Conclusion

While the community of physicians and health-care providers may be hesitant to recognize that their attitudes and actions could perpetuate stigma related to HIV infection and childbearing, providers felt that patients may feel stigmatized, preventing them from freely acknowledging their reproductive plans with their doctors (Finocchario-Kessler et al., 2010). Stigma undoubtedly remains a challenge for both patients and their providers. Just as a specialist would adhere to a specific protocol when evaluating a patient with a specific condition, HIV providers have certain medical benchmarks that should be met prior to the patient becoming pregnant. However, the discussion of reproductive desires should not be sidelined until patients meet their criteria, as this may deny women living with HIV the reproductive rights afforded by women who are uninfected (World Health Organization, 2006). Women's desires for children exist despite their health status (Finocchario-Kessler et al., 2010), and denying patients opportunities to address fertility counseling may result in HIV-infected patients distancing themselves from medical advice and in turn engaging in sexual behaviors that put women, partners, and newborns at risk (Yudin et al., 2012).

Practice implications

There is limited data published on physician attitudes regarding childbearing in HIV-infected women (Steiner, Dariotisa et al., 2013, Steiner, Finocchario-Kessler, & Dariotis, 2013; Yudin et al., 2012). Based on this study, we recommend that additional strategies are identified to enhance the dissemination and implementation of PCC protocols for HIV-infected women across the specialties of HIV medicine, OB/GYN, and primary care. It appears that physicians and their support staff of nurse practitioners, physician assistants, and case managers may also benefit from additional training on safer conception practices for HIV-infected women. Regardless of whether PCC is offered, many women living with HIV are becoming pregnant, both unintentionally and intentionally. The provision of education and PCC to increase patient knowledge may also empower women to communicate with their health-care providers, enabling them to make more informed reproductive decisions.

Condensation

Qualitative narratives from HIV/OB/GYN health-care providers underscore the urgent need for the uptake and utilization of comprehensive PCC protocols for HIV-infected women.

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Table 1

Provider interview.

The following questions address your impressions of those female patients who are HIV positive and care provided to them by health-care providers		
Major themes	**Topics**	
(1) Fertility intentions, planning	**a.**	Do women who are HIV positive want to have children?
	b.	Are most HIV-positive women planning on having children?
	c.	When? (e.g., specific plans?) In the future? (e.g., general intentions?)
	d.	Are most pregnancies planned or accidental?
	e.	Do women switch or stop using contraception to get pregnant?
(2) Knowledge and attitudes about safer conception practices	**a.**	What do women do to prevent infection of their partner if they want to get pregnant?
	b.	Is it a concern for their partners?
	c.	What do women know about safe methods to get pregnant without risking infecting their partners?
	d.	How do women choose a safer method of becoming pregnant? (safer means: one that might protect a partner from HIV infection)
	e.	Are women aware of the role of viral suppression in transmission or pregnancy?
(3) Safer conception counseling experiences with HIV-positive women among health-care providers	**a.**	Do doctors and nurses ask about women’s desires to get pregnant?
	b.	Which types of providers talk about fertility desires? What kinds of doctors or nurses?
	c.	What kinds of suggestions do they make about getting pregnant?
(4) Perceptions and interpretations of the counseling received with providers	**a.**	What kinds of attitudes do doctors or nurses have about HIV-positive women getting pregnant?
	b.	Are doctors supportive or not supportive of women’s plans for having children?
(5) Stigma	**a.**	How does HIV stigma impact social or health-care support for pregnancy planning?
(6) Structural barriers	**a.**	Are there any problems getting healthcare prior to or during pregnancy?