



Implementing a Pre-Exposure Prophylaxis Intervention for Safer Conception among HIV Serodiscordant Couples: Recommendations for Health Care Providers

Journal of Health Disparities Research and Practice

Volume 11 | Issue 2

Article 2

© Center for Health Disparities Research, School of Public Health, University of Nevada, Las Vegas

2018

Implementing a Pre-Exposure Prophylaxis Intervention for Safer Conception among HIV Serodiscordant Couples: Recommendations for Health Care Providers

Mari-Lynn Drainoni , *Boston University School of Public Health*, drainoni@bu.edu

Dea L. Biancarelli , *Boston University School of Public Health*, dealb@bu.edu

Ashley A. Leech , *Tufts Medical Center*, ALeech@tuftsmedicalcenter.org

See next page for additional authors

Follow this and additional works at: <https://digitalscholarship.unlv.edu/jhdrp>



Part of the [Health Services Research Commons](#), [Immune System Diseases Commons](#), [Infectious Disease Commons](#), [Translational Medical Research Commons](#), and the [Virus Diseases Commons](#)

Recommended Citation

Drainoni, Mari-Lynn; Biancarelli, Dea L.; Leech, Ashley A.; Sullivan, Meg; and Bazzi, Angela R. (2018) "Implementing a Pre-Exposure Prophylaxis Intervention for Safer Conception among HIV Serodiscordant Couples: Recommendations for Health Care Providers," *Journal of Health Disparities Research and Practice*: Vol. 11: Iss. 2, Article 2.

Available at: <https://digitalscholarship.unlv.edu/jhdrp/vol11/iss2/2>

This Article is protected by copyright and/or related rights. It has been brought to you by Digital Scholarship@UNLV with permission from the rights-holder(s). You are free to use this Article in any way that is permitted by the copyright and related rights legislation that applies to your use. For other uses you need to obtain permission from the rights-holder(s) directly, unless additional rights are indicated by a Creative Commons license in the record and/or on the work itself.

This Article has been accepted for inclusion in Journal of Health Disparities Research and Practice by an authorized administrator of Digital Scholarship@UNLV. For more information, please contact digitalscholarship@unlv.edu.

Implementing a Pre-Exposure Prophylaxis Intervention for Safer Conception among HIV Serodiscordant Couples: Recommendations for Health Care Providers

Abstract

Couples in HIV serodiscordant relationships frequently desire children. Although partners who are virally suppressed pose almost no risk of transmitting HIV to their partners, partners who are inconsistently on therapy may transmit HIV to their partners when attempting to conceive. Pre-exposure prophylaxis (PrEP) is an available safer conception strategy for these couples but is not consistently offered. We sought to better understand barriers to PrEP implementation for couples seeking conception and patient perceptions on what providers could do to encourage use. We conducted in-depth, qualitative interviews with 11 participants representing six couples taking PrEP for safer conception in a safety-net hospital in New England. Semi-structured qualitative interviews assessed the following: Relationship nature and contextual factors; attitudes and perceptions regarding PrEP for safer conception; experience within health care systems related to HIV and PrEP; and facilitators, barriers, and other experiences using PrEP for safer conception. Four key themes have important implications for implementation of PrEP for safer conception: Knowledge and understanding gaps regarding HIV and PrEP among both members of the couple, role of insurance and financing in decision-making, learning to manage and adhere to a treatment plan, and the need for providers to enhance knowledge and offer further support. Addressing barriers to safer conception strategies at multiple levels is needed to prevent HIV transmission within serodiscordant couples who desire children. Providers can play an important role in lowering these barriers through the use of multiple strategies.

Keywords

conception; HIV transmission; HIV prevention; patient-provider communication

Cover Page Footnote

Statement: All authors confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story. Conflict of interest: None declared. Acknowledgments: We would like to thank our study participants for their willingness to participate and open and honest communication about their experiences. Funding: The project was funded by a grant through the Boston University School of Public Health Catalyst Program; the larger study was funded by Gilead Sciences.

Authors

Mari-Lynn Drainoni, Dea L. Biancarelli, Ashley A. Leech, Meg Sullivan, and Angela R. Bazzi

19 Implementing a Pre-Exposure Prophylaxis Intervention for Safer Conception among HIV Serodiscordant Couples: Recommendations for Health Care Providers
Drainoni et al.



Journal of Health Disparities Research and Practice
Volume 11, Issue 2, Summer 2018, pp. 19-33
© 2011 Center for Health Disparities Research
School of Community Health Sciences
University of Nevada, Las Vegas

Implementing a Pre-Exposure Prophylaxis Intervention for Safer Conception among HIV Serodiscordant Couples: Recommendations for Health Care Providers

Mari-Lynn Drainoni, PhD, MEd, Boston University
Dea L Biancarelli, BS, Boston University
Ashley A Leech, PhD, MS, Tufts Medical Center
Meg Sullivan MD, Boston University
Angela R Bazzi, PhD, MPH, Boston University

Corresponding Author: Mari-Lynn Drainoni, PhD, MEd, drainoni@bu.edu

ABSTRACT

Couples in HIV serodiscordant relationships frequently desire children. Although partners who are virally suppressed pose almost no risk of transmitting HIV to their partners, partners who are inconsistently on therapy may transmit HIV to their partners when attempting to conceive. Pre-exposure prophylaxis (PrEP) is an available safer conception strategy for these couples but is not consistently offered. We sought to better understand barriers to PrEP implementation for couples seeking conception and patient perceptions on what providers could do to encourage use. We conducted in-depth, qualitative interviews with 11 participants representing six couples taking PrEP for safer conception in a safety-net hospital in New England. Semi-structured qualitative interviews assessed the following: Relationship nature and contextual factors; attitudes and perceptions regarding PrEP for safer conception; experience within health care systems related to HIV and PrEP; and facilitators, barriers, and other experiences using PrEP for safer conception. Four key themes have important implications for implementation of PrEP for safer conception: Knowledge and understanding gaps regarding HIV and PrEP among both members of the couple, role of insurance and financing in decision-making, learning to manage and adhere to a treatment plan, and the need for providers to enhance knowledge and offer further support. Addressing barriers to safer conception strategies at multiple levels is needed to prevent HIV transmission within serodiscordant couples who desire children. Providers can play an important role in lowering these barriers through the use of multiple strategies.

Keywords: conception, HIV infections, HIV prevention, patient-provider communication

Journal of Health Disparities Research and Practice Volume 11, Issue 2, Summer 2018

<http://digitalscholarship.unlv.edu/jhdp/>

Follow on Facebook: [Health.Disparities.Journal](https://www.facebook.com/Health.Disparities.Journal)

Follow on Twitter: [@jhdp](https://twitter.com/jhdp)

INTRODUCTION

With marked improvements in HIV treatment that have transformed HIV into a chronic, manageable illness, many HIV-infected individuals express similar life-goals as HIV-uninfected individuals, including desires to raise children (Deeks, Lewin & Havlir, 2013; Siegel, Meunier, Tocco & Lekas, 2017; Jones et al., 2016; Chen, Phillips, Knaouse, Collins & Miu, 2001). However, among couples with mixed HIV status, otherwise known as serodiscordant couples, conception and pregnancy can be a high-risk time for HIV transmission (Mugo et al., 2011). In serodiscordant couples where the female is HIV-infected and the male partner is uninfected, the risk of transmission can be mitigated through at-home insemination strategies (Zafer et al., 2016; Barnes et al., 2014; CDC, 2017). However, couples comprised of an HIV-infected male and uninfected female require sperm wash techniques that remain costly, and few fertility clinics offer these specialized services, creating health disparities for serodiscordant couples wishing to conceive (ASRM 2015; Leech et al., 2018). Alternatively, serodiscordant couples may elect to conceive via condomless sex. While men who maintain an undetectable viral load pose almost no risk of transmitting HIV to their partners, women who cannot confirm their partner's undetectable status remain at risk for HIV (CDC, 2017). Given that only 49% of the estimated 1.1 million people infected with HIV have achieved viral suppression, and that a high proportion of people living with HIV cycle in out of care and suppression (Yehia et al., 2015), many women in serodiscordant couples need additional HIV protection when attempting to conceive (CDC, 2017).

Pre-exposure prophylaxis (PrEP), currently available as the medication Truvada®, and in a recently approved generic form, is a CDC recommended prevention strategy for women who cannot reliably confirm their partner's HIV viral load but still desire children with their partners (Vernazza, Graf, Sonnenberg-Schawn, Geit & Meurer, 2011; Finocchiaro-Kessler et al., 2012; Heffron, Pintye, Matthews, Weber & Mugo, 2016; CDC, 2017; Center for Drug Evaluation and Research, 2017). Unfortunately, knowledge of PrEP among heterosexuals remains low, therefore many serodiscordant couples may not know to ask for PrEP (Walters et al., 2018). Additionally, PrEP adherence is critical to its efficacy. Although clinical trials have demonstrated the efficacy of PrEP for preventing sexually acquired HIV (Grant et al., 2010; Baeten et al., 2012; Thigpen et al., 2012; Karim, Kashuba, Werner & Karmin, 2011), adherence to daily oral regimens is required (Baeten et al., 2012, Amico et al., 2013). In two large trials outside the US that failed to show efficacy of PrEP among women (FEM-PrEP and VOICE), less than 40% of participants were sufficiently adherent as measured by drug levels (Van Damme et al., 2012; Marrazzo et al., 2015).

Health care providers can play an important role in encouraging PrEP uptake and adherence. For example, a study of serodiscordant couples in Kenya found that key factors in supporting PrEP initiation included confidence in medical providers and systems and perceived friendliness, support and empowerment from clinicians (Ngure et al., 2016). However, there are gaps in successful implementation of PrEP use for preconception in the US; a recent qualitative study of preconception counseling for couples in HIV serodiscordant relationships demonstrated that participants identified a lack of knowledge about safer conception strategies, limited access to providers knowledgeable about preconception counseling, received conflicting medical advice, and desired ongoing counseling and follow-up beyond what was routinely provided (Friedman,

Orlando, Anderson & Coleman, 2016). Therefore, the implementation of PrEP to prevent transmission in couples desiring conception warrants further exploration.

Given the importance of practitioners and counseling in supporting serodiscordant couples' PrEP uptake and adherence, we undertook a qualitative study of couples using PrEP for safer conception in an urban US medical center to better understand barriers to PrEP implementation and what patients believed providers could do to help support its use.

METHODS

Study Design and Participants

We recruited Boston-based couples enrolled in an ongoing four-site pilot study of PrEP for safer conception for HIV-infected male and HIV-uninfected female couples (i.e., the PrEPception Study; Clinical Trials Identifier: NCT02233192). All couples were taking PrEP for conception using a CDC protocol on clinical practice guidelines for PrEP for HIV-serodiscordant couples seeking conception (CDC, 2014). The protocol involves a detailed treatment plan including counseling on conception options, semen analysis for the HIV-infected male, regular documentation of HIV status, prescription of PrEP for HIV-uninfected women, combination anti-retroviral therapy (cART) adherence for their HIV-infected male partners, and fertility tracking and timing of intercourse (i.e., limiting unprotected intercourse to periods of fertility and using condoms when not attempting to conceive). The study also included baseline and one-year end-point surveys of both partners, monthly PrEP adherence surveys with the females, and documentation of pregnancy outcomes. For the qualitative sub-study, we recruited 11 participants from six couples (five males, six females) enrolled at Boston Medical Center, a large urban safety-net hospital. Participants provided written informed consent to participate; the Boston University Medical Center IRB approved all study activities.

Instrument Development and Data Collection

We developed semi-structured qualitative interview guides addressing the following domains of interest: 1) relationship nature and contextual factors; 2) attitudes and perceptions regarding PrEP for conception; 3) experience with the health care system related to HIV and PrEP; and 4) facilitators and barriers to the use of PrEP for conception. A trained qualitative interviewer with experience in the PrEPception Study protocol conducted in-depth, individual interviews with participants between September 2015 and January 2016. If both partners agreed to participate, we interviewed female and male partners at different times. We digitally recorded all interviews, which lasted between 19 and 59 minutes, with a mean of 42 minutes.

Data Analysis

A professional transcription company transcribed the audio recordings verbatim; the written transcripts were reviewed for accuracy of transcription. To conduct the analysis, standard qualitative methods including the basic procedures of grounded theory and constant comparative methodology (Pope, Zibland & Mays, 2000; Glaser and Strauss, 1967) were used. Analyses involved multiple rounds of coding and analysis. First, two researchers independently reviewed two transcripts to identify potential codes; the entire research team then met to discuss these potential codes and develop an initial coding scheme. This initial coding scheme included eight primary codes; these included financial considerations, fertility issues and decisions, normalcy, health beliefs and knowledge, PrEP decision making, social context, experiences using PrEP, culture and 17 sub-codes that further detailed the larger codes. Second, three members of the

research team independently coded two different transcripts using the initial coding scheme and noted any new observations or inadequacies of the coding scheme. The entire research team then met to discuss preliminary findings from this round of coding and ways to revise the initial coding scheme to allow for a better “fit” of existing codes to the new data. During this discussion, team members proposed new codes and subcodes where needed. The entire team discussed these code revisions until they reached consensus (i.e., agreement regarding code definitions and application), resulting in a final coding scheme. The final coding scheme included 15 primary codes and 14 subcodes. Relevant codes for this analysis included counseling, finances, health knowledge/beliefs, HIV (in general), PrEP decisions, PrEP knowledge and beliefs, PrEP use/experience, and recommendations for services. Finally, the team members applied the final coding scheme to the remaining transcripts using the qualitative software package NVivo, which also helped with data management and organization. The most frequently applied codes included HIV (in general) (95), PrEP use/experience (66), PrEP knowledge and beliefs (48), and counseling (42). After all coding was completed in NVivo, analyses was conducted by the entire research team and involved synthesizing coded data, identifying key emergent themes and connections between themes, and comparing themes across participants. Representative quotes to illustrate key themes were selected and presented below using pseudonyms to protect confidentiality.

RESULTS

Participant Characteristics

Table 1 describes characteristics of the study participants.

Table 1. Characteristics of Qualitative Study Participants – Six Couples (n=11)*

Variable	Male (n=5)	Female (n=6)	Total (n=11)
	N (%)	N (%)	N (%)
Median age (Q1, Q3)	39 (36-48)	35.5 (30-41)	37 (34-44)
Black Race	5 (100)	6 (100)	11 (100)
Hispanic/Latino	2 (40)	0 (0)	2 (18)
Born outside US	4 (80)	3 (50)	7 (64)
Currently employed	3 (60)	6 (100)	9 (82)
Health insurance			
Commercial	3 (60)	4 (67)	7 (64)
Medicaid	2 (40)	2 (33)	4 (36)
Highest level of education completed:			
High school	3 (60)	1 (17)	4 (36)

23 Implementing a Pre-Exposure Prophylaxis Intervention for Safer Conception among HIV Serodiscordant Couples: Recommendations for Health Care Providers
 Drainoni et al.

Some college	1 (20)	2 (33)	3 (27)
College	1 (20)	3 (50)	4 (36)
Attend religious services \geq weekly	4 (80)	5 (83)	9 (82)
Married	3 (60)	4 (67)	7 (64)
Has children	4 (80)	2 (33)	6 (55)
Children with current partner	1 (20)	1 (17)	2 (18)
Previous fertility treatment/safer conception attempts	NA	3 (50%)	NA

* 1 male partner declined participation

Core Themes

In interviews, participants described their experiences and those of their partners including challenges relating to desires to conceive, learning about PrEP as an option for safer conception, and PrEP experiences. The data revealed four key themes with important implications for the implementation of PrEP for safer conception: 1) gaps in knowledge about HIV and PrEP among both partners; 2) role of insurance and financing in decision-making; 3) importance of learning to manage and adhere to a treatment plan; and 4) desire for providers to create support structures related to HIV and conception. Our findings in each of these domains are described below.

Knowledge Gaps. A striking finding was the extent to which participants of both sexes held misperceptions about HIV and PrEP, even following education and counseling by health care providers as a prerequisite to starting PrEP. Participants indicated confusion in many areas, including disbelief that they or their partner had HIV, what an undetectable or low viral load meant, whether or not there was a cure for HIV, and how HIV is transmitted. Many of these beliefs were rooted in confusion from past or current partners not contracting HIV, which reduced their perceived need for PrEP. Some women expressed skepticism that their partners were HIV positive because they had not become infected with HIV. For example, female participant Efie stated ‘*I don’t believe my husband is HIV positive*’ because prior to starting PrEP they had unprotected sex and she had not contracted HIV. Others believed that HIV was curable. Female participant Amaka declared ‘*I look at HIV as any other disease...you treat it and it goes away.*’ Some men also expressed confusion or disbelief about their HIV status, explaining that their low viral loads meant they did not have the infection or, if they were infected, they would not be able to transmit it. For example, male participant Oko expressed disbelief saying, ‘*Me, personally...I don’t believe it. Because...back home all my previous women, they are all living healthy, nobody even have that kind of disease.*’

A final misconception was the belief that PrEP was a fertility treatment rather than an HIV prevention method. This misunderstanding was primarily expressed when participants addressed the role of financing and insurance in decision making about PrEP, as described below.

Journal of Health Disparities Research and Practice Volume 11, Issue 2, Summer 2018

<http://digitalscholarship.unlv.edu/jhdrp/>

Follow on Facebook: Health.Disparities.Journal

Follow on Twitter: @jhdrp

Role of Insurance and Financing in PrEP Decision-Making. All participants discussed experiencing financial stress, which was a core component of their decision-making surrounding conception options. Insurance often covered PrEP, but many insurers, including Medicaid, would not cover fertility treatment, making it prohibitively expensive. Even if fertility treatment was covered, there were other barriers such as a requirement to try natural conception for an extended period prior to coverage beginning. Additionally, most couples did not have difficulty conceiving and did not require fertility techniques to conceive, but considered assistive reproductive technology to conceive safely. Thus, PrEP ended up being a financially feasible option. A common sentiment was that PrEP was a more practical choice that was covered by their insurance. Female participant Mutesi said,

'She [the physician] also talked about the IUI [intrauterine insemination], the IUI and the IVF [in vitro fertilization]... the insurance I had would not cover it.'

Male participant Oko said, *'Because the sperm (wash) was -I think you have to spend a lot of money on that I think.'* Female participant Efi had previously tried assisted reproduction and described the financial barriers that she and her partner experienced:

'In fact it was a big problem. A whole lot of challenges. So it came to a point that we told them we are no longer interested. Because we have to be paying for the storage fee every month.'

PrEP was also viewed as more convenient than fertility treatments, which were perceived as requiring more visits, traveling greater distances to appointments, and demanding time off from work, which was challenging for these couples of limited means. Male participant Jean Caleb said

'It's easier because, she's worried about her job and she take her off time to come here, and to keep comin' and even the appointment to follow the appointment with the doctor, and that will be like I said, that will be more, so, us, if we can come here once that will be very helpful for her'

His partner Nina agreed, stating: *'At the time I think it [insemination] was the only option that worked for us, whereas with PrEP...it's actually a lot more convenient.'*

Learning to Manage and Adhere to a Treatment Plan. Many participants spoke about the importance of managing and adhering to their treatment plan, viewing this as a joint (couple) activity, responsibility, and challenge. For some participants, the fact that both members of the couple had to adhere to a medication regimen (the male to cART and the female to PrEP) meant that they could do it together, making it seem easier. Isaiah, who understood the importance of PrEP for safe conception, stated,

'To keep us safe is my main priority, to keep the baby safe is my main priority... We take our medication together every day...Just take it like it's a vitamin.'

Several male partners said they helped remind their female partners to take PrEP because they were more accustomed to taking HIV medication daily; several of the women also stated that their partners would remind them to take PrEP when they were taking their HIV medication. Because viral load suppression among the HIV-infected male partners was a clinical requirement for prescribing PrEP for conception to the females, the HIV-infected men in the sample were adherent to medication. These men described themselves, and were described by their female partners, as strongly supportive of adherence. Female participant Amaka stated,

25 Implementing a Pre-Exposure Prophylaxis Intervention for Safer Conception among HIV Serodiscordant Couples: Recommendations for Health Care Providers
Drainoni et al.

'He bought me a little container to put my medication in to always remember to take it at work...he's been supporting me to make sure that I take my medication every day because I tend to forget at times.'

In addition to male partner support, several women also described their own strategies for adherence. Female participant Nina, who initially thought that it might be challenging to take her pill every day, said she quickly learned to adhere because she understood the ramifications of not being adherent:

'It required my being very committed to taking the medication on time, every time...For me that is a challenge, because I'm just not a medication person at all. Like I don't do birth control, so it was a challenge for me, but obviously when you know the consequences could be so serious, you kind of get into the habit pretty quickly.'

For the women who did find adherence difficult, it was due to *'just remembering'* because they were *'not used to dealing with stuff like that'* and tended to forget with their busy schedules. Another obstacle to treatment management and adherence was learning manage PrEP side effects (actual or anticipated). Some women spoke of having headaches, dizziness, drowsiness, stomachaches, and female participant Efiie complained of *'being forced to eat because of the medication.'* Male partners were also a source of support while working through side effects or fear of side effects from the medication. Male participant Isaiah described how he tried to reassure his female partner after the doctor told her she might experience side effects, stating:

'You might go through some discomfort, or [something] like that...Don't think about none of that, [I told her], just think about it as a vitamin... if your mind is paranoid...you'll be that one percent that goes through all the bad side effects.'

Need for Increasing Support. Many participants spoke about the importance of obtaining more support and wondered if their providers could assist in that arena. Their prior limited awareness about PrEP and safer conception options led to fear and isolation that they hoped could be ameliorated for others. They suggested addressing this by ensuring that more providers knew about PrEP and offered it to patients. Female participant Hailey described how awareness could be improved via providers:

'I'm surprised that nobody knows about Truvada. And it's like why not spread that? Why not tell everybody that? Because that solves a lot of isolation. It solves a lot of problems.'

Participants also desired support from other serodiscordant couples who had used PrEP for conception. They believed that while they were considering all their options for safer conception, it would have been extremely helpful for them to hear about the experience of taking PrEP for conception directly from couples who have experienced it and hoped that their providers would set up these networks. Female participants were particularly interested in having contact with and support from other women who would understand what they were going through and felt that health care providers could play a role in identifying other couples. As stated by female participant Amaka:

'I would encourage if you could bring in couples who have used the PrEP to really try to talk to, the couples who are trying to go into it. Because like myself when... I started it, and I was like okay, and my husband has told me all of this information. It's true, but I don't believe him. So, he...brought me to his doctor, and the doctor told me...But-if there was a person like me and my husband and we come face-to-face, and we tell this person like, you

know, "It's true, it has worked for me." I believe it could be couples out there who are willing to come up and help other couples.'

DISCUSSION

Our results provide important information to consider when planning the implementation of PrEP for safer conception in the US. The four core themes identified have important implications for clinical practice and counseling processes.

First, participants held misconceptions about both HIV and PrEP. Participants learned about PrEP through their HIV providers and had received standard patient education about HIV from those providers. Yet, despite ongoing counseling, interviews with both male and female participants suggested a limited understanding about some facets of HIV and PrEP. As English was a second language for some participants, misunderstanding may have stemmed from language and health literacy barriers, as found in other studies of HIV (Murphy et al., 2010) and other diseases (Flores, 2006; David and Rhee 1998).

Second, financial stress was a major barrier to conception, and prior to the study, most couples were unaware of PrEP as an alternative risk reduction option to assisted reproductive technologies. Participants also described logistical and accessibility barriers to fertility treatment, which is unsurprising given the high cost and limited insurance coverage of fertility treatment in addition to accessibility challenges for HIV-positive individuals (Friedman et al., 2016; Sauer, 2006; ASRM, 2015). In addition, given the importance of how couples considered PrEP to be a more "natural" conception option (Bazzi, Leech, Biancarelli, Sullivan & Drainoni, 2017), PrEP is likely to be a highly promising, acceptable and affordable option for this population. As HIV is known to affect those with lower socioeconomic status, PrEP could potentially aid in closing this disparity in access for serodiscordant couples and safe conception care (Rubin, Colen & Link, 2010; Newmeyer et al., 2011).

Third, adherence was described as challenging for individuals not used to taking daily medications. This reflects findings from other studies on a range of health conditions (Ho, Bryson & Rumsfeld, 2009; Jones, Butler, Thomas, Peveler & Prevett 2006; Sabaté, 2003) showing that adherence may be particularly challenging for individuals who are not feeling ill or have conflictual feelings about taking medications due to concerns about possible side effects.

Finally, participants were vocal about the need for additional support and saw an important role for providers in this area. Participants believed that having connections to and support from other couples who were experienced with safer conception could help with adherence and treatment management. The value of peer support and education has been shown in a range of fields, including HIV interventions (Garfein et al., 2007; Wolitski, Gomez & Parsons, 2005).

Based on these core themes, we suggest the following specific strategies. Efforts are needed to enhance education, both for providers and members of serodiscordant couples, especially in light of the changing CDC guidelines in 2017. While the CDC no longer recommends PrEP for serodiscordant couples in which the HIV-infected partner is virally suppressed, PrEP is an important HIV prevention method for couples in which this is not the case (CDC, 2017). Since many people living with HIV cycle in and out of care, and thus maintain inconsistent suppression levels (Yehia et al., 2015), it is critical to increase providers' knowledge of PrEP and when it should be prescribed. Although HIV providers are more experienced with these issues, they are unlikely to see HIV-negative persons (Krakower, Ware, Mitty, Maloney & Mayer, 2014); women

desiring conception are most likely to be seen by primary care or women's health providers. Studies indicate that primary care providers are not likely to discuss sexuality issues with patients (Drainoni, Dekker, Lee, Boehmer & Relf, 2009) and have limited knowledge and experience prescribing PrEP (Arnold et al., 2012). We recommend that providers seeing uninfected partners collaborate with HIV providers treating infected partners of serodiscordant couples to establish networks for their own education and better support PrEP implementation.

All providers, but particularly those who work with women hoping to become pregnant, would be well-served to learn about the partners of those women. Studies have shown that strong patient-provider relationships contribute to better adherence and health outcomes among persons living with HIV (Beach, Keruly & Moore, 2006; Roberts, 2002). Accurate consumer knowledge has also been shown to be an important first step in the implementation of PrEP (Liu et al., 2014). Ideally, providers working with serodiscordant couples should establish strong relationships with both partners and provide HIV education to the couple together. It is critical to ensure that both partners understand what HIV means for the couple, how it affects children and transmission risks, while also addressing any misunderstandings. Providers should further explain how PrEP and other options for safe conception work and help troubleshoot coverage and financing issues for different safe conception options. These efforts could be informed by and adapted from similar models for couples counseling that have been proven effective in reducing HIV risks (Farquhar et al., 2004; Rosenberg et al., 2013; Sullivan et al., 2014).

Yet, joint counseling may not be enough or possible. Couples in our study still exhibited misconceptions and confusion about fertility treatments and safer conception after frequent joint counseling by two providers with strong knowledge and interest in PrEP. Utilizing additional counseling strategies such as the teach-back method, which has been recommended for improving low health literacy (Kountz, 2009) would be useful in ensuring the level of understanding necessary for adequate uptake of and adherence to PrEP. Additionally, although not necessarily the purview of individual providers, the education-understanding disconnect that we found highlights the need for careful design, piloting, evaluating, and disseminating effective education techniques. This need may be particularly critical for the topic of PrEP for safe conception, which involves concepts of horizontal (male to female partner) and vertical (mother to baby) transmission and communication regarding sophisticated medical innovations. Our findings point to a potentially fatal gap at the beginning of the "HIV prevention continuum": a lack of effective education about the basic concepts of HIV transmission, safer conception, and prevention options. Failure to educate patients in such early parts of this continuum could render it increasingly difficult to provide effective education later on regarding the importance of adherence or following other specific areas of safe conception treatment plans.

However, we acknowledge potential barriers to achieving high patient comprehension through joint couple counseling. First, HIV-infected men have been found to desire reproductive health services but also to face barriers to access (Khidir et al., 2017) In many cases, both partners are unlikely or unable to be seen in the same practice setting. Although, like teach-back, skills building can be integrated into ongoing couples' counseling and could be based on the Information-Motivation-Behavioral Skills model, which has been shown effective in chronic disease self-management including adherence to HIV treatment regimens (Fisher, Fisher, Amico & Harman, 2006; Gifford and Groessl, 2002) counseling is time consuming and poorly reimbursed by insurance. Even if a provider is willing to provide such counseling, it may be impossible to do

within the confines of a 20-minute clinical visit. Thus, providers need to consider novel and potentially more feasible education methods involving other teaching strategies and other members of care teams, such as patient navigators or nursing staff. Additionally, appreciating that providers may not have access to both members of the couple, it is critical that the female partner understand both her own and her partner's role in HIV prevention during conception. While cART is an effective form of HIV prevention (CDC, 2017), providers should stress that utilizing PrEP can act as an additional layer of protection that female participants have direct control over, which one recent pilot found was desired by serodiscordant couples and may be considered empowering for these women (Loufty et al., 2017). Especially in cases when the HIV-negative partner cannot confirm their partners' suppression levels and may not be in a position to negotiate this, PrEP offers a valuable prevention tool.

While some strategies will require larger infrastructure and organizational shifts, efforts to improve patient education about PrEP, couple-counseling for safe conception, and couple-provider relationships should be feasible for providers working within current systems. At the individual patient and larger contextual levels, there are available strategies to increase engagement that should be relatively simple to employ, such as the core activities of education, skill building and relationship building, by the clinician. Identifying methods to use other members of care teams to engage in skills-building and couples' counseling will be essential to fully operationalize these goals.

This study has limitations. First, participants received their services in one institution in Massachusetts; therefore, their views might not generalize to other similar couples desiring conception. However, given the health care environment in Massachusetts, we anticipate that barriers could be even greater in other settings characterized by lower awareness of PrEP and support through public insurance systems. Second, as in any qualitative study, although participants were assured of confidentiality and their responses appeared to be candid, we cannot exclude the possibility of biased or socially desirable responses. Nevertheless, we sought to examine participants' experiences in order to help address PrEP implementation issues, and we believe that our findings have important implications for clinical practice, patient education, and patient-provider communication.

CONCLUSION

Although barriers to accessing safe conception strategies involving PrEP exist for HIV serodiscordant couples at the individual, couple, system, and societal levels, there are multiple strategies that could be implemented to lower these barriers. The financial feasibility of PrEP and its potential role as an empowerment tool for safer conception could potentially decrease disparities for serodiscordant couples who wish to conceive. Additionally, while we focused on PrEP for safe conception among HIV serodiscordant couples, much of what we learned is broadly applicable to implementation of provider and health care interventions for a range of chronic and stigmatized health conditions.

ACKNOWLEDGEMENTS

Support was provided by the Boston University School of Public Health Catalyst Program and Gilead Sciences. We also would like to acknowledge the individuals who participated in this study and generously shared their experiences.

Journal of Health Disparities Research and Practice Volume 11, Issue 2, Summer 2018

<http://digitalscholarship.unlv.edu/jhdrp/>

Follow on Facebook: Health.Disparities.Journal

Follow on Twitter: @jhdrp

REFERENCES

- American Society for Reproductive Medicine (ASRM). (2015). Disparities in access to effective treatment for infertility in the United States: An ethics committee opinion, *Fertility Sterility*, 104 (5) 1104–10, doi: 10.1016/j.fertnstert.2015.07.1139.
- Amico KR, Mansoor L, Corneli A, Torjesen K, Straten A. (2013). Adherence Support Approaches in Biomedical HIV Prevention Trials: Experiences, Insights and Future Directions from Four Multisite Prevention Trials. *AIDS and Behavior*, 17 (6)1-13. doi:10.1007/s10461-013-0429-9.
- Anglemyer A, Rutherford GW, Horvath T, Baggaley RC, Egger M, Siegfried N. (2013). Antiretroviral therapy for prevention of HIV transmission in HIV-discordant couples. *Cochrane Database Systematic Review*, 11 (4) CD009153, doi:10.1002/14651858.CD009153.pub3.
- Arnold EA, Hazelton P, Lane T, Christopoulos KA, Galindo GR, Steward WT, Morin SF. (2012). A qualitative study of provider thoughts on implementing pre-exposure prophylaxis (PrEP) in clinical settings to prevent HIV infection. *PLOS One*, 7 (7) doi:10.1371/journal.pone.0040603
- Baeten, J. M., Donnell, D., Ndase, P., Mugo, N. R., Campbell, J. D., Wangisi, J., ... Celum, C. (2012). Antiretroviral Prophylaxis for HIV-1 Prevention among Heterosexual Men and Women. *The New England Journal of Medicine*, 367(5), 399–410. <http://doi.org/10.1056/NEJMoal108524>
- Barnes A, Riche D, Mena L, Sison T, Barry L, Reddy R, Shwayder J, Parry JP. (2014). Efficacy and safety of intrauterine insemination and assisted reproductive technology in populations serodiscordant for Human Immunodeficiency Virus: A Systematic Review and Meta Analysis. *Fertility Sterility*, 102 (2) 424–34, doi:10.1016/j.fertnstert.2014.05.001.
- Bazzi, A. R., Leech, A. A., Biancarelli, D. L., Sullivan, M., Drainoni, M.L. (2017). Experiences Using Pre-Exposure Prophylaxis for Safer Conception Among HIV Serodiscordant Heterosexual Couples in the United States. *AIDS Patient Care and STDs*, 31(8), 348-355. doi:10.1089/apc.2017.0098
- Beach MC, Keruly J, Moore RD. 2006. Is the quality of the patient-provider relationship associated with better adherence and health outcomes for patients with HIV? *Journal of General Internal Med*, 21(6) 661-5. doi: 10.1111/j.1525-1497.2006.00399.x
- Centers for Disease Control and Prevention. 2014. Pre-exposure prophylaxis for the prevention of HIV infection in the United States. <https://www.cdc.gov/hiv/pdf/guidelines/PrEPguidelines2014.pdf> accessed 7/27/18).
- Centers for Disease Control and Prevention. 2017. Pre-exposure prophylaxis for the prevention of HIV infection in the United States-2017 Update. <https://www.cdc.gov/hiv/pdf/risk/prep/cdc-hiv-prep-guidelines-2017.pdf> accessed 7/27/18).
- Center for Drug Evaluation and Research. (2017). ANDA Approval Reports - 2017 First Generic Drug Approvals. Retrieved July 30, 2018, from <http://digitalscholarship.unlv.edu/jhdrp/>
- Follow on Facebook: Health.Disparities.Journal
Follow on Twitter: @jhdrp

30 Implementing a Pre-Exposure Prophylaxis Intervention for Safer Conception among HIV Serodiscordant Couples: Recommendations for Health Care Providers
Drainoni et al.

- <https://www.fda.gov/drugs/developmentapprovalprocess/howdrugsaredevelopedandapproved/drugandbiologicapprovalreports/andagenericdrugapprovals/ucm597322.htm>
- Chen JL, Philips KA, Kanouse DE, Collins RL, Miu A. (2001). Fertility desires and intentions of HIV-positive men and women. *Family Planning Perspectives*, 33 (4) 144-52, 165.
- David RA, Rhee M. 1998. The impact of language as a barrier to effective health care in an underserved urban Hispanic community. *Mount Sinai Journal of Medicine*, 56(5-6) 393-7.
- Drainoni M, Dekker D, Lee Hood E, Boehmer U, Relf M. (2009). HIV medical care provider practices for reducing high-risk sexual behavior: Results of a qualitative study. *AIDS Patient Care and STDs*. 23 (5) 347-356. doi: 10.1089/apc.2008.0063.
- Deeks, S. G., Lewin, S. R., & Havlir, D. V. 2013. The End of AIDS: HIV Infection as a Chronic Disease. *Lancet*, 382(9903), 1525–1533. [http://doi.org/10.1016/S0140-6736\(13\)61809-7](http://doi.org/10.1016/S0140-6736(13)61809-7)
- Farquhar C, Kiarie JN, Richardson BA, Kabura MN, John FN, Nduati RW, Mbori-Ngaca DA, John-Steward GC. (2004). Antenatal couple counseling increases uptake of interventions to prevent HIV-1 transmission. *Journal of Acquired Immune Deficiency Syndrome*, 37 (5)
- Finocchiaro-Kessler, S., Sweat, M. D., Dariotis, J. K., Anderson, J. R., Jennings, J. M., Keller, J. M., ... Trent, M. E. (2012). Childbearing motivations and pregnancy desires among urban female youth: Does HIV-infection status make a difference? *AIDS Care*, 24(1), 1–11. <http://doi.org/10.1080/09540121.2011.596514>
- Fisher J, Fisher W, Amico K, Harman J. (2006). An information-motivation-behavioral skills model of adherence to antiretroviral therapy. *Health Psychology*, 25 (4) 462-73. doi:10.1037/0278-6133.25.4.462
- Flores G. (2006). Language Barriers to health care in the US. *New England Journal of Medicine*, 355 (3) 229-31. doi: 10.1056/NEJMp058316
- Friedman E, Orlando MS, Anderson J, Coleman JS. (2016). ‘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. *Womens Health Issues*, 26 (3) 351-56. doi: 10.1016/j.whi.2015.11.004.
- Garfein, R. S., Golub, E. T., Greenberg, A. E., Hagan, H., Hanson, D. L., Hudson, S. M., . . . Thiede, H. (2007). A peer-education intervention to reduce injection risk behaviors for HIV and hepatitis C virus infection in young injection drug users. *AIDS*, 21(14), 1923-1932. doi:10.1097/qad.0b013e32823f9066
- Gifford AL, Groessl EJ. (2002). Chronic Disease Self-Management and Adherence to HIV Medications. *Journal of Acquired Immune Deficiency Syndrome*, 31 (Suppl 3) S163-6.
- Glaser BG, Strauss AL. 1967. The Discovery of Grounded Theory: Strategies for Qualitative Research. Chicago, Aldine Publishing Company.
- Grant, R. M., Lama, J. R., Anderson, P. L., McMahan, V., Liu, A. Y., Vargas, L., ... Glidden, D. V. (2010). Preexposure Chemoprophylaxis for HIV Prevention in Men Who Have Sex with Men. *The New England Journal of Medicine*, 363(27), 2587–2599. <http://doi.org/10.1056/NEJMoa1011205>
- Heffron R, Pintye J, Matthews LT, Weber S, Mugo N. (2016). PrEP as Peri-conception HIV Prevention for Women and Men. *Current HIV/AIDS Reports*, 13 (3) 131-9, doi:10.1007/s11904-0160312-1.
- Ho PM, Bryson CL, Rumsfeld JS. (2009). Medication adherence: its importance in

31 Implementing a Pre-Exposure Prophylaxis Intervention for Safer Conception among HIV Serodiscordant Couples: Recommendations for Health Care Providers
Drainoni et al.

- cardiovascular outcomes. *Circulation*, 119 (23) 3028–35, doi:10.1161/CIRCULATIONAHA.108.768986.
- Jones RM, Butler JA, Thomas VA, Peveler RC, Prevett M. (2006). Adherence to treatment in patients with epilepsy: associations with seizure control and illness beliefs. *Seizure*, 15 (7) 504-8. doi:10.1016/j.seizure.2006.06.003
- Jones, D. L., Cook, R., Potter, J. E., Miron-Shatz, T., Chakhtoura, N., Spence, A., & Byrne, M. M. (2016). Fertility Desires among Women Living with HIV. *Plos One*, 11(9). doi:10.1371/journal.pone.0160190
- Karim, S. S., Kashuba, A. D., Werner, L., & Karim, Q. A. (2011). Drug concentrations after topical and oral antiretroviral pre-exposure prophylaxis: Implications for HIV prevention in women. *The Lancet*, 378(9787), 279-281. doi:10.1016/s0140-6736(11)60878-7
- Khidir, H., Psaros, C., Greener, L., O'Neil, K., Mathenjwa, M., Mosery, F. N., ... Matthews, L. T. (2018). Developing a Safer Conception Intervention for Men Living with HIV in South Africa. *AIDS and Behavior*, 22(6), 1725–1735. <http://doi.org/10.1007/s10461-017-1719-4>
- Kountz DS. (2009). Strategies for improving low health literacy. *Postgraduate Medicine*, 121 (5) 171-7. doi: 10.3810/pgm.2009.09.2065.
- Krakower, D., Ware, N., Mitty, J. A., Maloney, K., & Mayer, K. H. (2014). HIV Providers' Perceived Barriers and Facilitators to Implementing Pre-Exposure Prophylaxis in Care Settings: A Qualitative Study. *AIDS and Behavior*, 18(9), 1712–1721. <http://doi.org/10.1007/s10461-014-0839-3>
- Leech, A. A., Bortoletto, P., Christiansen, C., Drainoni, M., Linas, B. P., Roeca, C, Curtis, M, and Sullivan, M. (2018). Assessing access to assisted reproductive services for serodiscordant couples with human immunodeficiency virus infection. *Fertility and Sterility*, 109(3), 473-477. doi:10.1016/j.fertnstert.2017.11.039
- Liu, A., Cohen, S., Follansbee, S., Cohan, D., Weber, S., Sachdev, D., & Buchbinder, S. (2014). Early Experiences Implementing Pre-exposure Prophylaxis (PrEP) for HIV Prevention in San Francisco. *PLoS Medicine*, 11(3), e1001613. <http://doi.org/10.1371/journal.pmed.1001613>.
- Loutfy, M., Kennedy, V. L., Sanandaji, M., Barry, F., Ongoiba, F., Muchenje, M., . . . Regier, D. A. (2017). Pregnancy planning preferences among people and couples affected by human immunodeficiency virus: Piloting a discrete choice experiment. *International Journal of STD & AIDS*, 29(4), 382-391. doi:10.1177/0956462417728188
- Marrazzo, J. M., Ramjee, G., Richardson, B. A., Gomez, K., Mgodhi, N., Nair, G., ... for the VOICE Study Team. (2015). Tenofovir-Based Preexposure Prophylaxis for HIV Infection among African Women. *The New England Journal of Medicine*, 372(6), 509–518. <http://doi.org/10.1056/NEJMoa1402269>
- Mugo, N. R., Heffron, R., Donnell, D., Wald, A., Were, E. O., Rees, H., . . . Baeten, J. M. (2011). Increased risk of HIV-1 transmission in pregnancy. *AIDS*, 25(15), 1887-1895. doi:10.1097/qad.0b013e32834a9338
- Murphy, D. A., Lam, P., Naar-King, S., Harris, D. R., Parsons, J. T., & Muenz, L. R. (2010). Health Literacy and Antiretroviral Adherence Among HIV-infected Adolescents. *Patient Education and Counseling*, 79(1), 25–29. <http://doi.org/10.1016/j.pec.2009.07.014>
- Newmeyer, T., Tecimer, S. N., Jaworsky, D., Chihrin, S., Gough, K., Rachlis, A., ... Loutfy, M. R. (2011). Case Series of Fertility Treatment in HIV-Discordant Couples (Male Positive, Journal of Health Disparities Research and Practice Volume 11, Issue 2, Summer 2018 <http://digitalscholarship.unlv.edu/jhdrp/>
- Follow on Facebook: Health.Disparities.Journal
Follow on Twitter: @jhdrp

32 Implementing a Pre-Exposure Prophylaxis Intervention for Safer Conception among HIV Serodiscordant Couples: Recommendations for Health Care Providers
Drainoni et al.

- Female Negative): The Ontario Experience. *PLoS ONE*, 6(9), e24853. <http://doi.org/10.1371/journal.pone.0024853>
- Ngure, K., Heffron, R., Curran, K., Vusha, S., Ngutu, M., Mugo, N., . . . Baeten, J. M. (2016). I Knew I Would Be Safer. Experiences of Kenyan HIV Serodiscordant Couples Soon After Pre-Exposure Prophylaxis (PrEP) Initiation. *AIDS Patient Care and STDs*, 30(2), 78-83. doi:10.1089/apc.2015.0259
- Pope, C., & Mays, N. (2007). *Qualitative research in health care*. Oxford: John Wiley & Sons.
- Rosenberg, N. E., Pettifor, A. E., Bruyn, G. D., Westreich, D., Delany-Moretlwe, S., Behets, F., . . . Miller, W. C. (2013). HIV Testing and Counseling Leads to Immediate Consistent Condom Use among South African Stable HIV-discordant Couples. *Journal of Acquired Immune Deficiency Syndromes* (1999), 62(2), 226–233. <http://doi.org/10.1097/QAI.0b013e31827971ca>
- Rubin, M. S., Colen, C. G., & Link, B. G. (2010). Examination of Inequalities in HIV/AIDS Mortality in the United States From a Fundamental Cause Perspective. *American Journal of Public Health*, 100(6), 1053-1059. doi:10.2105/ajph.2009.170241
- Roberts, K. J. (2002). Physician-Patient Relationships, Patient Satisfaction, and Antiretroviral Medication Adherence Among HIV-Infected Adults Attending a Public Health Clinic. *AIDS Patient Care and STDs*, 16(1), 43-50. doi:10.1089/108729102753429398
- Sabaté, E. (2003). *Adherence to long-term therapies evidence for action*. Geneva: World Health Organization.
- Sauer, M. V. (2006). American physicians remain slow to embrace the reproductive needs of human immunodeficiency virus–infected patients. *Fertility and Sterility*, 85(2), 295-297. doi:10.1016/j.fertnstert.2005.08.019
- Siegel, K., Meunier, É, Tocco, J. U., & Lekas, H. (2017). Reproductive Desires and Considerations of HIV-Positive Men in Heterosexual Relationships in New York City. *AIDS and Behavior*, 22(6), 1736-1749. doi:10.1007/s10461-017-1864-9
- Sullivan, P. S., Stephenson, R., Grazer, B., Wingood, G., Diclemente, R., Allen, S., . . . Grabbe, K. (2014). Adaptation of the African couples HIV testing and counseling model for men who have sex with men in the United States: an application of the ADAPT-ITT framework. *SpringerPlus*, 3(1), 249. <http://doi.org/10.1186/2193-1801-3-249>
- Thigpen, M. C., Kebaabetswe, P. M., Paxton, L. A., Smith, D. K., Rose, C. E., Segolodi, T. M., . . . Brooks, J. T. (2012). Antiretroviral Preexposure Prophylaxis for Heterosexual HIV Transmission in Botswana. *New England Journal of Medicine*, 367(5), 423-434. doi:10.1056/nejmoa1110711
- Van Damme, L., Corneli, A., Ahmed, K., Agot, K., Lombaard, J., Kapiga, S., . . . for the FEM-PrEP Study Group, D. (2012). Preexposure Prophylaxis for HIV Infection among African Women. *The New England Journal of Medicine*, 367(5), 411–422. <http://doi.org/10.1056/NEJMoa1202614>
- Vernazza PL, Graf I, Sonnenberg-Schwan U, Geit M, Meurer A. (2011). Preexposure prophylaxis and timed intercourse for HIV-discordant couples willing to conceive a child. *AIDS*, 25 (16) 2005-2008, doi: 10.1097/QAD.0b013e32834a36d0.
- Walters, S.M, Rivera, A.V, Starbuck, L, Reily, K.H, Boldon, N, Anderson, B, Braunstein, S. Differences in Awareness of Pre-exposure Prophylaxis and Post-exposure Prophylaxis

33 Implementing a Pre-Exposure Prophylaxis Intervention for Safer Conception among HIV Serodiscordant Couples: Recommendations for Health Care Providers
Drainoni et al.

- Among Groups At-Risk for HIV in New York State. (2018). *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 77(1). doi:10.1097/qai.0000000000001600
- Wolitski, R. J., Gómez, C. A., & Parsons, J. T. (2005). Effects of a peer-led behavioral intervention to reduce HIV transmission and promote serostatus disclosure among HIV-seropositive gay and bisexual men. *AIDS*, 19(Supplement 1). doi:10.1097/01.aids.0000167356.94664.59
- Yehia, B. R., Stephens-Shields, A. J., Fleishman, J. A., Berry, S. A., Agwu, A. L., Metlay, J. P., . . . Gebo, K. A. (2015). The HIV Care Continuum: Changes over Time in Retention in Care and Viral Suppression. *Plos One*, 10(6). doi:10.1371/journal.pone.0129376
- Zafer, M., Horvath, H., Mmeje, O., van der Poel, S., Semprini, A., Rutherford, G., & Brown, J. (2016). Effectiveness of semen washing to prevent HIV transmission and assist pregnancy in HIV-discordant couples: a systematic review and meta-analysis. *Fertility and Sterility*, 105(3), 645–655.e2. <http://doi.org/10.1016/j.fertnstert.2015.11.028>