NATIONAL CLINICIAN CONSULTATION CENTER
Translating science into care

The 2020 National Perinatal HIV Hotline Roundtable Discussion:
Preventing Maternal HIV Transmission during Pregnancy and Breastfeeding

March 19, 2020 - Virtual Session

Introduction

The National Perinatal HIV Hotline (www.nccc.ucsf.edu) hosts roundtable discussions that coincide annually with the Conference on Retroviruses and Opportunistic Infections (CROI) to promote dialogue around challenging topics and build community among providers. Discussion notes are distributed via the ReproID HIV listserv. For more information on the listserv, the Hotline, or roundtable discussions, contact Marliese Warren at marliese.warren@ucsf.edu.

The 2020 National Perinatal HIV Hotline Roundtable Discussion was an opportunity to discuss clinical protocols and share best practices for decreasing the risk of maternal HIV acquisition while also supporting birthing people in having the pregnancy and postpartum experience that they desire.

As in years past, the discussion included both US- and internationally-based clinicians and researchers. Due to the SARS-CoV-2 pandemic, the 2020 Roundtable Discussion was held virtually. The format for this year's roundtable included a single large group discussion and dialogue of two cases; facilitators utilized a series of questions about each case to focus the discussion. We took notes on the discussions and coded key points into major themes, which are outlined below. The cases and discussion questions are included with the discussion notes.

A note on language: We acknowledge that not all people who get pregnant and give birth identify as women and not all people who identify as women can or will get pregnant and give birth. We made an effort to use gender-inclusive and person-first language throughout this document.

Cases for discussion

Case 1

29 y.o. G3P3 presented for HIV testing with the following history:

She delivered her third child 5 years ago and reported negative HIV testing during pregnancy and at delivery. She knew her husband had HIV but thought he had it "under control". The couple generally did not discuss his HIV status.

She breastfed all three children. When her third child was about one year of age, the child was diagnosed with failure to thrive and was tested for multiple conditions including HIV. The child was subsequently

diagnosed with HIV, so maternal testing was advised. The mother tested positive for HIV. In retrospect, based on timing of her prior testing, she most likely acquired HIV while breastfeeding and transmitted HIV to the infant via breastfeeding.

Discussion Questions:

1. **Did her prenatal care provider know her husband had HIV?** Probably not. Ideally, the patient's provider would initiate a discussion about partner status before breastfeeding begins.

2. **Should prenatal providers regularly ask if a partner has HIV or if a partner has been tested for HIV? How do you assess for HIV risk during pregnancy, knowing that most women have very low risk and may not be comfortable/willing to share their [known] risk factors or consider this possibility? How do you continue to assess for HIV risk to ensure that testing is done periodically and maternal infections are identified before delivery?**

Maternal HIV testing:

- Consider what happens at the first antenatal care (ANC) visit, including social and reproductive history, such as previous STI diagnosis. Note that conversations about HIV risk may not be routine for providers who do not focus on HIV care.
- Instead of asking direct questions about HIV status, may help to frame instead as "to ensure that you and your baby are well, we should do X, Y, Z" where X, Y, Z involves many of the already existing testing and care and incorporates HIV testing. Knowing the partner's status can be a way of protecting the baby. Modify ANC checklists to include many maternal infections that could be transmitted (group B strep, other STIs like herpes and syphilis, and viral hepatitis, etc.).
- This change would likely need to happen at a systems level. Suggested a joint letter to US medical professional societies with colleagues signing on as a group of experts, especially in light of the Ending the HIV Epidemic initiative intended to reduce new HIV infections by 90% by 2030.

Partner HIV status assessment:

- Among HIV-focused providers, it could be standard that partner HIV status is assessed routinely. However, in a general prenatal/clinical setting without an explicit HIV focus, it may not be standard practice to assess partner HIV status.
- Normalizing discussions and routinizing opt-out HIV testing, including among partners, was seen as a proactive, non-stigmatizing approach in Zimbabwe (a setting with high HIV prevalence). Qualitative work revealed that a shift to opt-out testing was accompanied by relief among female participants. Additionally, the testing shift became a conversation starter to invite male partners to test. However, even 20 years later, this approach has seen low uptake of testing among male partners.
- In the US, there is a similar situation with couples testing: providers are nervous about missing out on testing if pregnant people aren't tested immediately on entry to care, so, if the goal is to do couples testing with both partners tested together at the same time, it may be harder to offer women the chance to come back later with their partner.

- In Namibia, pregnant people are given the option to return with partners later for couples testing, but this approach may delay testing. Motivating "low risk" women to bring in partners for HIV testing remains a challenge, including in the US context with opt-out HIV testing.
- A woman declining to have their partner involved in testing is informative and allows one to take a different approach to care and could be an opportunity to talk about PrEP. A clinic in San Francisco has experience through a pilot linking pregnant people with partners of unknown status automatically to a PrEP coordinator and comprehensive services for partners (e.g. HIV and STI testing, vaccines like Tdap and influenza, and linkage to primary care). This strategy may be hard to implement more broadly across the US but uptake could improve if a systems-level recommendation were issued. Would medical professional societies be more willing to issue a recommendation to assess partner HIV status if it included a broader range of infections (instead of just narrowly focused on HIV)? It is possible in this scenario to also include questions about HCV, HSV, and other STIs.
- Another question providers can ask pregnant people routinely is whether they have new sexual partners. Without data to know which groups of women commonly have new partners during pregnancy, it would be wise to ask everyone rather than make assumptions.
- Could also say to the pregnant person: "It would be really important to know your partner's status"; engage the patient as a proactive participant rather than make it seem like she did something wrong.

Secondary distribution of HIV self-tests for partners:

- The US is not dispensing HIV self-tests to pregnant people for secondary distribution due to concerns of suicide/self-harm or lack of linkage to HIV care among those who test HIV-positive[1, 2,3]. More evidence needed on the risk of harms in this context.
- HIV self-test dispensation within prenatal care is ongoing broadly in East and Southern Africa and seems to be acceptable to patients and their partners.

3. **If the clinician had been aware of the patient's husband's HIV status, she might have been offered PrEP, especially during pregnancy and postpartum.** No discussion.

4. **Would there be circumstances when you would advise that she use PrEP during pregnancy and breastfeeding, regardless of the husband's ART adherence or viral load?**

Considering background HIV prevalence and PrEP eligibility is important in discussing PrEP as an option. Assessing risk in a low prevalence population remains an issue for evaluating PrEP eligibility. How do you

[1] Walensky RP, Paltiel AD. Rapid HIV testing at home: does it solve a problem or create one? *Ann Intern Med*. 2006;145(6):459-462. doi:10.7326/0003-4819-145-6-200609190-00010

[2] Ibitoye, M., Frasca, T., Giguere, R. *et al.* Home Testing Past, Present and Future: Lessons Learned and Implications for HIV Home Tests. *AIDS Behav* **18,** 933–949 (2014). https://doi-org.ucsf.idm.oclc.org/10.1007/s10461-013-0668-9

[3] Qin, Yilu, Tang, Weiming, Nowacki, Amy, et al. Benefits and Potential Harms of Human Immunodeficiency Virus Self-Testing Among Men Who Have Sex With Men in China: An Implementation Perspective. Sex Transm Dis. 2017;44(4):233-238. doi:10.1097/OLQ.0000000000000581.

discuss risk with patients in low prevalence regions/countries such as the US? Universal screening using risk scores would be important. Up until now it's a blanket approach, i.e., Ask all or none.

5. At what point do you consider testing other children in a family for HIV?
We did not discuss this aspect of the case.

Summary of Case 1

- Avoid stigmatizing questions - ask not just about HIV, but frame discussion around overall health and include all relevant infections and conditions.
- Ask pregnant people specifically if they know the HIV status of their partner(s).
- Advocate with organizations that set national guidelines to implement broader screening recommendations in pregnancy.
- In the US, we probably will be seeing increased implementation of self-testing, but more research is needed.
- High vs. low HIV prevalence settings require different considerations.
- Regarding recommendation to modify antenatal checklists, we should consider writing a letter and inviting colleagues to sign on. Put in the context of the Ending the HIV Epidemic Initiative. Would US medical professional societies be willing to issue this recommendation if it included a broader range of infections?

Case 2

19 y.o. G2P1 at 18 weeks' gestation diagnosed with HIV through routine prenatal HIV testing. The father of this pregnancy was also the father of her first child. The patient had negative HIV testing during her first pregnancy and at delivery of her first child 2 years prior. She had breastfed her first child. Once diagnosed during her second pregnancy, she disclosed her HIV status to her partner and asked him to get tested. She discovered that he knew he had HIV, was not in care, and had not disclosed his HIV status to her.

When she came for her first prenatal visit, her own mother and her 2-year-old were present. The toddler's grandmother commented that the child had swollen glands and asked if the child should be tested for HIV. The 2-year-old tested positive for HIV. In retrospect, the mother most likely acquired HIV while breastfeeding and passed the virus on to her infant.

Discussion Questions:

1. How might this young mother have known she was at risk?
In case 1, the patient knew the partner's HIV status, but the patient in this case did not know her partner's HIV status and therefore did not perceive herself being at risk.

As already discussed during the first case, providers routinely asking people who are pregnant or considering pregnancy if they know their partner's HIV status would be a good start. Some clinics in the US engage in this practice routinely but it is not the norm. Partner HIV status assessment is more

common in geographical areas with high HIV prevalence. This practice could become more routine in the US if recommendations came from an authoritative body (e.g. medical professional societies).

2. **How could she have known her partner's HIV status? Would she have considered PrEP if it had been offered to her during pregnancy and postpartum?**

See earlier discussion re: maternal HIV testing and partner HIV status assessment. This is also context-specific since implementation of assessing infection risk could be related to background HIV prevalence.

3. **What about TAF/FTC (Descovy) as PrEP in pregnancy and breastfeeding?**

Data on TAF/FTC (Descovy®) in pregnancy and breastfeeding:

- Preliminary data on TAF/FTC (Descovy®) use for HIV treatment during pregnancy are accruing and could inform safety discussions for TAF/FTC (Descovy®) use as PrEP during pregnancy. However, current data were perceived as insufficient – there are little to no data in pregnant or breastfeeding women overall; some data are available from women with HIV taking TAF/FTC for treatment.
- Discussants expressed concerns with dilution effect in pregnant women: there may be lower systemic drug levels in pregnancy with TDF/FTC (Truvada®)[4] – we don't yet know about TAF/FTC (Descovy®). At the *Women and HIV* meeting prior to CROI 2020, there was discussion about getting women involved in clinical trials before drugs are released. The implication is not that TDF/FTC cannot be used, it is that there may be a greater need for adherence during pregnancy.

Pill size and impact on PrEP adherence:

- Concerns were raised about pill size in both US clinical contexts and in qualitative research in Kenya.
- May be a matter of reassurance and support; doesn't seem to be a major problem in some participants' experience.
- Other participants indicated they routinely see patients that have trouble swallowing large pills.
- Has been explicitly brought up by women in research in Kenya.
- Participants in research in Kenya had questions about injectable formulations or smaller pills and how it would help with PrEP persistence.

Legal concerns:

- Some clients were concerned about Truvada® after lawsuits; this was an infrequently experienced concern among clinicians.

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[4] Pyra M, Anderson PL, Mugwanya KK, et al. Concentrations of TFV-DP during pregnancy among women using PrEP. Abstract 809. Presented at: Conference on Retroviruses and Opportunistic Infections. 2018. Boston, Massachusetts. Available at: http://www.croiconference.org/sessions/concentrations-tfv-dp-during-pregnancy-among-women-using-prep.

There is a role for more advocacy for including pregnant people in clinical trials and early studies of new PrEP agents, including novel preparations (injectable formulations, etc.).

4. Event-based dosing vs daily PrEP:

Who benefits from event-based dosing*?

- There can be confusion about whether event-based dosing/intermittent dosing works for people with vaginas. Some providers have taken to calling it "2-1-1 for anal sex" to be clear about who will benefit from non-daily dosing. However, people looking for information online may not find clear answers about whether it's a good strategy for them.
- Women have been asking about event-based dosing in Kenyan studies, especially in transition from pregnancy through the postpartum period, along with long breaks in sexual activity. The messaging around restarting PrEP is a challenge. If a woman is not sexually active, does she need to take PrEP daily? Would alternative dosing be possible? Continued assessment about when to continue or discontinue is both essential and challenging.
- Personal risk factors and behaviors often change over time. There are times when a woman might not be sexually active, e.g. postpartum, and might not want to remain on PrEP continuously but would like the option to return to PrEP.

* Event-based dosing of PrEP, or PrEP 2-1-1, involves taking Truvada® (tenofovir disoproxil fumarate /emtricitabine) around times that sex is anticipated rather than once a day. Dosing is two pills (a double dose) taken 2 to 24 hours before sex is anticipated, and then, if sex occurs, one pill 24 hours after the first dose, and another pill 24 hours later. If sex occurs multiple days in a row, one pill should be taken each day, until 48 hours after the last event.

Summary of Case 2

- Ask pregnant people specifically if they know the HIV status of their partner(s).
- Current data on TAF/FTC (Descovy®) are insufficient to recommend as PrEP alternative during pregnancy.
- Advocate for women and pregnant people to be included in clinical trials.
- Pill size can impact PrEP adherence, especially for pregnant people.
- There is interest in, but not enough information on, who can use event-based dosing or "2-1-1" dosing/intermittent dosing effectively.
- Personal risk is fluid and can change over time. Use of/desire for PrEP may also change over time, e.g. postpartum.

Next steps

- We will send a summary of the discussion to attendees.
- The Perinatal HIV Hotline will reach out to US medical professional societies re: recommending partner HIV assessment as part of routine prenatal care. If additional advocacy/support is desired or needed, will circulate request on ReproID Listserv.

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Discussion notes are distributed via the ReproID HIV listserv. The ReproID HIV Listserv is a dynamic forum for clinicians and other healthcare professionals who specialize in reproductive infectious diseases. Participants use the forum to discuss clinical cases, share clinical approaches and protocols, network with colleagues, and arrange patient referrals. For more information, or to join the listserv, please contact marliese.warren@ucsf.edu.

As always, we are stronger together and there are many people who contribute to the success of our annual Perinatal HIV Roundtable. We want to offer our gratitude to:

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