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"Everything I Needed from Her Was Everything She Gave Back to Me:" An Evaluation of Preconception Counseling for U.S. HIV-serodiscordant Couples Desiring Pregnancy

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A B S T R A C T

Objectives: We sought to evaluate preconception counseling (PCC) through a qualitative examination of the experiences of couples with serodiscordant human immunodeficiency virus (HIV) status desiring pregnancy.
Methods: Patients involved in HIV-serodiscordant relationships who received PCC between January 2013 and January 2015 were recruited to participate in 40-minute semistructured telephone interviews. Participants were asked about their experiences with PCC and the impact of counseling on their knowledge of safer conception strategies and reproductive decisions. Two researchers independently coded interview transcripts, and delineated common ideas to generate emerging themes from participants' responses.
Results: Eleven respondents completed the interviews, including nine women and two men. Six respondents were HIV positive. Our thematic analysis revealed that patients gained knowledge and confidence through PCC that conception was both possible and safe. They had varied reactions to assisted reproductive technologies that correlated with income level, and explored complicated weighing of personal risk of HIV transmission. Patients reported major challenges including poor access to PCC, difficulty identifying peak fertility periods, and lack of long-term conception follow-up.
Discussion: PCC is a valuable resource for patients involved in HIV-serodiscordant relationships. We recommend the following opportunities for improvement: developing practical safer conception clinical and counseling guidelines for HIV-affected couples, increasing patient access to and awareness of PCC services, distributing more helpful resources to identify peak fertility, and providing long-term support for patients.
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Since the advent of highly active antiretroviral therapy, marked decreases in morbidity and mortality have allowed women, men, and couples living with human immunodeficiency virus (HIV) infection to pursue childbearing (Palella et al., 2006; U.S. Department of Health and Human Services, Health Resources and Services, 2013). Current research finds that HIV status does not significantly alter patients' childbearing motivations or pregnancy desires, which are largely equivalent to the general population (Chen, Philips, Kanouse, Collins, & Miu, 2001; Finocchario-Kessler et al., 2012; Loutfy et al., 2009). In fact, the live birth rate among HIV-positive women in the United States increased by 150% in the era of highly active antiretroviral therapy as compared with a 5% increase among HIV-negative women during the same time period (Sharma et al., 2007). These data suggest that the benefits conferred by highly active antiretroviral therapy, including increased life expectancy, better quality of life, and decreased perinatal transmission, strongly influence patients' desires to have children (Steiner, Finocchario-Kessler, & Dariotis, 2013).

For serodiscordant couples, natural conception poses the risk of HIV transmission to the uninfected partner. Approximately half of the 200,000 HIV-serodiscordant opposite-sex couples in the United States desire future pregnancies (Lampe, Smith, Anderson, Edwards, & Nesheim, 2011; McMahon et al., 2014). However, the majority of HIV-positive patients treated at urban health clinics never discuss personal reproductive goals with a provider (Finocchario-Kessler et al., 2010a; Mindry et al., 2013).

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Although there is a clear need for preconception counseling (PCC) among HIV-positive patients, little is known about the effectiveness of PCC and the ways in which patients incorporate counseling into their reproductive decision making. Our objective was to perform a qualitative evaluation of HIV-positive patients' experiences with PCC. Specifically, we sought to understand how patients integrated PCC recommendations into their reproductive planning and identify barriers or challenges.

Methods

Study Population and Data Collection

A convenience sample of HIV serodiscordant couples from a larger PCC cohort study of HIV-affected couples was asked to participate. Couples who received PCC between January 2013 and January 2015 at a single urban academic medical center were mailed a recruitment letter and telephoned. The medical center has a large HIV clinic that has more than 20,000 visits per year. The HIV clinic offers primary care and several specialty services, for example, obstetrics/gynecology, dermatology, neurology, gastroenterology, and psychiatry. The clinic demographics reflect the HIV epidemic in Baltimore: 77% of patients are Black, 34% of patients are women, and 85% of patients have public insurance or are uninsured (Moore, Keruly , & Bartlett, 2012). Oral informed consent was obtained to conduct a semistructured telephone interview that was audio recorded and transcribed. A pilot interview was performed with one couple to improve the wording of the interview guide, which a single interviewer followed. The interview guide included collecting demographic information and asking open-ended questions to engage participants in conversation. Specifically, participants were asked to reflect on topics discussed during PCC and to describe any behavioral changes made afterward. They were asked questions about their knowledge of safer conception strategies, assisted reproductive technologies (ART), and pregnancy outcomes; perception of HIV risk; pregnancy desire; changes to conception practices; and recommendations to improve the PCC services. The Johns Hopkins Institutional Review Board approved this study.

PCC Structure

PCC was offered by primary care or infectious diseases providers from within the academic medical center or surrounding community health clinics. Patients who desired counseling were referred to the obstetrics/gynecology clinic to consult with two physicians who specialize in HIV women's reproductive health. Counseling consisted of one or more outpatient clinic visits with either the female patient or both members of a serodiscordant opposite-sex couple. The contents of the counseling session were tailored to the specific health needs of each individual or couple. However, the general structure of the counseling session described by Boelig, Coleman, Keller, Sewell, and Anderson (2015) was followed. First, patients were provided with effective strategies for conception that reduce the risks of viral transmission to partners and fetuses. Safer conception strategies that were discussed included, but were not limited, timed condomless sex, manual self-insemination, ART, and antiretroviral therapy or pre-exposure prophylaxis. Second, initiate interventions that will maximize maternal health and optimize obstetrical outcomes. Third, identify and stabilize any chronic medical illnesses or psychosocial issues that may increase the risk of adverse pregnancy outcomes. Finally, tailor counseling to each patient's unique perspective, circumstances, and risk comfort level.

Data Analysis

We conducted a thematic content analysis of the transcribed interviews to identify major themes from participants' responses. Two researchers independently read all transcribed interviews to generate preliminary thematic codes. Common themes were retained to create a preliminary coding list used to independently analyze the data. The research team met weekly to combine related codes into broader emergent themes. This method allowed researchers to explore interconnected concepts and relationships that arose from the transcripts.

Results

Sample Description

Of 23 eligible patients who received PCC during January 2013–January 2015, 11 (48%) participated in this study. Difficulty contacting participants was the primary barrier to recruitment, specifically lack of current address or phone number in the medical record. Participants included nine women (ages 31–39 years) and two men (ages 40–42 years). Five patients (45.4%) were Black, 4 (36.4%) were non-Hispanic White, 1 (9.1%) was Hispanic, and 1 (9.1%) was Asian. Median annual household income was $62,000. The majority (8 [73%]) had an undergraduate or graduate degree. There were five women and one man who were HIV positive. HIV was diagnosed a mean of 7 years (range, 2–10) before the interviews. All HIV-negative participants reported disclosure from their HIV-positive partner at the beginning of the relationship.

Emerging Themes: PCC Provided Patients with Knowledge and Confidence

Participants shared that before PCC, they did not know whether it was possible to conceive without HIV transmission to the HIV-negative partner or child. Some participants noted concerns about HIV interfering with the ability to become pregnant.

> I honestly, we didn't know if it even was going to be possible. Just after meeting with her [the provider] it's just like, you know yeah—it is possible. It is possible to do it safely, or as safe as possible. (HIV-negative woman, 38 years old)

> It was a surprise to both my husband and I when we found out [about his status]. And I was like, okay, I'm not going to have kids with him. So, it did allow me to learn that I can still have kids with him. Which…I thought that was over. I thought that option wasn't available without myself or the child getting it [HIV]. (HIV-negative woman, 39 years old)

Doubts about the possibility of conception were expressed to varying degrees. Some HIV-negative patients chose to be with an HIV-positive partner believing they were giving up the chance to have children entirely. Other participants expected that achieving pregnancy without HIV transmission required a medically intensive process. They were surprised to learn that their providers recommended timed condomless sex in certain scenarios if the HIV-positive partner had an undetectable viral

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