Facilitators and Barriers to Accessing Reproductive Health Information Among Women and Men Affected by HIV

A Qualitative Perspective

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Introduction

• Annually 50,000 women and men are infected with HIV in the U.S. (1.2 million). Women account for 26% of reported cases and the majority of them are of childbearing age.

• More and more individuals living with HIV/AIDS report intention to become parents at some point in their lives.

• In 2006, 8,700 infants were born in the U.S. to women infected with HIV, an increase from 6,000 live births reported in 2000 to women with HIV.

• MTCT greatly reduced in the U.S. but disparities persist. African-American children had the highest rate of transmission (9.9/100,000) as compared to Latino (1.7/100,000) and White (0.1/100,000).
It has been estimated only 45% of women with HIV are engaged in care and that only 32% have an undetectable viral load. This underutilization of health care services contributes to missed opportunities to provide reproductive health information and treatment.

Reproductive health care is largely targeted at women and is bundled with contraception services.

Little is known about the reproductive healthcare needs of women and men affected by HIV.
Purpose

• To examine and explore factors which facilitate accessing reproductive health information and treatment (RHI/T) for women and men living with HIV and the barriers that exist when attempting to access reproductive health information and treatment.
This qualitative grounded theory study utilized face to face interviews with 8 men and 6 women ages 26-44 who identified as wanting to have biological children, had been diagnosed with HIV, and/or had a partner living with HIV.

The study took place in the U.S. over 8 months in 2014-2015. Interviews were audio recorded and transcribed verbatim by the PI.

Charmaz’s constructivist perspective of Grounded Theory was used as the framework for data analysis and interpretation.
Facilitators

- Supportive HCPs that ask about reproductive intention and are supportive of having children.
- Social support groups that support having children and provide factual information about achieving a pregnancy after diagnosis.
- HCPs that answer questions about how to have a healthy baby.
- Web sites that provide factual up to date information.
- Families that provide nonjudgmental support for the desire to have children.
Barriers

- Not being asked about reproductive intention by HCPs.
- Perceived inability to disclose to HCPs about wanting children.
- Assumptions about reproductive intention related to sexual identity. Gay men and lesbian women are often not asked about reproductive intention by HCPs.
- Men are not asked about reproductive intention by HCPs.
Barriers

• Focus is still on safe sex practice.
• Information is often not provided about PrEP for a non-infected partner.
• Not being treated as part of a couple that desires children.
• Older women (over 35) are not considered as fertile by healthcare providers and therefore not desirous of having children.
The Message Behind Safe Sex Messages

- Safe sex (consistent condom use) has drastically reduced transmission of HIV to uninfected partner(s).
- An all or nothing message that allows little room for discussions about healthy conception.
- “I felt like I had to hide the fact that I wasn’t using condoms... we’re trying to have a baby so we aren’t going to use condoms but I hid it from my doctor. I did feel dishonest but I told her why eventually.”
“He (HCP) was very concerned telling us we have to be very cautious. We told HIM that there are medications to take to ensure a healthy baby...he said that’s true but you should be cautious. He said give it a shot but he was 50-50. I felt I wasn’t getting a direct answer. I am really concerned about having a healthy baby and he wasn’t going there with us. I want a baby without the virus.
Inclusion of Men

- Every male that participated in this study reported that he had *never* had a HCP inquire about reproductive intention.
- No male participant had children and all wanted them.
- The male participants believed it was the role of the HCP to address the topic; that they as the patient should receive information.
Inclusion of Men

• It was too stressful to bring the topic up as they were concerned about being dismissed especially if they had admitted to being bisexual or MSM.

• “I’ve been going to the same doctor for 7 years and he never asked me about having kids.”

• “I had to bring it up and he told me to go to my girlfriend’s doctor.”
Community groups hold classes on staying healthy. Health educators come in, give talks and answer questions.

Web sites are good but I need a way to know that what they’re saying is factual.

There’s not a lot out there on having kids for us.
Findings suggest that barriers to accessing reproductive health care exist at many levels. Health care providers may not be asking patients with HIV about reproductive intention, care is often shared amongst many providers including HIV specialists, Ob/Gyn providers, primary care providers and each may assume that another provider is providing reproductive health care. There are missed opportunities for sharing information due to brief appointment times that are focused on managing HIV only.
Conclusions

- Patients may inadvertently contribute by having an expectation that the HCP will broach the subject. They may also have sensed a negative attitude about wanting children so they are reluctant to initiate the conversation.
- Facilitators can be in the form of support groups that often have HCP or health educators share information in a group setting, the ability to access information using the internet and relationships with HCPs.
Nursing and interprofessional interventions to improve the accessibility of reproductive health information are increasingly important. These interventions may be in the form of asking patients to develop a reproductive life plan (RLP) and to use that plan as the starting point for discussing reproductive intention. Annual screening about reproductive intention for women and men. HIV support groups are an additional source of information.
Recommendations

• Education targeted to both patients and HCPs about methods for safe conception: PrEP, discussions of when/how to conceive.

• Achieving an undetectable viral load and timing of conception to reduce transmission risk to an uninfected partner.

• IUI with sperm washing (if available).
References

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Questions, Comments

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