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Characterizing Healthcare Professionals Practices, Facilitators, and Barriers in Delivering Preconception Counseling: Perceived Impact on Prevention and Improvement of Outcomes for Birthing People Living with HIV

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An abstract of

A thesis submitted to the Faculty of the

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Abstract

Background: Integrating preconception counseling (PCC) into HIV care is crucial for improving reproductive health outcomes for birthing people living with HIV. Despite its importance, there are various challenges in effectively delivering PCC in this context.

Goal: This project aims to explore how healthcare providers approach and deliver PCC, the barriers and facilitators faced in incorporating PCC into HIV care, and the impact of its integration on reproductive outcomes.

Methods: Seven healthcare professionals participated in in-depth interviews, which were transcribed and coded using a pre-developed codebook in MAXQDA. The data was analyzed to identify themes related to current PCC practices, perceived barriers and facilitators, and its impact on outcomes for birthing people living with HIV.

Results: Providers frequently discussed PCC, integrating these discussions into routine visits and emphasized ongoing conversations about fertility desires. Interdisciplinary and multidisciplinary collaboration between specialties was noted as beneficial. However, time constraints, lack of resources, and institutional and systemic barriers were significant obstacles. Patient-related barriers, cultural beliefs and socioeconomic factors also hindered effective PCC delivery into HIV care. Providers highlighted that PCC integration empowers patients and improves health planning, leading to better reproductive outcomes for birthing people living with HIV.

Conclusions: Systematic integration of PCC into HIV care is essential for enhancing reproductive health outcomes for birthing people living with HIV. Addressing barriers through policy changes, increased training, and resource allocation can significantly improve PCC delivery and empower birthing people living with HIV in their reproductive health decisions.

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Table of Contents

Chapter I: Introduction

Introduction and Rationale

The HIV/AIDS epidemic is a global public health problem causing illness and deaths, afflicting 39 million persons in 2022 (HIV.gov, 2023). In the United States, an estimated 1.2 million people are living with HIV, and there were 32,100 new cases in 2021 (HIV.gov, 2023). Several minority populations are disproportionately burdened by this disease. More specifically, minority groups that are excessively impacted include racial and ethnic groups, such as Black and Latino communities, Black, indigenous, and women of color, men who have sex with men (MSM), and young people (KFF, 2021). While there was an overall 12% decline in HIV diagnoses from 2017 through 2021, there is an uneven distribution of people with HIV across the country. For example, the South is the region with the highest rates of new diagnoses (HIV.gov, 2023). Fifty-one percent of women aged 25-44 accounted for HIV diagnoses among women in 2018, where eighty-five percent of these women reported that heterosexual sex was the mode of transmission (KFF, 2020).

Compared with other modes of HIV transmission, teens and young adults are mostly at high risk of sexual transmission, and those under age 35 accounted for 57% of new diagnoses in 2019 (KFF, 2021). These facts suggest that HIV is significantly impacting young people, and heterosexual sex is the primary mode of transmission for women. Therefore, it is essential to target this demographic group to empower individuals with the awareness and knowledge of practices that promote prevention, early HIV detection and optimal use of life-saving antiretroviral therapy (ART), and to address reproductive health needs aimed at reducing the risk of mother-to child HIV transmission (Matthews et al., 2018).

Policy and laws affect HIV prevention and treatment in the United States and promote HIV infection, especially in the South. For example, healthcare access for low-income individuals is limited due to Medicaid eligibility, particularly in states like Louisiana and Alabama (Adimora et al., 2014). At present, there are political efforts to weaken the Affordable Care Act, limit the protections for LGBTQ+ people, and policies that restrict access to sexual and reproductive health services. Actions that restrict access to these services include efforts to undermine organizations such as Planned Parenthood, which has implemented efforts to address the HIV epidemic in the United States (The Lancet HIV, 2019). Additionally, southern states often do not have adequate sex education and outdated laws that hinder the implementation of effective and successful prevention efforts (Adimora et al., 2014). The AIDS Drug Assistance Program also has issues with states that contribute less than the national average to nothing while cutting benefits and capping enrollment that continue to limit access. Furthermore, laws surrounding syringe exchange programs further hurt prevention efforts (Adimora et al., 2014).

Mother-to-child transmission (MTCT) of HIV can occur during pregnancy, childbirth, and breastfeeding (CDC, 2023). In the instance a mother is not virally suppressed or not taking ART, MTCT ranges from 15% to 45% during pregnancy, childbirth, or breastfeeding (World Health Organization, n.d.). HIV can be transmitted to the fetus during pregnancy as the virus can pass through the placenta. Transmission can also occur during labor and delivery if the baby is exposed to HIV in the blood and other bodily fluids of a mother living with HIV (The American College of Obstetricians and Gynecologists, 2023). Though consistent and correct use of current antiretroviral therapies has shown to decrease transmissibility of HIV as undetectable equals untransmittable (U=U), this is not the case for breastfeeding. The risk of HIV transmission for

women living with HIV who are on ART with an undetectable load is very low but not zero (HIV.gov, 2023).

Interventions to prevent mother-to-child transmission have successfully decreased the occurrence of perinatal HIV. There has been a 41% decrease in perinatal diagnoses due to MTCT from 2015 to 2019, as there were 143 cases in 2015 and 84 in 2019 (CDC, 2022). To avoid MTCT, taking ART therapy as prescribed has been shown to reduce the viral load to an undetectable level and keep it suppressed to reduce the risk to less than 1% (CDC, 2023). In addition, consistently giving the newborn baby HIV medications for 2 to 6 weeks after birth will also contribute to reducing the risk (CDC, 2023). For people who do not have a suppressed viral load, a scheduled cesarean delivery before labor and rupture of membranes can reduce the risk of transmission (The American College of Obstetricians and Gynecologists, 2018). Since breastfeeding also poses a risk for transmission of HIV, baby formula or pasteurized donor human milk are other options that eliminate the risk. Furthermore, food should not be pre-chewed by anyone who is living with HIV (CDC, 2023). The combination of all of these interventions protects a potential baby by reducing the risk of MTCT leading to perinatal HIV.

There have been challenges and barriers to preventing MTCT. Some of these challenges include lack of awareness of HIV infection status in pregnant people, or lack of early awareness of pregnancy in people ith HIV. Others who know that they are living with HIV may be unsure of how to prevent and safely plan a pregnancy or are unaware of interventions that prevent perinatal transmission (CDC, 2022). Though consistent HIV treatment can offer protection to the fetus, nausea and vomiting associated with pregnancy can result in malabsorption of ARTs and interfere with successful treatment. Another challenge faced by people with HIV, especially

accentuated by disruptions associated with COVID-19 pandemic, is the inability to consistently see their HIV care provider (CDC, 2022).

Moreover, stigma and discrimination are permeating issues that lead to challenges and may inadvertently promote MTCT. Stigma surrounding HIV testing impacts MTCT if women decline testing during pregnancy out of fear of being stigmatized by healthcare providers. Others may believe the stereotypes of what type of woman needs to be tested for HIV (Arora & Wilkinson, 2017). Women who are living with HIV may avoid initial access or adhere to medical care due to their healthcare providers enacting stigma towards them, as one woman noted in a study that she dealt with "dehumanizing interactions" from her provider (Arora & Wilkinson, 2017). Addressing such challenges is crucial and requires innovative strategies to expand access that is impacted by systemic barriers.

There are disparities in rates of mother-to-child transmission as HIV disproportionately impacts certain racial and ethnic groups. The majority of new HIV infections, the most significant prevalence, and the highest rates of HIV-related deaths observed among women living with HIV in the U.S. are Black women, making them disproportionately impacted by HIV (KFF, 2020). Though Black women only make up 13% of the female population in the country, they account for 58% of HIV diagnoses among women, the rate of new cases was 15 times higher than white women, and dying of an HIV-related illness is the seventh leading cause of death for this group aged 25-44 (KFF, 2020). The disproportionate impact of HIV in these racial and ethnic groups is compounded by limited access to care and the ability to successfully provide perinatal HIV diagnoses. Among all people with perinatal HIV, 63% are Black, and 22% Hispanic (Gutin, 2015). Though there have been practical medical and technological advances

and many interventions that reduced the rate of MTCT, a gap still exists that inequitably affects marginalized communities that hinders their access to successful treatment.

Social and economic factors are additional challenges to preventing MTCT. For example, poverty is a contributing factor that impacts healthcare access in people living with HIV and prevents them from consistent treatment. Accessing healthcare and staying on treatment is also a challenge for pregnant people who inject drugs or use other substances, are uninsured, mentally ill, incarcerated, or experiencing homelessness (CDC, 2022). In addition to poverty, other structural factors, including lack of employment opportunities, inability to access healthcare, and limited transportation infrastructure, contribute to the level of healthcare engagement for women living with HIV (American Psychological Association, 2022).

There exist several interventions and strategies to address disparities in mother-to-child HIV transmission. As there are pregnant people who are unaware of their HIV status and may be living with HIV, it is recommended that there is an opt-out approach used for testing instead of opt-in. This means that HIV testing will be included for all pregnant people as part of their standard healthcare encounters unless they decline (CDC, 2021). Using this approach increases testing rates, increases the number of pregnant women who are made aware of their HIV status, increases the number of people who are being successfully treated, and reduces MTCT (CDC, 2021). CDC has been heavily invested in tailoring interventions for HIV prevention for pregnant people through state programs, local health departments, and community-based organizations, which includes the Ending the HIV Epidemic in the U.S. initiative. Furthermore, CDC has been working to enhance the HIV prevention workforce and include communication resources for providers and patients (CDC, 2022).

Preconception counseling (PCC) is crucial in optimizing reproductive health and outcomes for people of reproductive age (Simone et al., 2018). While the importance has been recognized, a serious gap exists between the current state and the optimal standards for PCC that are both accessible and comprehensive. The gap is exacerbated for those living with HIV as they experience unique challenges in reproductive health and family planning (Steiner et al., 2013). Despite its importance and its awareness, preconception counseling continues to be underutilized. Underutilization of PCC, health promotion, and risk reduction are missed opportunities that lead to economic costs and health disparities and inhibit empowerment through making informed decisions regarding family planning (Khekade et al., 2023). This proposed research project is significant as it will have the potential to inform improvements in the reproductive health outcomes of people living with HIV while also contributing to discussions on inclusivity and patient-centered care in the United States healthcare sector.

Overview of PCC in HIV care

What is PCC?

Preconception counseling (PCC) is a form of health education and promotion that encompasses assessing risks, implementing interventions for those risks, and optimizing health outcomes before conception to decrease adverse maternal and fetal outcomes (Fowler et al., 2023). During PCC, patients are educated on how their current health issues will impact a pregnancy and how their modifiable health risks can be addressed (Callegari et al., 2015). PCC is carried out with nonpregnant individuals and couples who have reproductive potential to discuss healthy habits (Fowler et al., 2023).

The main goal is to treat or stabilize conditions and improve health through ongoing and tailored interventions and care of those looking to start a family throughout their reproductive

life (HIV.gov, 2023). PCC requires an interdisciplinary approach with consistent documentation in the patient's healthcare records to enhance their healthcare and reduce the chances of perinatal morbidity and mortality. Some concerns and topics that are explored are pregnancy planning and spacing, chronic disease and medication review, genetic disorders and carrier status, immunity and immunizations, sexually transmitted infections (STIs) and cervical cancer screening, nutrition and supplements, weight, exercise, substance use, and toxin and environmental exposures (Fowler et al., 2023).

Significance of PCC

Maternal mortality rates in the developed world are one of the highest in the United States with chronic health issues contributing to the growing incidence of maternal deaths. Additionally, the U.S. ranks low compared to similar countries in infant mortalities due to preterm birth and birth defects (Callegari et al., 2015). In the United States, about 700 people die from complications related to pregnancy annually where among documented instances of maternal mortality, 31.3% occur during pregnancy, 16.9% occur the day of delivery, and 51.7% occur after postpartum. Data pulled from 13 state maternal mortality review committees from 2013-2017 revealed that over 60% of these deaths were preventable. Pregnancy related deaths have increased in the United States though the rate has decreased around the globe (AAFP, 2020). Additionally, racial and ethnic disparities are disproportionate related to maternal, fetus, and infant mortality and morbidity where mortality statistics are highest in Black fetus and infants (AAFP, 2022).

PCC is used to identify health risks and modify them to improve maternal and infant outcomes before pregnancy and also reduce unplanned pregnancies (Simone et al., 2018). Since there are a number of physiological processes that are crucial before conception for an embryo's

development that occur before a woman is aware that she is pregnant, intervention is crucial before conception for health promotion and mitigating risks (Khekade et al., 2023). It has been found that pregnancy outcomes are improved and the offspring has a longer term health status when adverse health behaviors are addressed before pregnancy (Steel et al., 2016).

Context of PCC in HIV care and reproductive health

For people living with HIV, preconception counseling goals are to encourage pregnancy planning, decrease the number of unintended pregnancies, enhance health prior to pregnancy, reduce adverse outcomes, and ensure transmission prevention for partners and children (Hoyt et al., 2012). Women who are living with HIV need comprehensive care that is specialized to address their unique needs (Hoyt et al., 2012). Comprehensive care should address minimizing risks of mother-to-child HIV transmission and transmission of HIV to partners and emphasize safer conception recommendations to include suppressing viral levels before and during pregnancy and at the time of delivery to prevent HIV transmission (Simone et al., 2018).

For people living with HIV who also have reproductive potential, interventions provided through PCC support the reproductive goals of those living with HIV while also reducing the incidence of HIV (Matthews et al., 2018). Of all women living with HIV, 70% are sexually active and in 2010, about 26,700 individuals who were in their reproductive years had acquired HIV (Raley, 2014). A study of 745 women living with HIV found that 61% were sexually active where 61% of these women were of reproductive age (Dionne-Odom et al., 2018). Additionally, about 8,500 women out of 230,360 women diagnosed with HIV give birth in the United States (Sutton et al., 2018). According to data, a large percentage of pregnancies in both women living and not living with HIV have unplanned and unintended pregnancies (Simone et al., 2018). Among pregnant women living with HIV in the United States who had been surveyed, 68%

expressed that they either inconsistently used or did not use any contraception in the month that they conceived (Jones et al., 2016). Women who are living with HIV have various medical and psychosocial issues, some associated with HIV, which could increase the likelihood of perinatal and sexual transmission of HIV and other adverse pregnancy outcomes (Boelig et al., 2015). For people living with HIV, preconception care has the goal of decreasing the risk of both vertical and horizontal HIV transmission (Simone et al., 2018). The risk of fetal loss, preterm delivery, low birth weight and birth defects are also reduced during preconception counseling for people living with HIV (Jones et al., 2016).

A published report indicates that women who have experienced unplanned pregnancies are less likely to use contraception, and another 49% report getting pregnant without clinical consultation (Jones et al., 2016). Current recommendations are informed by data that demonstrate that safer conception and prevention of perinatal HIV transmission are attained by suppressing viral load to undetectable levels before conception and throughout the pregnancy (Simone et al., 2018).

PCC Approaches and Labor & Delivery

Current approaches of PCC used by healthcare providers

Healthcare providers are crucial for people who are living with HIV that also have reproductive potential to aid in informed reproductive decisions and promote health before pregnancy (HIV.gov, 2024). Current guidelines recommend that providers maintain ongoing discussions with patients living with HIV about their reproductive desires and plans. While taking into account potential drug interactions, contraceptive counseling should also be provided to patients to offer all available methods or refer to services. The importance of viral suppression before conception to prevent perinatal transmission by adhering to antiretroviral therapy should

be emphasized in addition to educating patients on safer sex practices and various interventions for substance use disorders (HIV.gov, 2024). Throughout pregnancy and postpartum, infant feeding options should be reviewed through patient-centered, evidence-based counseling. Effectiveness, changes in pharmacokinetics, hepatitis B status, and potential adverse outcomes for both the pregnant person and fetus should all be considered when selecting ART regimens (HIV.gov, 2024).

In a provider survey, only 26% reported that they offered PCC. Though 39-57% of women in the reproductive-age group reported that they intended to get pregnant, more than 30% of these women reported that they did not have any conversations with their provider about getting pregnant in 2009 (Gokhale et al., 2017). Using the 2013-2014 Medical Monitoring Project (MMP), 49% of HIV care providers provided comprehensive reproductive health counseling to their female patients who are living with HIV. It was also found that it was 48% more likely that primary care providers would provide reproductive health counseling compared to others (Gokhale et al., 2017). In another study, 98% of women acknowledged that it is crucial to have optimal health before pregnancy and the benefits of receiving health information, but almost four in ten of these women stated that they did not receive preconception counseling from their providers. Only 14% of people were receiving preconception care during their visits to providers in another study (AAFP, 2020).

STI screening assessment should also occur during PCC appointments which should include gonorrhea, chlamydia, syphilis, and HIV (ACOG, 2019). While women living with HIV have a similar prevalence of chlamydia and gonorrhea compared to women who are not living with HIV, the majority are exposed sexually and tend to have a history of other STIs. These STIs can lead to pelvic inflammatory disease (PID) which causes tubal damage and leads to infertility

and research has shown that PID may be more severe in women living with HIV (Hoyt et al., 2012). It is also crucial to be routinely tested for hepatitis B and HCV in addition to other STIs. Screening for these sexually transmitted diseases reduces risks of adverse pregnancy outcomes and neonatal infections while also preventing transmission to sexual partners to reduce transmission within communities (Workowski & Bolan, 2015). Those who are at high risk of infection are identified and targeted to linkage of care and prevention efforts (Workowski & Bolan, 2015).

Birthing people living with HIV should be counseled on the importance of ART with emphasis on suppressing their viral load to an undetectable level before pregnancy (ACOG, 2019). ART will contribute to optimizing the health of the person living with HIV while also reducing transmission to both their partner and infant during pregnancy (Matthews et al., 2018). One randomized control trial, HPTN 052, showed adherence to ART to be beneficial in reducing the risk of transmission as it decreased the risk of HIV transmission to partners by 96% (Workowski & Bolan, 2015). The PARTNER study demonstrated that with a lower viral load compared to HPTN 052, there were no cases of transmission after a follow up of about 1.3 years and about 58,000 unprotected sexual acts (HIV.gov, 2024).

Strategies of engaging those with reproductive potential living with HIV in PCC

Preconception counseling for people living with HIV should be tailored to maximize long-term health, minimize risk of perinatal transmission, and consider the possibility of effects on the fetus due to antiretroviral treatments. To reduce the risk of HIV transmission to the partner, administering pre-exposure prophylaxis (PrEP) and considering artificial insemination are the safest ways to procreate (ACOG, 2019). Transitioning to a transmasculine individual or being gender diverse does not deter them from desiring biologically related children. Therefore,

gender diverse people may have special needs where their providers need to discuss pregnancy intentions and health just like cisgender individuals (ACOG, 2021). Preconception counseling can also be tailored to those who are dealing with infertility issues. Screening for infertility can help identify those who may need support in improving their fertility before attempting pregnancy. This would benefit couples as infertility issues would increase the risk of HIV exposure with minimal chances of pregnancy (Matthews et al., 2018).

There exists notable gaps in women's knowledge of HIV despite its substantial impact on their population. Health literacy relies on basic literacy skills such as reading and interpreting information to comprehend health-related material, apply that information to health decisions, and understand current developments and public health issues. Since customs and beliefs influence people's ability to understand and respond to health information, this is also important in health literacy (Thompson et al., 2015). Culture, ethnicity, and language are also important when delivering PCC as 59% of women in the Women Living Positive study expressed that these factors had an effect on the care they received. This was reported more by Black and Hispanic women and women living in the south (Squires et al., 2011). Providers must choose PCC strategies that align with the needs, preferences, and cultural backgrounds of the individual or couple. While aligning PCC to patients, evidence-based interventions should be implemented and tailored to meet their health needs and collaborate with other healthcare professionals to ensure both comprehensive and coordinated care (Fowler et al., 2023).

Some current preconception care models are those that require coordination of services or deliberate organization of patient care activities and information sharing with other team members and providers through referrals (Simone et al., 2018). Comprehensive HIV care and linkage and referral are two models that can be used to implement preconception counseling in

HIV care. PCC can be incorporated where HIV providers and physicians with specialty in obstetrics and gynecology (OBGYNs) work together in large medical facilities where other specialists are located, or by linkage to care through referrals for clinics where comprehensive services are unavailable (Steiner et al., 2013). A third model has also been suggested where individual HIV care providers or teams use referrals to complement their clinic-based services (Simone et al., 2018).

Shifting the language to one that embraces sexual wellness instead of focusing on absence of disease, condom use, or adherence to ART, would reflect a holistic approach to sexual HIV transmission. Instead of focusing on the science of eliminating sexual HIV transmission, this strategy acknowledges reproductive and sexual desires to promote sexual satisfaction as worthy objectives to nurture sexual wellbeing, engaging with patients, and being able to fulfill sexual experiences (Weber & Grant, 2015). Respect, compassion, and nonjudgmental attitudes are effective interviewing and counseling skills that are crucial to obtain comprehensive sexual history. Successful strategies include using open ended questions, nonjudgmental language that is understandable, and normalizing language (Workowski & Bolan, 2015).

Women's desires to have children are influenced by interpersonal and social factors that include gender expectations and desires of family members and partners for women to have a child. It is also suggested that guidance from a healthcare provider has less influence on desires in comparison to their partner's desires (Jones et al., 2016). Overall, the results of Jones' study indicated that women's reproductive desires were highly influenced by both partners and providers compared to other factors (Jones et al., 2016). Researchers also found that the role of being a mother had a positive impact on self-realization, self-esteem, and healthy life-sustaining behaviors on women who are living with HIV

Both men and women living with HIV show high fertility desires and intentions (Simone et al., 2018). Research suggests that 70% of women living with HIV are sexually active while 25-30% desire to have children (Raley, 2014). One study showed that 55% of women living with HIV in the United States expressed a desire to have children and 42% of those women intended to become pregnant (Raley, 2014). In the United States, pregnant women living with HIV were surveyed where results showed that half of the couples had a desire to become pregnant and 36% of couples agreed on a past pregnancy after discussion (Jones et al., 2016). In Jones' study that focused on fertility desires of women living with HIV, 73% of the participants already had children and 82% desired to have even more children, and 48% were actively trying to become pregnant. While all women in the study were living with HIV, 46% of their partners were also living with HIV (Jones et al., 2016).

A framework that is based on reproductive rights acknowledges that everyone, including people living with HIV, have the right to "decide freely and responsibly the number, spacing, and timing of their children and to have access to the information, education, and means to do so" that is "free of discrimination, coercion, and violence" (Matthews et al., 2018). Since the preconception period is a crucial time period to improve both maternal and fetal health outcomes, PCC acknowledges the health status of both parents to impact the health of the fetus (Khekade et al., 2023). Preconception counseling emphasizes health promotion and education by informing and guiding people on their lifestyle choices to adopt healthier behaviors while also screening for pre-existing medical conditions. These individuals are empowered to make informed decisions during their pregnancy to support their health, minimize risks, and have a healthier pregnancy (Khekade et al., 2023). Since PCC addresses health risks and problems and

bridges the gap in the continuum of care, it reduces the risk of global maternal and child mortality and morbidity (Dean et al., 2014).

Preconception counseling emphasizes healthcare engagement as physicians identify the childbearing goals and reproductive plan of the patient at every visit (AAFP, 2022). Endorsing and supporting the reproductive and sexual rights of people living with HIV within guidelines, policies, and programs that are focused on safer conception builds trust between healthcare providers and people living with HIV. This is crucial as there is a history of violations towards sexual and reproductive rights for people living with HIV (Matthews et al., 2018). Some implications include ensuring that women living with HIV have the right ro care and support, access to comprehensive care that is compassionate and supportful in financial, psychological, institutional, legal, and physical areas, discussions and ongoing education to clarify sexuality and fertility, and packages of sexual and reproductive health services. This helps with self awareness and the ability for people living with HIV to trust their own decisions (Salamander Trust, 2014).

Since health equity is such a struggle in maternal health though it is essential for the long term health of parents and their offspring, telehealth is able to bridge the gaps. Offering telehealth can remove barriers to care for those who lack transportation or live in rural areas, have accessibility to sub-specialists that are located far, or a larger choice of providers for patients of color to choose from (U.S. Department of Health and Human Services, 2023). Evidence is growing that technology-based interventions can be effective, especially for adolescents in the context of sexual and reproductive health as this age group consistently use technology (Bickmore et al., 2020). A conversational agent was designed to be able to simulate PCC to women by assessing risks, providing tailored advice, elaborates on the risks, and provides suggestions on how to address those risks. Using the conversational agent demonstrated

an increase of participants taking action or maintaining risks during PCC compared to the control group (Jack et al., 2020).

Collaboration between HIV care and reproductive health care can help with meeting the reproductive needs of women living with HIV since they are already connected through the healthcare system. The approaches HIV care providers may take to reproductive health may not meet all of the needs for their patients. Different areas can include screening for cervical cancer, interpartner violence, sexual dysfunctions, pre and interconception planning, and testing for STIs (Tanner et al., 2018). This collaboration is also crucial during the healthcare transition process from pediatric and adolescent care to adult HIV care as research displays challenges in transitioning and only 50% of youth who transitioned remained in adult care after 12 months. Successful transmission is important as it would help with maintaining a low viral load due to adhering to ART and reducing MTCT (Tanner et al., 2018).

Research has shown that HIV care primarily focuses on pregnancy prevention when focusing on reproductive health. This approach has major consequences for patients utilizing PCC and prenatal care and can increase the risk of MTCT (Tanner et al., 2018). Integrating reproductive health care into HIV care can offer comprehensive care to women living with HIV which can enhance care engagement, health outcomes, birth outcomes, and reduce unintended pregnancies as this population has diverse pregnancy desires (Tanner et al., 2018).

Role of PCC in improving reproductive health outcomes for people living with HIV

Contribution in improving health and minimizing disparities

Since PCC educates and guides people on maintaining healthy life choices such as avoiding harmful substances and managing stress while also screening for pre-existing medical

conditions such as hypertension and diabetes to manage issues and optimize health, potential risks are minimized as these conditions are addressed early (Khekade et al., 2023). Risk factors are identified before the person gets pregnant and working to treat or stabilize conditions to optimize outcomes and address the needs of people throughout the various stages of reproductive life (HIV.gov, 2024). There is active participation with individual management plans facilitated by discussion on diet, weight, exercise, smoking, use of alcohol and drugs, environmental risks, and their vaccination status. These discussions and individualized management plans create opportunities to optimize maternal and infant outcomes (New York Department of Health, 2018).

Most general recommendations are the same for PCC in people who are and are not living with HIV although management of HIV before and during pregnancy has many special considerations. Counseling still includes maintaining a healthy lifestyle and diet while also being encouraged to cease use of smoking, recreational drugs, and alcohol (Loutfy et al., 2012). About 40% of people living with HIV are smokers, half drink alcohol, and studies indicate that there is a problem with alcohol abuse. Alcohol abuse is important to address and as it is linked to disease progression and reduction of adherence to ART (Hoyt et al., 2012). Studies have also shown that there are women who have acquired HIV through drug use which is associated with risky behaviors and can lead to transmitting HIV and getting other STIs (Hoyt et al., 2012). People struggling with these addictions can be referred if support is needed during PCC appointments to optimize outcomes. PCC also offers testing for the risk of genetic diseases and integrates prenatal screening. Furthermore, prospective parents should receive STI tests regardless of symptoms (Loutfy et al., 2012).

Impact on maternal and child health outcomes

Preconception counseling helps prevent adverse pregnancy outcomes from underlying chronic issues including diabetes, thyroid disease, hypertension, and mental disorders. Screening and tailoring interventions that prevent and manage chronic diseases decrease the risks of issues such as birth and neonatal complications, miscarriages, preeclampsia, low birth-weight, and postpartum psychiatric illness (Lassi et al., 2014). Addressing maternal diabetes before pregnancy, during PCC, decreased perinatal mortality by 69% and congenital malformations by 70% (Lassi et al., 2014). Since the year 2000, pregnancy in women living with HIV has increased by 30% and 85% have reported that they have had at least one unplanned pregnancy. Adherence to antiretroviral therapy reduces the risk of mother-to-child HIV transmission to under 1% demonstrating that access to timely and appropriate reproductive health counseling and services is important (Gokhale et al., 2017).

Preconception counseling recognizes that the health and development of a future child begins before conception. Since this period assesses both parents' health status before conception, PCC optimizes fetal development because the parents' health status influences the wellbeing of the fetus (Khekade et al., 2023). As 2.4 million babies globally are affected every year by neonatal and birth disorders that increase mortality, long-term disabilities, and healthcare costs, preconception care is crucial in addressing neonatal and birth disorders (Khekade et al., 2023). Since genetic counseling and testing are a part of preconception counseling, couples are able to assess the risks of their child inheriting genetic disorders and explore options to minimize any potential risk (Khekade et al., 2023). In the United States, preterm birth is the leading cause of morbidity and mortality in infants. Respiratory distress syndrome and developmental delay are associated with preterm births (Shapiro-Mendoza, 2016). Access to preconception counseling

achieves higher levels of wellness and modifies risk factors to reduce the risk of preterm births, also reducing the risks of morbidity and mortality associated with preterm births (Shapiro-Mendoza, 2016).

Tobacco, alcohol, and drug abuse are associated with negative pregnancy and fetal outcomes. Smoking leads to low birth weight, miscarriages, preterm birth, and small for gestational age. This risk increases by two-fold for pregnant people living with HIV and smoked during their pregnancy (Hoyt et al., 2012). Those who abuse opiate drugs have complications that include low birth weight, neonatal withdrawal, deficits in neurobehavior, and perinatal mortality where alcohol can lead to stillbirth, fetal alcohol syndrome, and other learning difficulties. Preconception counseling is key to identifying and addressing substance abuse during preconception counseling to decrease risk of adverse pregnancy outcomes (Hoyt et al., 2012).

Effectiveness in optimizing reproductive outcomes among birthing people living with HIV

Ideally, PCC should comprehensively address pre– and post-delivery considerations. It is important for people living with HIV to be provided with infant feeding counseling that is evidence-based and tailored to their needs that also supports informed decision-making before conception (HIV.gov, 2023). Replacement feeding is an intervention that uses formula or pasteurized donor human milk to eliminate perinatal transmission (HIV.gov, 2023). There exists access to expertise in breastfeeding through a lactation consultant or lactation support provider for those who wish to breastfeed regardless of their status (HIV.gov, 2023). There also exists interventions for babies after birth to protect them from perinatal transmission for healthy development. Once born the interventions include detailed physical examination, appropriate

evaluation for the possibility of other infectious diseases, routine primary vaccinations, monitored for toxicity related to ART while in utero, and starting ART treatments as soon as possible (HIV.gov, 2024).

The benefits of ART extends past only protecting birthing women and their babies because PCC offers several strategies for couples to conceive with the reduced risk of horizontal HIV transmission. Initiating ART when diagnosed has the ability to improve their health while also reducing morbidity and mortality and reducing the transmission of HIV (Matthews et al., 2018). In addition to the birthing person taking ART, PCC can be offered to address further protection by recommending pre-exposure prophylaxis (PrEP) when trying to conceive. Other strategies include vaginal self-insemination, medical male circumcision, treatment for STIs, and limiting unprotected sex to peak fertility days limits HIV exposure while also maximizing the likelihood of pregnancy (Matthews et al., 2018).

Mother-to-child transmission of HIV in the United States varied between 15-30% before the widespread use of effective ART, prompting CDC to initially recommend that women living with HIV not conceive. Guidelines began to change in 1995 when the combination of ART and reproductive technologies reduced the risk to less than 1%, allowing for people living with HIV to safely conceive (Gokhale et al., 2017). The randomized clinical trial, ACTG076-ANRS024, is an example in reducing MTCT using ART during the second and third trimesters, at delivery, and in the neonatal period as this trial showed a two-thirds reduction. The levels of perinatal transmission continued to decrease as better ART was made available (Mandelbrot et al., 2015). One study showed that starting ART before pregnancy and having a low viral load led to zero cases of MTCT among almost 2700 pregnant people in comparison to a few cases for those who either started ART after the first trimester or ART was stopped even when having a low viral

load (Mandelbrot et al., 2015). This study shows how ART significantly decreases perinatal transmission and when starting before or during pregnancy. The prevention of perinatal transmission is an example for treatment as a prevention (Mandelbrot et al., 2015).

A significant portion of providers that specialize in HIV care also offer primary care services and many people living with HIV prefer this. HIV care providers who also function as primary care providers tend to be the most consistent contact within the health system for their patient (Gokhale et al., 2017). While improved health outcomes are associated with engagement in treatment, adherence to medications, and attending appointments, statistics indicate that 50-59% of people living with HIV in the U.S. are retained in HIV care. However, pregnant women living with HIV have been shown to better adhere to medications and attend appointments (Jones et al., 2013). This is demonstrated by the University of Miami/Jackson Hospital's Prenatal Immunology Clinic (PRIM) where adherence to prenatal care visits were above 95%. The hospital uses psychoeducational groups and supportive healthcare providers to encourage patients to engage in the healthcare system and treatment. Statistics such as these grow support for the integration of primary care and HIV care to improve retention rates and link ongoing care (Jones et al., 2013).

PCC provides patients living with HIV knowledge and confidence. One study highlighted that before PCC, couples affected by HIV were unaware that they were able to conceive without transmission to their partner or child. Further analysis showed that participants thought that they would have to give up the opportunity to have children or would have to go through a medically intensive process (Friedman et al., 2016). Adherence to ART is effective in optimizing reproductive health outcomes. In addition to the HPTN 052 and PARTNER studies, a prospective cohort study with 161 couples who were virally suppressed using ART and natural conception

led to 144 natural pregnancies with no vertical or horizontal transmission of HIV (HIV.gov, 2024). Overall, advancements in HIV treatments have led to an improved quality of life and reductions in MTCT have led to increased pregnancies in women living with HIV (Boelig et al., 2015).

Perceived barriers among healthcare providers

Women living with HIV avoid discussing pregnancy desires and sexual behaviors with their providers due to the fear of disapproval and conversations on fertility desires with providers may focus on contraception instead of conception (Jones et al., 2017). Patients emphasized various barriers such as geography, gaps in awareness of services, inability to locate informed providers, and receiving contradicting information on conception options (Friedman et al., 2016).

Societal and medical stigma discourages people living with HIV from getting pregnant though medical and behavioral developments have allowed people living with HIV to have biological children with minimal risk of transmission (Steiner et al., 2013). There are also variations in preconception counseling and communication though there is advanced HIV care in the United States as conversations regarding desires and intentions were more prevalent among young white women who were in relationships (Raley, 2014). Other issues that are prevalent include knowledge on PCC, failing to recognize the significance in PCC, and assumptions on patients seeking care when needed (Simone et al., 2018).

While combination antiretroviral therapy has prolonged life expectancy to have a productive life which could include having and raising children for people living with HIV, there has been an insufficient focus on developing safe conception programs despite efforts at advocacy (Mindry et al., 2013). Providers find it challenging to give preconception care to women living with HIV, though there have been medical advancements for HIV including ART

(Raley, 2014). In the United States, preconception counseling is not consistently integrated into primary or HIV care though there are recommendations from the CDC, AAFP, ACOG, and the Public Health Services Panel on Treatment of Women with HIV and Prevention of Perinatal Transmission (Simone et al., 2018). Limited knowledge, time constraints, and specializations were barriers that providers emphasized (Coll et al., 2016). A survey done on HIV care providers that attended the International Antiviral Society-USA course in NYC in 2013 reported that only 26% of those providers were familiar with the HPTN 052 study funded by the NIH which showed a significant reduction in HIV transmission between partners with an early initiation of ART (Gokhale et al., 2017). Studies have suggested that primary care providers have challenges locating clinically relevant information, lack of trained providers, lack of space for preconception services, and the lack of confidence that providers will adopt preconception counseling (Steel et al., 2016). HIV care providers in Los Angeles reported in a qualitative study that they were concerned as reproductive technologies tend to be financially unattainable and would be financially unattainable (Gokhale et al., 2017).

Problem Statement

Though the importance of preconception counseling has been recognized to optimize reproductive health and fetal outcomes, the current state of PCC is not meeting the expectations for the ideal standard of comprehensive preconception counseling in the United States (AAFP, 2020). Low utilization rates and issues regarding access, especially for marginalized groups, emphasize the need for improving PCC (AAFP, 2020). Research indicates that limited awareness for both patients and providers, stigma for those living with HIV, and lack of trained providers all contribute to the disparities in PCC and pregnancy outcomes (Simone et al., 2018). These areas

result in the inability to adequately implement health promotion and reduce risks before conception.

There needs to be more clarity between what is provided regarding PCC and what should be offered for individuals and couples. There is an urgent need to optimize preconception counseling in ways to improve maternal health and reduce adverse outcomes in newborn children. The identification and reduction of risk factors and health issues, in addition to the empowerment of individuals and couples to make informed decisions regarding family planning, is inhibited by the underutilization of preconception counseling.

Though there have been advancements in preconception counseling and knowledge about reproductive health, there are gaps in integrating routine preconception counseling for people with HIV into healthcare services in the United States (Matthews et al., 2018). Limited studies emphasize that awareness, inconsistent implementation, stigma, and time requirements contribute to underutilization. Additionally, research on tailoring preconception counseling to the needs of diverse populations, especially people living with HIV, is limited. This crucial gap emphasizes the necessity to explore evidence-based strategies to enhance preconception counseling to improve HIV care and empower people living with HIV by ensuring equitable access to improve reproductive outcomes. The Ryan White Program, funded through the Health Resources and Services Administration (HRSA), has supported preconception counseling as a core component of this federal program (HRSA Ryan White HIV/AIDS Program, 2023).

Purpose Statement

This study will involve exploring how healthcare providers approach and deliver preconception counseling (PCC) to birthing people living with HIV, identify the facilitators and barriers they encounter, and assess the perceived impact of these practices on preventing HIV

transmission and improving reproductive health outcomes. This special study project (SSP) aims to examine and understand the current evidence-based approaches and delivery methods of PCC, assess the maternal and child health outcomes of PCC, and examine the perceived barriers healthcare providers have when incorporating PCC in HIV care. By analyzing and synthesizing these topics of interest, this special studies project aims to provide perspectives that may inform strategies to enhance reproductive health services and HIV care for birthing people living with HIV.

Research Questions

This study will respond to the question, *how do healthcare provider practices, facilitators, and barriers in delivering preconception counseling impact the prevention and improvement of outcomes for birthing people living with HIV?*

To ensure there is an in-depth analysis for the research, the following sub-questions will support the main research question:

Question 1: How do healthcare providers currently approach and deliver preconception counseling (PCC) for people living with HIV?

Question 2: What are the perceived barriers among healthcare providers in incorporating preconception counseling into HIV care?

Question 3: How does the integration of preconception counseling into HIV care improve reproductive outcomes for people living with HIV?

Significance Statement

While there have been advancements in treating and preventing the transmission of HIV, the United States continues to have an HIV/AIDS epidemic impacting the target population of interest, especially for people who are currently of childbearing age. However, there is a need to

identify and address critical gaps in HIV care to confront the unique challenges in reproductive health, and to expand on limited published research. This current study strives to identify the specific practices, facilitators, and barriers experienced by healthcare providers in delivering preconception counseling (PCC) to birthing people living with HIV, and to understand the perceived impact of these factors on preventing HIV transmission and improving reproductive health outcomes. The research results can potentially inform improvements in the health of marginalized groups to create a more inclusive and patient-centered healthcare model. Overall, the findings of this study may inform improvements in healthcare to enhance reproductive rights and empower individuals living with HIV by encouraging advocacy efforts and policy changes to ensure that there exists comprehensive patient-centered PCC for birthing people living with HIV integrated into HIV care.

Chapter II: Methods

A qualitative research approach was utilized to gather in-depth interviews among key informants to gain insights and perspectives from healthcare professionals who work with birthing people living with HIV on their experiences and challenges in delivering PCC.

Population and Sample

The population of this study consisted of healthcare professionals who offer PCC to individuals living with HIV. The sample included diverse healthcare professionals, such as physicians, HIV providers, and other healthcare professionals. The rationale for selecting this population was to understand the current practices, challenges, and facilitators regarding PCC in HIV care. Participants in this study were recruited nationally and locally from a variety of healthcare clinics, hospitals, and organizations – primarily targeting healthcare professionals who

work with those living with HIV. This population was selected to gather a comprehensive perception of the practices and challenges that various healthcare professionals face in various settings.

Procedures

Participants for this study were recruited using a purposive sampling method to gather a diverse set of healthcare professionals locally and nationally who have experience in delivering PCC for birthing people living with HIV. Healthcare professionals were identified by reviewing professional directories and healthcare organization websites. HRSA's RWHAP Community of Practice (CoP) toolkit, Preconception Counseling, including Sexual Health Toolkit (https://targethiv.org/library/preconception-counseling-including-sexual-health-toolkit?utm_source=bpURL) was an additional source utilized to identify participants. Finally, social media platforms were used to identify and reach out to potential participants that were not included from professional directories and healthcare organization websites or the CoP toolkit. The identified professionals were contacted directly via email with an overview of the study and an invitation to participate. We aimed to interview at least ten healthcare professionals who delivered PCC to birthing people living with HIV. Outreach activities included mention of the survey and an invitation to participate in the study.

Data were collected qualitatively through in-depth interviews to gain insights into participants' experiences and practices while delivering PCC for birthing people living with HIV. An interview script and a set of questions were developed based on the overall research question and sub-questions in addition to the literature regarding PCC for birthing people living with HIV. The interview guide included open-ended questions based on current approaches to delivering PCC, facilitators, perceived barriers in providing PCC and improving reproductive outcomes

through PCC. A codebook was generated based on each question in the interview guide to categorize themes from interview responses.

Interviews were scheduled and occurred in July 2024 and conducted via Zoom virtual platform. Each interview began with a brief introduction of the study and verbal consent to participate in the study and record the conversation. The interviews lasted 40 to 70 minutes and included an informal conversation based on the interview guide. As an appreciation for participation, participants were sent HRSA's Preconception Counseling, including Sexual Health Toolkit, a blueprint for identifying and implementing changes and improvements to delivering PCC to people living with HIV (https://targethiv.org/library/preconception-counseling-including-sexual-health-toolkit). All interviews were recorded and then transcribed for data analysis.

Instruments

An interview guide was developed as the primary data collection instrument for this study. The interview guide was developed to allow for in-depth discussions utilizing open ended questions based on the research sub-questions to ensure that relevant topics were covered.

The Zoom video conferencing platform was used and each interview was recorded and automatically transcribed by Zoom. MAXQDA software was used to code and analyze each of the transcripts. The transcripts were coded using a pre-developed codebook. The codebook was uploaded into MAXQDA prior to the coding process.

Data Analysis

The transcripts were uploaded to MAXQDA from Zoom for data analysis after reviewing them for accuracy and removing identifiers. The pre-developed codebook was used to code each of the transcripts systematically. No additional codes were added as the codebook covered the

relevant themes and topics discussed during the interview. Instead, some codes were combined as overlaps among certain areas were identified, and to streamline the analysis process. The coding process identified the current approaches to PCC, facilitators, challenges in providing PCC, improving reproductive outcomes through PCC, and some recommendations to improve PCC in HIV care.

Ethical Considerations

This study was reviewed and determined by the Institutional Review Board of Emory University (STUDY00008064) to be exempt, although it is considered human subjects research. It met the criteria for exemption under 45 CFR 46.104(d)(2)(ii). This exemption is for research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) and meets the following criteria: “any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation.”

Chapter III: Results

The results examine and characterize how healthcare professionals currently approach and deliver PCC for birthing people living with HIV, the perceived challenges that professionals face, and how integrating PCC into HIV care are perceived to improve reproductive outcomes for birthing people living with HIV. Of 77 persons contacted through outreach efforts, eleven people were interested in participating, three expressed that they were not the right fit, and seven were interviewed by interviewer-guided in-depth interviews. Professionals were all women and

included a case manager and executive director, a nurse practitioner, two OBGYN physicians who are reproductive infectious disease fellows, two infectious disease physicians, and a primary care provider with a specialty in sexually transmitted infections. Additionally, five of the professionals work in an academic hospital, three out of the seven participants were from a RWHAP organization, and two participants represented non-profit HIV/AIDS organizations In addition to the interviews, participants were asked to identify sources of information that they used in their practice.

How do healthcare providers currently approach and deliver preconception counseling (PCC) for people living with HIV?

All seven (100%) of the healthcare professionals openly discussed the variety of topics covered during PCC, which included use of contraceptives, the importance of staying virally suppressed, safe conception practices, immunizations, and nutrition. Additionally all of the providers mentioned addressing HIV transmission risks prior to and during pregnancy, making sure to emphasize the risks based on viral load and viral suppression. The typical approach taken by six (86%) of healthcare professionals include integrating contraception, viral suppression, safe conception, immunizations, nutrition, and transmission risks within their routine HIV care visits and tailoring discussions based on each patient's individual needs and concerns. Five (71%) of participants expressed that they have routine check-ins and ongoing conversations with patients during regular health check-ups to be updated on reproductive goals by their patients.

All healthcare professionals mentioned that they adhere to the latest available national guidelines for PCC counseling sessions for the best practices regarding PCC in the context of birthing people living with HIV. These guidelines include the Department of Health and Human Services's (DHHS) *Prepregnancy Counseling and Care for People of Childbearing Age With*

HIV (HIV.gov, 2024) and the Center for Disease Control and Prevention's *Recommendations to Improve Preconception Health and Health Care* (CDC, 2006). In addition to national guidelines, all utilized other additional resources in their counseling sessions to ensure comprehensive care that included the websites Hive (hiveonline.org) and The Well Project (thewellproject.org). Three (43%) of healthcare professionals collaborate with pharmacists to manage oral contraceptives and ART regimens for their patients. All participants utilized interdisciplinary and multidisciplinary collaboration and referral-based systems to specialists to address various medical conditions or concerns.

What are the perceived barriers among healthcare providers in incorporating preconception counseling into HIV care?

Healthcare professionals identified several barriers that hinder incorporating effective PCC into HIV care. Barriers identified include time constraints, lack of PCC specific training, institutional and systemic challenges, and socioeconomic factors and cultural barriers. These various barriers impact the delivery and effectiveness of PCC being integrated into HIV care.

All healthcare professionals expressed identified barriers when trying to incorporate PCC into HIV care. Time constraints were a barrier identified by six (86%) of interviewed professionals. They noted that they are unable to address all of their health issues including their HIV care, leaving insufficient time to discuss PCC comprehensively. In addition to time constraints, the complexity of care was also mentioned as professionals noted that there are a variety of medical issues and concerns that they have to address, including HIV care, and reproductive health within the limited available time.

Training was identified as a barrier by healthcare professionals. Regarding training, only two (29%) mentioned receiving formal PCC training in the context of HIV, specifically in

reproductive health and HIV care. While five (71%) of professionals mentioned that they did not receive specific training on PCC in HIV care, all believed that they had gained the knowledge and awareness to effectively deliver PCC and its importance for birthing people living with HIV.

Systemic and institutional barriers were also mentioned as challenges for healthcare professionals. Two (29%) of professionals mentioned needing to refer patients to OBGYNs for PCC discussions when they cannot address all needs. Four (57%) of participants highlighted limited access to specialized providers, the location of their organizations, and the lack of available times for patients to schedule as barriers and two (29%) participants mentioned the lack of Medicaid expansion as a barrier leading to limited access to care.

Regarding patient barriers, there were both socioeconomic factors and cultural beliefs that posed challenges in integrating PCC into HIV care. All of the participants discussed that most of their patients faced at least one of the following: limited financial resources, lack of health insurance, challenges with drug abuse, struggles with mental health issues, and lack of transportation. They mentioned that these issues negatively impact their patients' motivation to engage in PCC and to actively adhere to PCC recommendations. Three participants discussed cultural and religious beliefs as barriers in conflict with PCC recommendations, posing a challenge to effective counseling.

How does the integration of preconception counseling into HIV care improve reproductive outcomes for people living with HIV?

All healthcare professionals highlighted that integrating PCC into HIV care specifically improves their birthing patients living with HIV reproductive outcomes. All emphasized that the integration of PCC into HIV care empowers their patients as they are given comprehensive knowledge about PCC and HIV. It was discussed that patients can better advocate for themselves

and their care and have the knowledge to make informed decisions that align with their reproductive goals. Three (43%) of healthcare professionals noted that their patients become more engaged in their care and better adhere to their treatment.

All seven healthcare professionals discussed that their patients can better plan and maximize health before pregnancy when engaging in PCC sessions. All participants discussed tailoring their PCC sessions based on the needs and wants of each patient to address each patient's health issues and make sessions more relevant and appropriate in addressing concerns. Professionals emphasized that they have observed successful outcomes as pregnancies are healthier and pre-existing health conditions are addressed prior to pregnancy and before they give birth. Three (43%) of the participants noted that their patients better adhere to ART regimens as they are more motivated to become or stay virally suppressed to decrease the risk of HIV transmission to their fetuses and partners.

Chapter IV: Discussion

This study explored how healthcare providers approach and deliver PCC to birthing people living with HIV, identify the facilitators and barriers they encounter and assess the perceived impact of these practices on preventing HIV transmission and improving reproductive health outcomes. The themes that emerged from the in-depth interviews included providers' current approaches, perceived barriers and facilitators among providers, and reproductive outcomes from PCC's integration into HIV care. The findings were contrasted with our literature review, consisting of 19 published articles and peer-reviewed sources on PCC for birthing people living with HIV, published between 2014 and 2024. The results from this study have the potential to inform improvements in the health of birthing people living with HIV and create a more inclusive and patient-centered healthcare model that empowers them.

How do healthcare providers currently approach and deliver preconception counseling (PCC) for people living with HIV?

Healthcare professionals initiate and approach PCC discussions during their routine care visits by asking questions regarding their plans for reproductive intentions, current contraception use, and their health status. These questions and patients' responses act as indicators to prompt providers to approach and start discussing PCC. For example, a provider stated, "I'll say to the patient, have you considered having a family. Are you thinking about it? Would you wanna talk about it? And then we open up the conversation". This aligns with the literature review as Gokhale et al. (2017) stated that comprehensive health counseling was offered by half of HIV care providers in the study along with an improvement for primary care providers to be more likely to provide reproductive health counseling, from 26% to 48%. In contrast, Tanner et al. (2018) found that an HIV clinic site did not initiate conversations on PCC nor was it discussed until a patient communicated that they did not want to use contraception. Through comprehensive assessments and conversations, healthcare professionals tailor PCC to address the needs and wants of each patient. Patient medications, immunizations and screenings, and medical history are all reviewed to address healthcare gaps and optimize pregnancy outcomes. It was explained by one physician, "we review any medical history that might have an impact on pregnancy and discuss potential risk associated." Discussing birth spacing and customizing contraception on patient preferences are other areas that providers talk about regarding PCC. During counseling sessions, providers take the time to educate their patients and answer various questions to enhance their understanding on safely conceiving while living with HIV and their fertility while also addressing concerns and misinformation. A provider highlighted, "trying to dissolve some misunderstandings about conception and sexual health and pregnancy in general."

The literature substantiates these findings where Jones et al. (2016) and HIV.gov (2024) highlighted that PCC addressed knowledge gaps that patients have, giving providers the opportunity to educate them. PCC allows providers to keep patients updated and educated on pregnancy while living with HIV.

PCC counseling sessions allow providers to address transmission risks to their fetuses and partners for birthing people living with HIV. Providers have continuous discussions with their patients about their viral loads, where undetectable levels are equated to untransmittable virus (U = U), the importance of adherence to ART regimens, and prevention of other STIs. Providers discuss that it is crucial to regularly monitor viral loads and adhere to antiretroviral medications to maintain an undetectable viral load as it prevents HIV transmission. A provider stated, "even outside of thinking about contraception or conception, always talking about viral loads and risk of transmissibility. So like we're always talking about U=U even outside of sex." This is consistent with published literature, which shows that PCC can contribute to the suppression of viral loads, prevention of mother-to-child transmission of HIV, and reduction of adverse pregnancy and fetal outcomes (Boelig et al., 2015; Gokhale et al., 2017; HIV.gov, 2024; Matthews et al., 2018; New York Department of Health, 2018). Having these conversations allows healthcare professionals to address viral loads and viral suppression to decrease the risk of HIV transmission.

Healthcare professionals utilize multidisciplinary and interdisciplinary approaches that allow PCC to be integrated into HIV care. Collaboration occurs between OBGYNs, nurses, HIV specialists, primary care physicians, case managers, peer advocates, fertility specialists, pharmacists, and other healthcare professionals. These teams allow for comprehensive and holistic ways of care tailored to each individual case's needs to optimize health and reproductive

outcomes. One practitioner shared, “My more complicated patients that need preconception counseling usually have other medical conditions, not just their HIV. In such cases, I refer them to my OBGYN colleagues or maternal-fetal medicine specialists.” Friedman et al. (2016) also found that primary care or infectious disease providers who worked within academic medical centers or community health clinics did offer PCC but also referred their patients to OBGYNs that specialize in women’s reproductive health who were living with HIV. Similarly, Simone et al. (2017) reported that all 92 HIV clinicians in their study utilized individual or team-based approaches to PCC where half reported referrals to other providers within their institution or other organizations. Throughout care, there are regular check-ins to discuss viral load, adherence to ART, change medications based on need, and revisit any other health issues. A case manager explained, “we do it during pregnancy. We redo that care plan after delivery because we know change. And then every 6 months we're reviewing it as well”. These regular check-ins allow for continuous patient care to ensure optimal health and address ongoing needs.

National guidelines and protocols are followed and used by healthcare professionals, as many do not have clinic-specific protocols. The DHHS and NIH guidelines, CDC, and ACOG, are some resources followed during PCC sessions. An HIV care provider explained, “I follow what's in the DHHS perinatal guidelines…so I am very familiar with them. Before I was as familiar, I used to periodically pull them up and get updates.” Other sources of support come from online platforms such as HIVE (hiveonline.org) which is a family-centered HIV clinic that develops resources and guides regarding HIV and pregnancy and The Well Project (thewellproject.org) which is another online resource that prioritizes women and provides tools for them to thrive with HIV. These sources create patient-facing materials that healthcare professionals direct their patients to for additional guidance. A case manager shared, “there are a

few very nice patient-facing materials that have been developed by The Well Project that are that our case managers use". Specifically, Simone et al. (2018) emphasizes that the CDC and US Office of Population Affairs, ACOG, the Public Health Services Panel on Treatment of Pregnant WLH, and the Prevention of Perinatal HIV transmission all offer recommendations for counseling and services. The literature highlighted inconsistencies regarding the use of guidelines and protocols Coll et al. (2016) found that contraception was often emphasized over exploring fertility desires, and PCC was infrequently addressed despite the availability of recommendations, protocols, and brochures. HIV.gov (2024) also reported that providers often fall short of current guidelines for comprehensive reproductive counseling. National guidelines, protocols, and patient-facing materials guide professionals in PCC and help their patients understand safe conception.

What are the perceived barriers among healthcare providers in incorporating preconception counseling into HIV care?

It was found that providers faced many barriers that hindered them from being able to deliver PCC to their birthing patients living with HIV effectively. Limited resources are a barrier, as there can be a lack of support staff, specialists, and clinic-based guidelines to follow. One healthcare professional stated, "we don't always have the resources or support to provide comprehensive preconception counseling". Gokhale et al. (2017) supported this finding as they pointed out that certain advanced reproductive technologies were unavailable for patients because specialists do not offer them due to lack of inquiries, concern for child wellbeing, and absence for laboratory procedures. While there were mentions of training and conferences offered by various organizations, there was a lack of specific training in PCC in the context of HIV care. The lack of formal training can lead to inconsistent practices and care variability

between patients and organizations. It was mentioned by an infectious disease specialist that "not all healthcare providers have the necessary training in preconception counseling, which affects the quality of care". This aligns with the literature review as it was found that participants expressed that they had difficulties finding knowledgeable providers on PCC for people living with HIV as they would receive outdated information and be referred to providers with expertise in HIV (Friedman et al., 2016). Systemic issues within the healthcare system create other barriers to integrating PCC into HIV care. Some constraints include high patient loads, appointment lengths, limited availability, and the lack of institutional support for PCC. One provider explained, “any preventative health care you're trying to address their HIV care, preconception counseling, contraceptives, STI testing all within that 15 minute window.” This challenge is supported by Tanner et al. (2018) which found that providers often prioritize contraception and prevention over discussing fertility desires due to time limitations and institutional protocols. Healthcare professionals are burdened by systemic issues within the healthcare system that impact the opportunity for thorough PCC.

Stigma and lack of awareness for patients are other barriers that hinder PCC from birthing people living with HIV. Some patients lack awareness of PCC, which prevents them from seeking this counseling. One professional noted, "a lot of patients don’t understand why preconception care is important, especially if they’re not planning to get pregnant soon." Not being aware of PCC services can lead to missed opportunities in maximizing health prior to conception, which may lead to various issues during pregnancy and postpartum. Past experiences of stigma discourage patients from seeking and involving themselves in PCC. Outside of societal stigma, patients have experienced stigma from providers outside of HIV care, intake personnel, and receptionists. It was noted by a professional that "the stigma around HIV and having

children makes it hard for patients to open up about their reproductive plans." This is also mirrored in the literature review as findings from Cuca and Dawson Rose (2015), where patients recounted stigmatizing interactions with healthcare providers regarding their desire to have children. Additionally, Leyva-Moral et al. (2018) noted that many physicians remain skeptical about the reproductive intentions of people living with HIV, which hinders open and supportive PCC conversations.

Socioeconomic factors and cultural beliefs of patients are other challenges in practice that healthcare professionals face when integrating PCC into HIV care. There exist cultural and religious beliefs that discourage conversations between patients and healthcare professionals about reproductive health. An OBGYN mentioned, "cultural beliefs can make it challenging to discuss contraception and reproductive planning openly." Cultural barriers such as these have to be navigated in a sensitive manner that respects their culture. Limited access to health insurance and financial constraints are some socioeconomic factors that are challenges to integrating PCC into HIV care. A nurse highlighted, “many of our patients face financial barriers that make it difficult to access preconception care.” This is mirrored by Gokhale et al. (2017), a report indicating that providers believed patients would be unable to afford reproductive technologies. Addressing socioeconomic factors through systemic changes is crucial for patients to receive equitable access.

Personal issues such as life and health challenges and unplanned pregnancies are other factors that make it challenging to integrate PCC into HIV care. Patients may not be focused on PCC as they face daily challenges within their lives, such as financial constraints, taking care of children, mental health issues, drug abuse, or unstable living situations. It was emphasized by a professional, “It's usually the 8,000 other things that are competing priorities, or that are just

providing repeated hurdles for them that may be mostly related to social terms." Providers also deal with many unplanned pregnancies. Unplanned pregnancies, especially for those with health challenges, hinder the opportunity for optimizing health and cause a missed opportunity for focusing on PCC. A provider stated, "I have a patient who became pregnant unexpectedly who was sick and we just didn't have time to really focus on the family planning piece." This is consistent with the literature review as multiple studies found that women living with HIV were more likely to have chronic medical conditions and more likely to smoke, consume alcohol, and do drugs (Arab et al., 2017; HIV.gov, 2024).

How does the integration of preconception counseling into HIV care improve reproductive outcomes for people living with HIV?

We speculate that the integration of PCC into HIV care enhances reproductive outcomes for birthing people living with HIV. Patients are empowered as they are provided with comprehensive education and knowledge regarding PCC and HIV care. This leads to empowerment as it enables patients to make informed decisions regarding their reproductive health. One professional highlighted that "information from PCC empowers patients, allowing them to advocate for themselves in various care environments." Patients can maximize their health by better planning before conception, which leads to healthier pregnancies and postpartum outcomes. Healthcare professionals highlighted that maximizing health prior to conception is crucial to optimize health outcomes. It was explained, "it allows people to maximize their own health before conceiving both from an HIV standpoint and from the standpoint of other conditions." This is consistent with the published literature, which shows that PCC, when combined with consistent use of ARTs, contribute to the suppression of viral loads, prevention of mother-to-child transmission of HIV, and reduction of adverse pregnancy and fetal outcomes

(Boelig et al., 2015; Gokhale et al., 2017; HIV.gov, 2024; Matthews et al., 2018; New York Department of Health, 2018). Specifically, Boelig et al. (2015) and Matthews et al. (2018) found that early initiation of ART during preconception counseling can significantly decrease the risk of HIV transmission to partners and improve pregnancy outcomes. This integration provides a holistic approach to patient care by providing comprehensive care coordination. Patients can receive comprehensive and consistent care to address both HIV-related illnesses and conditions that are unrelated before and throughout their reproductive journey. This is done by collaborating with other specialists, enhancing the quality of care and improving outcomes. A professional stated, "we have a nutritionist, we have nurses, and we have therapists. So if there's a need, I would refer them." Published literature discussed collaborative teams for holistic care to optimize health as Gokhale et al. (2017) found that 56% of practices in their study expressed using an integrated team. This collaboration helps improve reproductive outcomes as various needs are holistically addressed to optimize health prior to pregnancy.

Integrating PCC into HIV care also improves the relationship between the patient and healthcare professional and improves the patient's adherence to ART regimens. It was noted that many birthing people are unaware that they can have children, though they have HIV. Consistent interactions between the patient and professional foster open communication as relationship and trust building occur through each interaction. It was stated, "regular interactions build trust, making patients more likely to share their reproductive plans and seek advice." Open communication allows professionals to tailor PCC as patients feel more comfortable communicating their intentions and desires. Understanding the importance of viral suppression in preventing HIV transmission to both partners and fetuses motivates patients to adhere to medication. One professional mentioned, "framing PCC in the context of preventing perinatal

transmission motivates patients to adhere to their antiretroviral medications." Adhering to ART regimens is effective in decreasing the risk of perinatal transmission, which contributes to better reproductive outcomes.

Limitations and Delimitations

The reliance on self-reported data is a limitation of this study as it is subject to recall and social desirability biases. The sample size was another limitation, as it only included seven persons of 77 targeted during outreach, and findings are not readily generalizable and unable to capture diverse experiences by other healthcare professionals. We deliberately targeted healthcare professionals who deliver PCC to birthing people living with HIV, as focusing on this population allows for exploration within a practical context. This study also included participants who work in HIV care and have varying levels of expertise in the field to get a comprehensive understanding of PCC practices. Incorporating a literature review with the IDIs may help identify gaps that were not identified in the interviews and substantiate findings from the interviews.

Chapter V: Public Health Implications & Recommendations

This study highlighted the various gaps and opportunities for integrating PCC into HIV care. Addressing these gaps is significant to optimize health and improve reproductive health outcomes for birthing people living with HIV. The public health implications from this study include the overall understanding of PCC in HIV care and the delivery by healthcare professionals in healthcare settings.

The interviews highlighted gaps in training as an important barrier, consistent with other published reports (Coll et al., 2016; Friedman et al., 2016; Gokhale et al., 2017; Raley, 2014). This emphasizes that there is a need for formal education and ongoing training on PCC in the context of birthing people living with HIV. Healthcare professionals need accessible materials that emphasize the best practices and modules on reproductive health for this population that are easily digestible. Training should include the medical aspects of PCC and the various factors that influence a patient's decisions on their reproductive potential. The interviews found that understanding the unique needs and preferences of birthing people living with HIV is crucial and influences the adoption of patient-centered approaches for counseling sessions. This is important as the literature review found that providers overlooked the reproductive goals and fertility desires of birthing people living with HIV and focused on contraceptives and condom use (Coll et al., 2016; Jones et al., 2017; Tanner et al., 2018). Culturally sensitive and accessible patient-facing material was also emphasized as a need in the interviews as it could give patients the confidence and knowledge to make informed decisions while allowing healthcare professionals to guide discussions and use best practices. This is also mirrored in the literature as it discussed the various assumptions that providers had on their patients abilities and knowledge (Coll et al., 2016; Gokhale et al., 2017)

The interviews revealed that multidisciplinary care teams and systematic approaches can also help address the various gaps. Involving various healthcare professionals creates a collaborative care model that holistically addresses all aspects of a patient’s health, including their reproductive health, to optimize health and enhance the delivery of PCC. Integrating multidisciplinary teams in PCC’s effective delivery was supported by the literature where various sources used integrated team and referral based approaches (Friedman et al., 2016, Gokhale et

al., 2017; Simone et al., 2018). The development of standardized guidelines and protocols can facilitate the integration of PCC into routine HIV care. Establishing specific guidelines and incorporating prompts into the electronic medical record would help ensure consistent care, as the discussions will occur regularly. The literature highlighted that there were inconsistencies within the integration of PCC into HIV care though there are guidelines, emphasizing the need to ensure systematic approaches within routine care (Arora & Wilkinson, 2017; Coll et al., 2016; Gokhale et al., 2017; HIV.gove, 2024; Simone et al., 2018; Tanner et al., 2018).

Chapter VI: Conclusion

In conclusion, this study has identified the specific practices, facilitators, and barriers experienced by healthcare providers in delivering PCC to birthing people living with HIV and to understand the perceived impact of these factors on preventing HIV transmission and improving reproductive health outcomes. This study found that healthcare professionals make efforts and strategies to integrate PCC into HIV care. At the same time, there are challenges in practice related to systemic and institutional barriers, cultural beliefs, and socioeconomic factors. The integration of PCC into HIV care for birthing people living with HIV has the opportunity to holistically address health concerns through comprehensive care, improve reproductive outcomes, and enhance patient empowerment through informed decision-making. The study also highlights perceived barriers that must be addressed with systematic approaches, ongoing training, and patient-centered care models. These key findings can inform practice, policy, community stakeholders, and research for improvements. The integration of PCC into HIV care must remain a priority within practice, policy, and research to ensure that birthing people living with HIV have access to holistic, patient-centered care that is tailored to support their needs and desires in the reproductive journey.

Chapter VII: References

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