PrEP and Women: Increasing Uptake and Continued Use

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Abstract

Human immunodeficiency virus (HIV) remains a significant public health issue globally. While HIV prevention efforts have largely focused on men who have sex with men, in recent years, women have taken on a large percentage of disease burden, especially Black women. HIV can be prevented through the use of pre-exposure prophylaxis (PrEP). However, research suggests that women are rarely ever prescribed PrEP and if they do take it, they eventually discontinue use. Understanding the reasons why women are not taking PrEP is paramount in fighting the HIV epidemic.

This master's thesis engages multiple methods to discuss the opportunity of PrEP as an HIV risk reduction strategy for women and to investigate the context of women's PrEP decision-making and intervention opportunities to support women's uptake and adherence to PrEP. An analysis of interviews conducted with women in Pittsburgh, PA through the STD-to-PrEP Demonstration project suggest that women face many barriers to use PrEP and that current approaches to PrEP care are insufficient in meeting the everyday needs of women. A rapid review of literature showed the lack of intervention strategies for women. The public health significance of this research is that it shows the need for robust and targeted women-centered PrEP interventions that address women's concerns by providing effective solutions through individualized approaches.

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List of Abbreviations

ACHD - Allegheny County Health Department

AGYW - Adolescent Girls and Young Women

CDC - Center for Disease Control and Prevention

DOH - Department of Health

FSW - Female sex workers

HIV - Human Immunodeficiency Virus

IPV - Intimate partner violence

PA-NEDSS - Pennsylvania National Electronic Disease Surveillance System

PrEP - Pre-exposure Prophylaxis

PWID - People who inject drugs

SHN - Sexual Health Navigator

STI - Sexually Transmitted Infection

United States- US

Preface

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1.0 Introduction

Human Immunodeficiency Virus (HIV) remains a significant public health issue for women worldwide. Globally, there are approximately 38 million people living with HIV, with about 1.7 million new diagnoses observed in 2019 [World Health Organization (WHO), 2020]; 48% of new diagnoses were among women [UNAIDS, 2020]. In the United States (US) there were 37,968 new HIV diagnoses in 2018 [Centers for Disease Control and Prevention, 2020], where close to a fifth (19%) were among women [Centers for Disease Control and Prevention, 2020]. Women of color are disproportionately affected by HIV in the US. Forty two percent of new HIV diagnoses in 2018 were among Black or African American individuals [Centers for Disease Control and Prevention, 2020]. Approved by the Food and Drug Administration (FDA) in 2012, PrEP is an established biobehavioral HIV prevention method, though remains significantly underused by women in the US ["PrEP for Women", 2019]. Approximately 5% of US PrEP prescriptions filled in 2016 were among women [Huang et al., 2016]. This master's thesis discusses the opportunity of pre-exposure prophylaxis (PrEP) as an HIV risk reduction strategy for women and investigates the context of women's PrEP decision-making and intervention opportunities to support women's uptake and adherence to PrEP.

The research on which this thesis is based used multiple methods to understand the factors that influence women's decision-making process in taking PrEP, as well as to understand what interventions currently exist to support women's PrEP use. A content analysis of qualitative interview transcripts (n=10) collected by STD-to-PrEP Demonstration Project, a longitudinal study investigating barriers and facilitators across the PrEP care continuum, examined factors influencing the PrEP decision-making process. A rapid review of literature identified existing peer-

reviewed literature of PrEP interventions for women. While this is a small and specific subset of women enrolled in a demonstration project in Pittsburgh, their input allows us to better understand barriers and facilitators to women's PrEP use, and together with evidence from the literature review, determine public health implications and recommendations for supporting women and PrEP use.

The specific aims of this thesis are to:

1. Understand how women describe their PrEP decision-making process, including barriers and facilitators to use, among a sub-sample of women in Pittsburgh, Pennsylvania.
2. Identify and synthesize existing peer-reviewed published literature focused on interventions around women's PrEP engagement.
3. Discuss implications on public health practice and intervention development for women and PrEP.

2.0 Background

2.1 HIV Among Women in the United States

HIV remains a significant public health issue for women worldwide. According to UNAIDS, of the 1.7 million new cases of HIV in 2019, women accounted for 48% of those cases [2020]. Of the nearly 38,000 new HIV diagnoses in the US, 16% were women [Centers for Disease Control and Prevention, 2020]. 64.5% of those diagnoses were among Black women [Centers for Disease Control and Prevention, 2020]. According to the Centers for Disease Control and Prevention (CDC), when looking at categories for most-affected populations, Black women who participate in heterosexual contact had more cases than Black men who have heterosexual contact, Hispanic women/Latinas who have heterosexual contact, and White women who have heterosexual contact [2020]. Further, the majority of these women are from southern states, which have the highest burden of HIV with a rate of 15.6 per 100,000 people for new HIV diagnoses [Centers for Disease Control and Prevention, 2020].

2.2 HIV Risk Reduction/Prevention Strategies for Women

Current HIV prevention strategies include PrEP, male and female condoms, abstinence, regular STI testing and treatment, using clean needles when injecting drugs, and syringe services programs [Centers for Disease Control and Prevention, 2020]. While these are all considered effective methods of prevention by the CDC, barriers to use among women remain. Condoms are effective

at preventing HIV and other STIs though many women reported in the literature cited that they did not want to use condoms [Carley et al., 2019]. For example, a study in Zimbabwe that examined levels of prevention coverage among female sex workers (FSW) found that almost half of the women who were adherent to condoms and/or PrEP needed additional strategies [Fearon et al., 2019]. Gaps in condom use adherence were observed by source of condom [Fearon et al., 2019]. For example, women used condoms when they received the condoms from a peer educator but did not use them if they came from a client [Fearon et al., 2019].].

STI testing is also an HIV risk reduction option. Health care settings such as Planned Parenthood and other similar clinics offer testing and treatment at little to no cost. However, STI and HIV-related stigma remains, and women are often discouraged from testing [Balfe et al., 2010]. In a study that looked at chlamydia testing specifically, women "strongly associated chlamydia and chlamydia testing with stigma and felt that only irresponsible, promiscuous risk takers were at risk of contracting infection" [Balfe et al., 2010, pg. 131].

Finally, clean needles and syringe service programs offer another HIV risk reduction strategy. In a study looking at barriers to syringe service programs, the most frequently reported barriers were "being unaware of the existence, never having a problem obtaining clean needles, and fear of being seen or disclosing drug use" [Lancaster et al., 2020, pg. 2268].

2.3 PrEP Among Women

Given the limitations of existing HIV prevention options, PrEP, a biobehavioral HIV risk reduction strategy, offers an opportunity to expand prevention strategies for women. Approved by

the FDA in 2012, PrEP, a daily oral emtricitabine-tenofovir (Truvada) medication with a fixed-dose combination of tenofovir disoproxil fumarate (TDF) and emtricitabine (FTC), is a valued component of HIV prevention in the US. In 2014 CDC recommended PrEP as a biobehavioral prevention method to reduce HIV incidence among people who are uninfected but at high risk for HIV acquisition ["PrEP for Women", 2019]. PrEP is 99% effective if taken as prescribed ["PrEP for Women", 2019]. In the US, an estimated one million people are eligible to use PrEP [30]. Despite this, prescription numbers remain relatively low. In 2018, approximately 78,000 persons filled prescriptions for PrEP, the majority of which (68.7%) were white [Huang et al., 2016] and only 7% were women [AIDSVu, 2018]. This highlights the need for understanding the barriers and facilitators to PrEP uptake among women.

Current CDC eligibility guidelines for PrEP may present challenges to women being prescribed PrEP. Existing literature suggests that these guidelines may be too restrictive when it comes to women, and health care providers may be missing opportunities to prescribe PrEP to women who would benefit from its use. One study at a Planned Parenthood in Connecticut found that of women who reported known HIV risk factors or motivation to take PrEP were not considered PrEP eligible by existing CDC guidelines [Calabrese et al, 2019]. The authors suggest that current eligibility guidelines are focused on past/current actions and not on future actions/intentions that may put women at risk resulting in many women not considered good PrEP candidates [Calabrese et al., 2019]. Another article that reviewed charts from a sexual health clinic found that the majority of women taking PrEP are those in sero-discordant relationships and that high-risk women might be not being considered for PrEP use [Blackstock et al., 2017].

2.4 Barriers to Women's Use of PrEP

Because of the diversity in a broad population like women, a number of barriers have been reported to using PrEP. In a study that surveyed women in high HIV burden counties, they found the following barriers to be most commonly reported: poverty, incarceration, unemployment, distrust of providers and locations where HIV prevention services are offered, displeasures associated with safer sex practices, intimate partner violence (IPV), challenges related to gendered power, cultural issues, stigma associated with HIV and women's sexual behavior, and a lack of intervention strategies that address risk across multiple levels [Abrams et al., 2020]. Another article among women attending an obstetrics and gynecology clinic found that potential PrEP barriers included the need to use a condom, cost, daily adherence, short-term side effects, long-term risk of kidney disease and decreased bone density, necessity of seeing a health care provider four times per year and picking up medications monthly [Carley et al., 2019]. In general, the literature tended to divide women into five different groups: (1) people who inject drugs (PWID); (2) intimate partner violence (IPV); (3) Black women; (4) female sex workers (FSW); and (5) adolescent girls and young women (AGYW).

In another study with PWID assessing barriers to PrEP use, they split barriers up into individual, interpersonal, clinical and structural levels [Biello et al., 2018]. At the individual level were low PrEP knowledge and limited HIV risk perception, concerns about side effects, and competing health priorities and needs due to drug use and dependence. At the interpersonal level they reported negative experiences with healthcare providers and HIV-related stigma within social networks. The clinical and structural level barriers included poor infrastructure for PrEP delivery and low provider capacity/willingness to prescribe PrEP to PWID, the process of obtaining PrEP,

homelessness, criminal justice system involvement, lack of money or identification to fill prescriptions, and transportation difficulties [Biello et al., 2018]. In a study that examined PrEP in PWID in Washington, DC, the authors found that barriers to PrEP use included provider education and willingness to prescribe PrEP [Kuo et al., 2016].

Several studies examined barriers to PrEP for women who experience IPV. One study found barriers such as fear of side effects/negative health outcomes, low risk perceptions, partner interference, and not prioritizing HIV [Braksmajer et al., 2019]. In a study that looked at women who experienced IPV and were seeking care at a family planning clinic, PrEP barriers included limited awareness, misconceptions about PrEP, healthcare provider mistrust, HIV risk perceptions, concerns and fears of partner reaction and perceived short and long-term side effects [O'Malley et al., 2020]. Another study found that taking a daily pill could exacerbate an already unsafe situation in which relationship power is imbalanced and follow-up requirements every three months could be challenging [Willie et al., 2017].

Several studies specifically examined PrEP barriers for Black women. In a study done among Black college age women, perceived barriers included cost, side effects, and taking the medication every day [Chandler et al., 2020]. Another study of Black women in the Bronx found that barriers included frequency of, and stigma associated with medical visits, and the burden of pill-taking for multiple health concerns [Collier et al., 2017]. Another study that interviewed Black women in Chicago found that women were concerned about PrEP side effects, stigma, cost, interactions with other medications and how PrEP affects fetal development [Hirschhorn et al., 2020]. Another study that looked at differences in PrEP interest between men and women found that women were less likely to perceive themselves to be at risk for HIV and that Black patients perceived their risk to be lower than white patients [Roth et al., 2019]. Lastly, a survey found that several barriers for

Black individuals exist including low self-perceived risk, HIV conspiracy theories and mistrust of government, and lack of awareness that PrEP can prevent HIV [Ojikutu et al., 2018]. Study participants also expressed a greater interest in pills rather than other PrEP prevention methods being studied at the moment, such as vaginal gels or rings [Flash et al., 2014].

Several studies looked at barriers to use among FSW. Two studies found that oral PrEP as the only FDA approved biomedical prevention method is a barrier because in order to create more access, especially for FSW, there needs to be more diverse prevention options such as the vaginal rings or gels [Peitzmeier et al., 2017; Pines et al., 2019]. A study done in Zimbabwe found that FSW's knowledge of PrEP is low, which prevents them from access since they are unaware of its existence [Mudzviti et al., 2020]. A study in China among 1,611 FSW found that while women were interested in PrEP, most participants had never heard of PrEP prior to study participation. [Peng et al., 2012].

Existing literature also identifies barriers to PrEP use among AGYW. A study conducted in South Africa found that while most people involved in prescribing and implementation of PrEP think that AGYW need to use PrEP, the existing biases and power relations within these communities meant that they were unwilling to facilitate PrEP access [Nakasone et al., 2020]. The authors found that this was because of community norms around adolescent sexuality. In that case, PrEP providers viewed themselves as "guardians of youth health" and were fearful PrEP "would increase sexually risky behavior and divert drugs from those living with HIV" [Nakasone et al., 2020, pg. 7]. Another study of young adults experiencing homelessness in the US found that 84% of participants were eligible for PrEP but only 66% perceived themselves at risk for HIV [Santa Maria et al., 2019]. The authors also highlight that current prescribing guidelines for PrEP focus on clinical monitoring protocols which leaves this group of individuals out of the conversation

because of their "lack of identification, lack of health insurance, low healthcare utilization, lack of jobs and therefore stable income, transportation needs, and unstable housing" [Santa Maria et al., 2019, pg. 579]. Finally, among young people and adolescents at risk for HIV a common barrier was confidentiality when they are on their parent's insurance [Moore et al., 2019].

Lastly, two studies, although not specific to a particular sub-group of women, identify barriers with implications for all women. A study in South Africa examined the relationship between depression, stigma, social support, optimism about PrEP and PrEP adherence. The authors found that depressive symptoms were common among women and were associated with lower PrEP adherence [Velloza et al., 2020]. Another study focused on engaging pregnant women in PrEP care found that if women were offered PrEP during pregnancy, they would use it [Seidman et al., 2016]. However, they also found "gaps in screening and gaps in linkage to care before, during, and after pregnancy" [Seidman et al., 2016, pg. 632]. They noted that women who have just had children are more often lost-to-follow-up and because of this, miss opportunities for HIV prevention [Seidman et al., 2016].

2.5 Facilitators to PrEP Use Among Women

Research examining facilitators to PrEP use has identified reasons that make PrEP easy to use or why people wanted to use it. Focus groups with Black and Latina women in New York highlighted four facilitators to use among study participants including insurance plan coverage of PrEP, PrEP will provide a contingency plan if condoms fail, PrEP reduces HIV incidence in the community, and learning that there are few side effects associated with taking PrEP [Collier et al., 2017]. Clinical trial research provides evidence around facilitators of PrEP use and adherence

among women. In the FEM-PrEP study, participants cited several reasons for adhering including personal motivations and adherence strategies [Corneli et al., 2015]. Another clinical trial, the HPTN 067/ADAPT Study, reported that the biggest facilitator to use was promoting a positive relationship between participants and study staff [Ojeda et al., 2019]. The authors suggest that providers make sure that they have an open dialogue and build trust with the patients and also understand the "social, political, economic, and historical factors that affect how patients view the providers and use the medication" [Ojeda et al., 2019, pg. 9].

Understanding facilitators across the entire PrEP care continuum is essential to supporting women. A study exploring facilitators across the PrEP care continuum among women prescribed PrEP at an urban sexual health clinic found that factors motivating participants to seek out PrEP included "having a known HIV risk factor such as a sexual partner living with HIV, learning about PrEP through friends, or trusted providers" [Park et al., 2019, pg. 326]. They also found facilitators for linkage to "PrEP care, initiation, and continuation included positive interactions with informed and culturally competent staff, access to a discreet and convenient clinic, and insurance" [Park et al., 2019, pg. 326].

2.6 Gaps That Currently Exist in Engaging Women in PrEP Care

Existing literature provides important insight into PrEP care for women, though a number of gaps exist. The first is a lack of knowledge about HIV/PrEP among women. In a study that looked at a way to improve future PrEP interventions, a component of their theory was using observational learning, "which is behavior change from observing role models perform desired behavior", they believe "this could increase knowledge of PrEP by improved outreach efforts, expanded

marketing, and educational activities by peers or other trust individuals" [Biello et al., 2018, pg. 9]. Another study among heterosexual patients seeking care in a STI clinic found a perception of low risk among participants with the authors suggesting that PrEP use will likely remain low unless efforts are made to "improve risk perception, knowledge about PrEP, and safe sex methods" [Khawcharoenporn et al., 2012, pg. 231]. Studies specifically focused on Black women found that women were interested in using PrEP [Garfinkel et al., 2017] but were frustrated that PrEP is not being offered/advertised to them [Auerbach et al., 2015]. This contributes to a distrust of medical institutions among Black women since a prevention method exists but is not offered to them and they said it felt as though they were being left out of the conversation about something that can seriously impact them [Getty et al., 2018].

Women-centered advertising is necessary to support women's awareness and uptake of PrEP. Women often report that they perceive PrEP to not be for them since it is not advertised to them, which may also have implications for women's HIV risk perception [Hirschhorn et al., 2020; Nobles et al., 2020]. In a study among Black women in Chicago, participants who reported seeing PrEP advertisements found them not to be impactful as they were not targeting women in their communities and suggested three areas of improvement: (1) targeted advertising; (2) sharing information about PrEP through social networks, community events, and support groups; and (3) increasing PrEP-related communication among medical providers [28]. A study that looked at what role Instagram plays in risk perceptions and communication for PrEP found that when the term "#HIV" was searched the images that appeared were underrepresented people with high risk for HIV and very few images including Black women [Nobles et al., 2020].

There is also a gap in providing culturally competent care. Some studies postulate that this is the reason that women, especially Black women, are not engaging in care. An article that looked at

social media to understand Black women's perspectives on PrEP found that interventions aimed at Black women need to address concerns about safety preemptively because some women may be very concerned about side effects, especially their reproductive health [Hill et al., 2018]. Another aspect to culturally competent care is ensuring the right person is talking about PrEP. In a study that examined people's trusted sources for PrEP information, the authors found that the majority of people identified some type of health provider [Jones et al., 2020]. Another study that looked at patient recommendations for PrEP information dissemination in Atlanta, Georgia, found that women wanted information about PrEP through educational materials and directly from family planning providers, and that clinics were the best sites for PrEP information [Sales et al., 2019]. Another study among women at an urban obstetrics/gynecology (OBGYN) clinic in Philadelphia, Pennsylvania, found that most women felt it was important for the OBGYN or primary care provider to be the one to have the conversation about PrEP. However, it is important to note that 14% of the women were uncomfortable with the idea of talking to a provider about PrEP and "20% of the women were unsure if they would be comfortable" [Koren et al., 2018, pg. 493]. While some studies found that women trust providers to talk to them about PrEP information, it is important to understand the impact of medical mistrust on women's decision-making, especially among Black women. In a study that explored HIV-related mistrust and willingness to use PrEP among Black women, they found that knowledge and willingness to use PrEP was low, though when the conversation was shifted to empowerment women were more interested in PrEP. The authors suggest that "interventions that focus on empowerment through cultural or racial pride may help to increase uptake" in those communities [Ojikutu et al., 2020, pg. 2932].

3.0 Methods

This thesis uses multiple methods to understand the factors that influence women's decision-making process in taking PrEP, as well as to understand what interventions currently exist to support women's PrEP use. Data for this thesis include existing qualitative interview transcripts (n=10) collected by STD-to-PrEP Demonstration Project, a longitudinal study investigating barriers and facilitators across the PrEP care continuum, and a rapid review of literature to identify PrEP intervention for women.

3.1 Qualitative Interviews

3.1.1 Data Source

Data used in this qualitative analysis are from the ongoing STD-to-PrEP Demonstration Project collected from August 2020 onward by investigators from the University of Pittsburgh Graduate School of Public Health (mPI: Krier, Friedman). The STD-to-PrEP project is a demonstration project testing an intervention utilizing STI surveillance data to identify and engage individuals with high STI burden in accessing PrEP in Allegheny County, Pennsylvania. The project is done in collaboration with state and local health departments.

3.1.2 Data Collection

The Pennsylvania Department of Health (DOH) tracks reportable sexually transmitted infections (STI) diagnoses throughout the state using the Pennsylvania National Electronic Disease Surveillance System (PA-NEDSS). For the STD-to-PrEP demonstration project, a priority list of individuals with their fourth incident STI is shared with the Allegheny County Health Department (ACHD) HIV navigation staff for targeted PrEP navigation services. Navigation services involve discussion of PrEP as an HIV prevention option, referral to a PrEP provider if desired, referral to community-based resources, and introduction of demonstration project participation to those 18 years of age or older. Contact information for interested individuals is shared with the University of Pittsburgh project team, which proceeds with informed consent and project enrollment. Surveys and interviews over a six-month period assess PrEP care continuum, including decision-making, linkage-to-care experience, uptake, and discontinuation. Survey measures were selected based on established valid and reliable measures, and interview guides were designed to capture context around PrEP decision-making. Surveys are done electronically, and interviews are conducted over the phone. Following completion of surveys and interviews, participants receive electronic Amazon gift cards ($30-35) as a thank you for their time. The STD-to-PrEP Demonstration Project (STUDY19060124) was given a non-human subject designation by the University of Pittsburgh Institutional Review Board (IRB).

3.1.3 Data Description

The complete STD-to-PrEP Demonstration Project includes approximately 102 women and men. Data for ten women were used for this thesis. Informed consent was completed prior to the

phone interview, which was conducted by the University of Pittsburgh sexual health navigator and took 35 minutes. The interview included questions around HIV prevention/PrEP decision making process, PrEP uptake, and STI attitudes and decision-making. Participants were told that their name would not be included in the audio recording, they could decline to answer any questions, and could withdraw at any point in time. Interviews were audio-recorded and transcribed verbatim.

Ten interview transcripts were purposively selected to include women across PrEP interest categories and included interviews with women who accepted a PrEP referral (n=3) or were still in the contemplation phase of deciding to take PrEP (n=7). No personal identifiers such as name, date of birth, phone number or email were included in the interview transcripts so that confidentiality could be maintained. Demographic information (i.e., age, race, ethnicity) of the ten participants was also shared. Of the ten women included, eight identified as Black non-Hispanic, one identified as White non-Hispanic, and one did not disclose race/ethnicity. The age of the participants ranged from 23 years old to 33 years old. One participant did not share age data. The average age of the nine participants that provided age was 27. Before beginning the analysis of the interviews, an IRB application (STUDY21020114) was submitted and was exempt from IRB approval as it was given a nonhuman research designation.

3.1.4 Analysis

Interview transcripts were managed and analyzed in Dedoose, a web-based qualitative data management software. In order to effectively analyze the interviews, a form of grounded theory method was used [Foley & Timonen, 2015]. Geraldine Foley and Virpi Timonen describe grounded theory as “a systematic set of techniques and procedures that enable researchers to identify concepts and build theory from qualitative data” [2015, pg. 1197]. The larger purpose of

this theory is to identify and explain how and why people behave in certain ways [Corbin & Strauss, 2008].

There are three stages in coding: initial, intermediate, and advanced [Chun et al., 2019]. Initial coding is used to start breaking up the data to compare different experiences looking for similarities and differences [Chun et al., 2019]. This coding is done by understanding what the participants say they are "doing, feeling, and being" [Foley & Timonen, 2015]. Once categories begin to develop, intermediate coding begins and involves the formation of abstract concepts and the refinement of core categories[Chun et al., 2019]. The purpose of this stage is to get a better idea of what is happening in the data [Chun et al., 2019]. The third and final stage of coding is advanced coding. In advanced coding the researcher is attempting to identify a theory. Birks and Mills proposed a storyline technique to assist in this stage of coding. They define storyline as "a strategy for facilitating integration, construction, formulation, and presentation of research findings through the production of a coherent grounding theory" [Birks & Mills, 2015, pg. 180]. This process builds a story that helps to draw a line between all the categories identified [Chun et al., 2019].

Throughout the process of coding, one of the most important tools to use is memo writing. In Chun et al.'s articles, they state that memos are meant to detail "why and how decisions were made related to sampling, coding, collapsing of codes, making of new codes, separating codes, producing a category, and identifying relationships abstracted to a higher level of analysis" [2019, pg. 4], referencing the work of Birks and Mills [2015].

3.2 Literature Review

3.2.1 Search Strategy

To contextualize the qualitative interview analysis, a rapid review identified existing peer-reviewed published literature focused on interventions engaging women in PrEP care. Relevant literature was identified through a combination of terms related to PrEP, women, and intervention. Appendix A outlines the full Medline search. The search was conducted in November 2020 and was changed slightly to get a more targeted search for articles that specifically mentioned women. All publication dates were considered for inclusion. Helena VonVille, a Research and Instruction Librarian at the University of Pittsburgh's Health Sciences Library System, provided input and guidance regarding the search strategy. An initial title and abstract screening ensured selected studies broadly reflected inclusion and exclusion criteria. Full text documents of articles meeting inclusion criteria were then obtained and reviewed for final eligibility.

3.2.2 Inclusion Criteria

Articles included met the following criteria: (1) PrEP focused; (2) cisgender women; (3) intervention focused; (4) peer-reviewed; and (5) written in English. Articles were excluded if they: (1) the majority of the sample were transgender women, transgender men, men who have sex with men, or cisgender men; (2) included HIV-positive participants; (3) did not focus on an intervention to promote uptake, adherence, or compliance to PrEP; (4) were not an original study; (5) included participants of doctors/pharmacists/students/etc.; (6) were not a study about PrEP; and (7) other

(e.g., PrEP was only a small portion of the study's focus, the study was not completed yet, and information about improving clinical trial adherence that was not generalizable).

3.2.3 Data Extraction and Analysis

The full set of articles was reviewed to understand women's interest in PrEP, barriers to use, facilitators to use, interventions that currently exist, and suggestions for potential interventions.

4.0 Results

4.1 Qualitative Interview Findings

Results of the analysis conducted with data from the interviews with women in the STD-to-PrEP Project (n=10) revealed the decision-making process that women go through when determining whether they should take PrEP. In the end, the core category was decision-making influences and there were five sub-categories:

1. HIV, PrEP, and STI Knowledge
2. Stigma and Risk Perception
3. Barriers to PrEP Use
4. Facilitators to PrEP Use
5. Women's Preferences for PrEP Outreach

A total of 28 codes were organized into the five sub-categories. Each of these codes and categories offered insight into the women's decision-making process and factors that influence women's decision-making process for taking PrEP (see Figures 1 and 2 below for a breakdown of the coding process). The following sections will discuss codes in each sub-category and how the content in each contributes to the decision-making process.

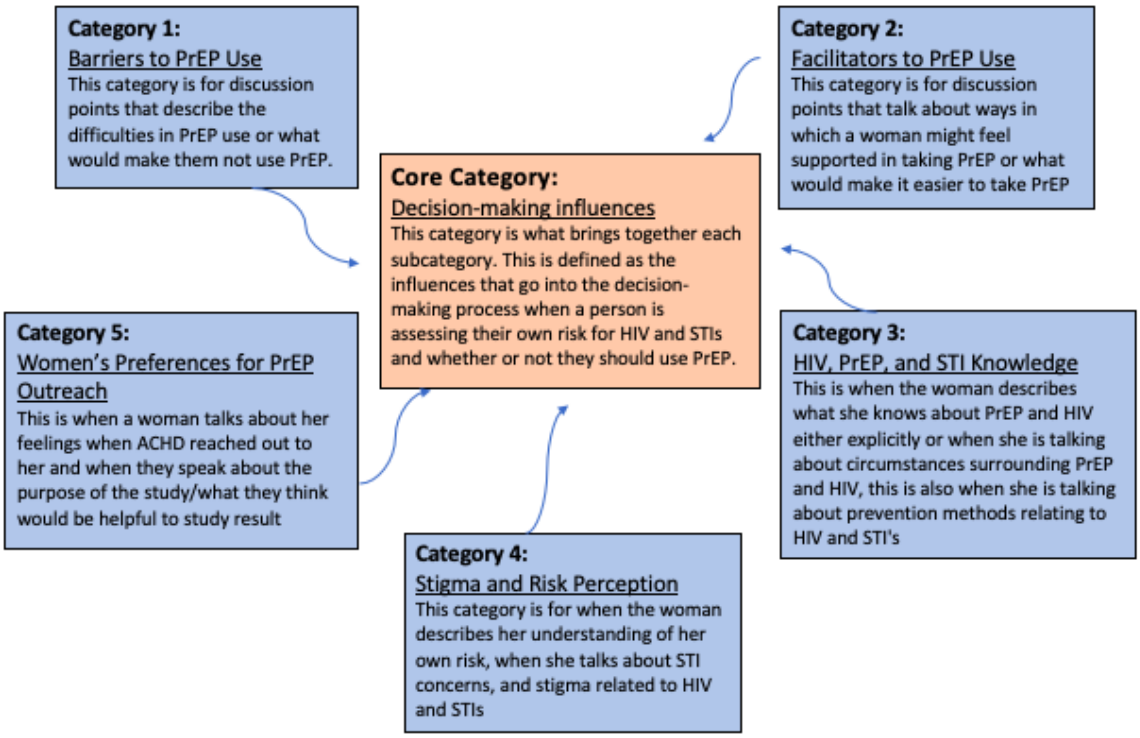

Figure 1. Chart of Core Category and Subcategories

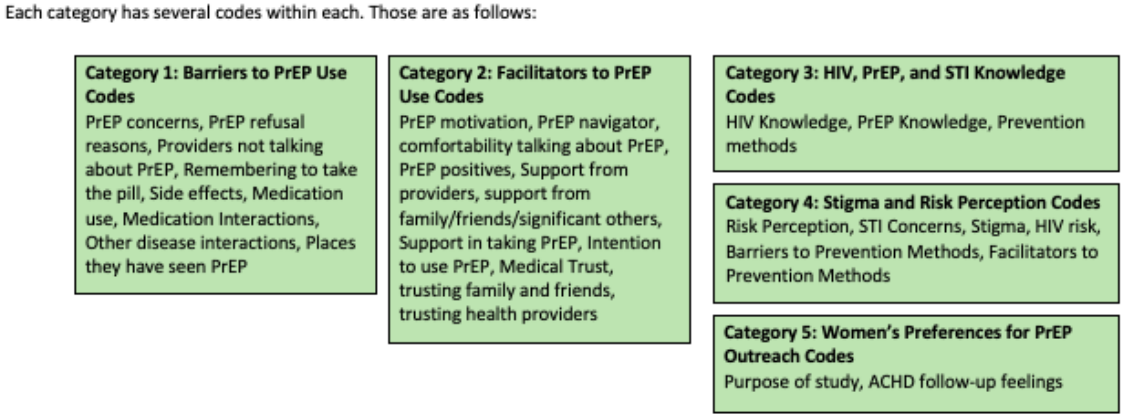

Figure 2. Chart of Codes within the Subcategories

4.1.1 HIV, PrEP, and STI Knowledge

HIV, PrEP, and STI knowledge included codes such as HIV knowledge, PrEP knowledge, and prevention methods. The definitions for these codes can be found in memo 1 in Appendix B.

When reporting HIV prevention methods, respondents described their use of condoms, abstinence, and/or HIV testing. Women spoke about ensuring that their partners were tested before they became intimate or deciding to forego condom use. HIV knowledge was present throughout the interviews in that participants understood that HIV risk increases when having multiple sex partners. However, there were misconceptions about HIV risk. One woman assumed that everyone who has HIV is medicated for it.

While knowledge about STIs was evident in this sample of women, knowledge about HIV and HIV risk perception was low. The following quote elucidates an important point within this sample of women. A woman spoke about being more worried about STIs than HIV because *"you won't come across HIV more than chlamydia or I guess gonorrhea or anything like that."* While It is possible that this does not show a lack of knowledge about HIV or HIV risk, but a well-informed personal risk benefit analysis, the distinction between HIV and STI worry is important to note.

There were also a large number of questions that were asked particularly about side effects of PrEP and how it provides protection. With that being said, most women knew that generally PrEP was for HIV protection.

Lastly, the women did note that they thought it was for "gay couples" because of the advertisements they had seen for PrEP. It was also noted in an interview that spoke about commercials for PrEP that *"nobody brings it up because this is the first time hearing it. I only saw commercials about it, but not in a physician, never. Even with my annual gynecologist visits, they*

don't really- it's always birth control, never STD or STI prevention." While STI knowledge was evident in this sample of women, knowledge about HIV and HIV risk was low.

4.1.2 Stigma and Risk Perception

Codes for this category included risk perception, STI concerns, stigma, HIV risk, barriers to prevention methods, and facilitators to prevention methods. The definitions for these codes can be found in memo 1 in Appendix B.

Content in this category made it clear that these women understood HIV risk behavior, most often citing having multiple sexual partners. In some of their answers, there was a level of stigma associated with HIV was demonstrated in that they were very insistent that they were not participating in behaviors that would put them at risk for HIV. One woman said, *"I'm not really concerned because I don't put myself out there like that."* Another woman stated, *"I am only sleeping with one person, and I think it's for people who have multiple sexual partners."* Lastly, a woman stated, *"I kind of just don't think that PrEP is for me but maybe other people that are more out there, more sexual.".* They had an understanding of risky behavior but did not associate their multiple STIs with risk.

Three of the ten women in this cohort acknowledged some level of HIV risk by agreeing to take PrEP, but seven of the other women said they have never been concerned about HIV and that they do not view themselves at risk. For example, when one woman was asked if she has ever felt concerned about her risk for HIV she responded *"No, because I feel that I'm not doing at-risk behaviors to get HIV.".* Another participant stated:

I'm not too concerned because I haven't really had sexual intercourses with anybody. And when I do, they're not new partners for the most part. They're always the same people. But then because you don't know who they're having sex with, so that becomes a problem as well because they could be having sex with somebody that HIV-positive, and we don't know, and they come back and have sex with me.

Content in this category can be closely associated with HIV, PrEP, and STI knowledge because less knowledge about those subjects can create lower risk perceptions. Women were also asked about barriers and facilitators to prevention methods. Most of the women said that condoms were their form of prevention against HIV and STIs, but then said things like *"alcohol", "getting caught up in the moment", and "not liking the feeling"* are barriers to prevention methods, particularly condoms.

Perhaps the most powerful quote in this interview analysis speaks about stigma and possible intervention opportunities for educating about HIV and PrEP:

Is there any way that- I don't know how to word it. All right. So it's like a lot of people have this stigma about HIV where it's like, 'Oh if I hug you, I will catch it. If I kiss you, I will catch it. If you're positive, I'll automatically catch it'. However, like I said, one of my closet friends has it , and she has taught me so much about the disease and I'm like 'Wow. It's amazing that we're not taught these things ahead of time.

4.1.3 Barriers to PrEP Use

Barriers to PrEP use included interview codes such as PrEP concerns, PrEP refusal reasons, providers not talking about PrEP, remembering to take the pill, side effects, medication use,

medication interactions, other disease interactions, and place they have seen PrEP. The content related to these codes gave insight into what barriers exist for women in Pittsburgh, Pennsylvania, and taking PrEP. For definitions of these codes, see memo 1 in Appendix B.

In general, women have a lot of concerns about how PrEP impacts other aspects of their life such as their other illnesses. One woman asked, "*If you have diabetes or maybe high blood pressure or something does it affect you differently?"* Another woman was concerned about how it might interact with respiratory illnesses and polycystic ovary syndrome (PCOS).

Remembering to take the pill and side effects were the most common barriers to PrEP use among this sample of women. They often commented that they had other medications they are supposed to take daily already, and they cannot remember to do that so they would definitely not remember to take PrEP every day. One woman asked how often PrEP was taken and when informed that it was a daily medication, the woman replied *"Yeah. I can't even remember to take a birth control pill."* Another woman said:

I don't take pills, so that would be difficult, me remembering to take that every single day. That's why I don't take birth control, because I mess it up. I don't know. I can't take pills on the regular. I've never had to. So, me just doing it out of the blue, it becomes a problem.

Several respondents cited potential side effects as a barrier to PrEP uptake (n=9). Most people referenced not wanting to experience any side effects as they are especially sensitive to medication side effects, one woman claiming:

I don't think my body is going to have a good reaction to it. I'm allergic to most antibiotics too, so I have reactions to that. So, imagine me taking just a random-kind of, I guess it's kind of like

birth control but not like a birth control, it just kind of stops- not stops you, but prevent you from getting it. I just think my body's not going to react to it good.

Others were genuinely curious about the side effects as they were unsure of what side effects were associated with PrEP. In one instance, the interviewer asked if there are any other challenges to PrEP other than taking it every day; the woman responded, *"No, other than if there are side effects."* When women were asked why they would not take PrEP, variety of responses were observed in addition to what has already been mentioned including: needing more information to feel comfortable making that decision, not considering themselves at risk for HIV at the time of the interview, not being concerned about their HIV risk at all, and thinking that once you start the medication, you have to take it forever.

4.1.4 Facilitators to PrEP Use

Facilitators to PrEP use included interview codes such as PrEP motivation, PrEP navigator, comfortability talking about PrEP, PrEP positives, support from providers, support from family/friends/significant others, support in taking PrEP, intention to use PrEP, medical trust, trusting family and friends, and trusting health providers. The definitions for these codes can be found in memo 1 in Appendix B.

The most common answer when women were asked about the pros of PrEP was that it can prevent HIV. The amount of trust these women have for their medical care providers is particularly striking. In every interview the women cited trusting their providers, specifically their gynecologists and obstetricians. This was most often in response to the questions; "who are people you trust to learn about health from?" and "who are people you trust to talk about your sexual

health and HIV prevention?" Others also cited trusting their friends, family, or significant other in regard to these same questions, but those who cited providers were in the majority. Another aspect of this category was how women could be supported in their PrEP use. Women typically said that frequent visits with medical providers, having an alarm to remind them to take the pill, having the resources to do their own research on PrEP, and support from significant others would support their PrEP use. Further, being armed with information about PrEP, understanding HIV epidemiology in their area, having PrEP navigators to help them through the process, having some training on how to talk to their partners about PrEP, and if it were a once a month or even once a week pill rather than daily would be helpful in supporting their PrEP use. Lastly, an important aspect of PrEP facilitation is understanding how comfortable women felt talking about it and in this specific subset, women said they would feel comfortable discussing PrEP with their providers or a PrEP navigator and preferred that the conversation took place face-to-face.

4.1.5 Women's Preferences for PrEP Outreach

Content related to this category allowed for understanding how women can be more comfortable when contacted for PrEP initiation. The interview codes for this category included health department follow-up feelings and study reactions. Definitions of these codes can be found in memo 1 in Appendix B.

Women's reactions to health department follow-up were mixed. They ranged from dislike to not minding. One woman said, "I thought it was kind of- I don't remember signing anything to release my information, so I was kind of surprised, but I didn't mind." Another woman said, "Yeah I didn't care. It didn't bother me." On the other hand, one woman said, "It was okay. I just prefer to be

notified when I'm about to get those type of calls, so I know to step outside if I'm at work or something." Lastly, other women described being upset, for instance:

I kind of didn't like it. I felt like my privacy was- I know it's something they got to tell, but I felt like it's a lot that- I felt like that was a personal, private thing that I didn't like. I don't like that. I know that somebody got to-they got to report them, but yeah, for me, personally, that's something I don't like. Like I said, me, personally, I don't talk about my sexual life unless it's with my sexual partner or doctor. So, yeah, it's kind of embarrassing and a little shameful.

4.2 Literature Review Findings

The rapid review yielded 675 articles eligible for preliminary screening; of those, 123 underwent full-text screening and 59 were deemed eligible for review inclusion. Of those 59 articles, only five were intervention focused. The other 52 articles served as background. This points to the lack of intervention strategies present. Few women-centered interventions exist to support women's uptake and adherence to PrEP. The interventions that do exist ranged from educational videos to multi-level programming. The first article discussed the results of piloting an intervention that was a video about post-exposure prophylaxis (PEP) and PrEP. They found that of their sample, "89% rated the video as good or better" [Bond & Ramos, 2019, pg. 7]. The regression for the data was done, it was found that factors relating to higher scores for the video were "not engaging in any current drug use, using condoms all the time in the past 3 months, higher household income, lower education level, and less experience of sexual abuse as an adult" Bond & Ramos, 2019, pg. 7].

Similarly, another article evaluated a computer-based training program to teach adults who at risk for HIV about PrEP. The study was targeted towards teaching PWID about HIV and PrEP. The program modules contained educational material and multiple-choice questions. The participants received immediate feedback for responses and incentives when they answered correctly. The modules were divided into three parts, the first about HIV, the second about PrEP, and the third about HIV risk behaviors. The study found that HIV and PrEP knowledge increased following the completion of each module [Getty et al., 2018].

The next article was also technology-based. This study "adapted an SMS platform to send PrEP-tailored, theory-based SMS that also allowed for clients to communicate with a remote nurse" [Pintye et al., 2020, pg. 55]. The study found that the texts "expanded support for PrEP and created additional opportunities for women to have a dialogue about PrEP outside a clinic setting" [Pintye et al., 2020, pg. 55]. The women were able to ask questions and get answers in real time about their PrEP use and that was found to be a big facilitator to use [Pintye et al., 2020].

One article looked to address the issue of messaging around PrEP. This article discussed the process for creating a palm card that had information about HIV prevention and PrEP. A palm card is typically a small card that lists brief, relevant information on a certain topic. The authors tested the card among experts and community members who found the card to be "informative and potentially motivational" [Collier et al., 2018, pg.13]. The majority of the reviewers said that it served as motivation to start engaging with a healthcare provider to get more information or access to HIV prevention and at the very least motivate women to start having conversations with sexual partners about risks [Collier et al., 2018].

The last article looked at discussed the intervention called CHRP-BB (bio-behavioral community-friendly health recovery program). This is an intervention for opioid-dependent people

who use drugs. The intervention has several steps. The first is that individuals were screened for eligibility and if eligible, they were referred for additional screening to be prescribed PrEP. Those who initiated PrEP are part of the study. The intervention is a manual guided intervention comprised of four, 50 minute weekly group meeting that address HIV risk behaviors and PrEP adherence among high risk people who use drugs in treatment [Shrestha et al., 2019]. The groups were led by trained facilitators. The material for the groups were given using three modalities: verbal, visual, and experiential. The groups were taught content relating to drug and sex related HIV risk reduction, PrEP basics, motivation to encourage PrEP use/adherence, problem solving skills, facilitators of PrEP adherence, enhancing decision-making related to PrEP, and overcoming stigma [Shrestha et al., 2019]. The intervention also included daily texts where participants received PrEP reminders. The intervention was found to be effective, retention was high throughout the intervention, and attitudes towards the program were positive [Shrestha et al., 2019]. These interventions are summarized in Table 1.

Table 1. Women-centered PrEP Interventions

Intervention Name	Method of Delivery	Key Components	Important Notes
PEP and PrEP Video [Bond & Ramos, 2019]	Video	An educational video about PEP and PrEP.	Does not seem geared towards those most at risk Highest scores were from those who did not use drugs and reported always using condoms
HIV and PrEP [Getty et al., 2018]	Computer training program	Three modules that contained educational materials and multiple-choice questions. Participants received	All PWID were in methadone treatment centers when training was completed, this might not be appropriate for those

		immediate feedback and incentives.	not ready for treatment.
SMS Platform [Pintye et al., 2020]	Cell phone	The program allowed for women to receive PrEP tailored messaging and created opportunities for women to ask questions and get answers in real time.	The study was done in Kenya; however, this could help to alleviate barriers with women because the prevention specialist would be able to immediately address any concerns at the time of taking PrEP.
PrEP Messaging [Collier et al., 2018]	Palm Card	The card contained information about HIV prevention and PrEP that providers could take into appointments with patients to provide motivational information.	The card was tested among experts and community members who found the card to be informative and motivational enough to start engaging with the healthcare provider to get more information or at least start having conversations with their partners.
CHRP-BB [Shrestha et al., 2019]	Weekly group meetings/cell phone	This intervention is a manual guided intervention comprised of four, 50 minute weekly group meeting that address HIV risk behaviors and PrEP adherence among high risk people who use drugs in treatment [Shrestha et al., 2019].	The treatment was found to be effective, retention was high, and attitudes towards the program were positive. However, the PWID were in treatment once again so this may not be appropriate for someone who is not ready for treatment.

Table 1 Continued

5.0 Discussion

The qualitative analysis of interview data revealed many gaps in the current PrEP care provided. The comprehensive review of literature pointed to lack of comprehensive, flexible women-centered PrEP interventions. The results of this thesis show that women w face many barriers to using PrEP as an HIV prevention strategy and that addressing those concerns and providing effective solutions will require individualized approach.

While the literature review demonstrated that in general women were interested in taking PrEP, aside from women who experience IPV, where the interest was mixed [Carley et al., 2019; Kuo et al., 2016; Kwakwa et al., 2016; Peitzmeier et al., 2017; Rubtsova et al., 2013; Taggart et al., 2020; Willie et al., 2020], the content analysis of the ten interviews shows that PrEP interest for women in Pittsburgh, PA is low. A Of the ten interviews analyzed for this study, only three of those ten were interested in PrEP use and starting PrEP.

The literature indicated that the major barriers for women taking PrEP were poverty, incarceration, unemployment, distrust of providers and locations where HIV prevention services are offered, dislike of condom use, IPV, challenges related to gendered power, cultural issues, stigma associated with HIV and women's sexual behavior, and a lack of intervention strategies that address risk across multiple levels [Abrams et al., 2020]. These barriers were identified and contextualized in women's discussion of HIV and HIV risk in the interviews. Women's perception of HIV risk varied by participant and a distinction between STI risk and HIV risk offers important leverage point for education efforts. The interview also highlighted that significant stigma still exists related to HIV and women's sexual behavior. Furthermore, women expressed concerns over

medicinal cross-reactions with PrEP and the potential impact on other chronic illnesses. They were also very concerned with daily dosage of PrEP and the side effects associated with PrEP. This informs researchers that PrEP knowledge and HIV knowledge are low in this cohort of women. This is further elucidated in the interviews when participants were asked about what they knew about PrEP and they were not sure.

The literature demonstrated that facilitators to PrEP use among women included PrEP being covered by insurance plans, PrEP as a good contingency plan if condoms fail, PrEP reduces HIV incidence in the community, and lastly, learning that there are few side effects associated with taking PrEP [Collier et al., 2017], as well as personal motivations and adherence strategies [Corneli et al., 2015]. The interview analysis reflects those same facilitators to PrEP use among women. Protection from HIV was a critical facilitator for PrEP use in relation to condom failure or not using condoms; having reminders to take the pill were also cited, and having support from family, friends, or their significant other. However, an area where the most difference was found is the level of concern for side effects. Once the interviewer explained what the side effects were, that did not change how women perceived the risk of them. They were still hesitant to use PrEP after learning the side effects. While there are few side effects, it is important to consider how the severity of those side effects impacts women's decision-making.

Several articles in the rapid review of intervention literature provided recommendations to improve PrEP engagement among women, which included using theories or models [Adams et al., 2020; Biello et al., 2018; Roth et al., 2019; Shrestha et al., 2017]. Of these, the Information-Motivation-Behavior Skills model offers great potential for PrEP intervention development for women. The results from using the model found three components for interventions to target specifically for people who use drugs: (1) Understanding PrEP-related information like

effectiveness, side effects, adherence, perceived affordability, and risk compensation; (2) Personal motivation like acceptability, anticipated HIV stigma, safe sex initiation, safe drug use practices, perceived and controlled risk of HIV and social motivation like prevention altruism, peer values and medication use, peer sex and drug use norms, dyadic decision making; (3) The development of practical behavioral skills in adhering to PrEP medications, managing side effects, negotiating PrEP use, sustaining motivation, and safe sex drug use practices in the context of PrEP [Shrestha et al., 2017]. Although this model was specifically referencing use of PrEP by women who inject drugs, the general areas they focus on for an intervention are applicable in the interview cohort.

The interviews found that women did not have a clear understanding of what exactly PrEP is including its effectiveness, side effects, adherence, perceived affordability, and risk compensation. The women also expressed concern about not being able to adhere to PrEP because they had to remember to take the pill daily or they lacked an adequate social support system. This model could be useful in combating the barriers that were seen in this specific cohort.

Another area for improvement found in the literature was providing culturally appropriate care and to that extent changing the target audience for PrEP advertisements. The literature suggested understanding who these women trust to receive information from [Park et al., 2019] and how relationships play a role in PrEP decision-making, especially in regard to IPV [Atkins et al., 2010; Holmes et al., 2020; Willie et al., 2017; Willie et al., 2019]. The interview analysis found that a large majority of these women trusted their medical provider to give them health information or sexual health information. This was inconsistent with what the literature cited. The literature alleged that women, especially Black women, have a history of provider mistrust which needs to be considered in engaging them in care. It is important to note that eight out of the ten women were Black women.

To that end, for this cohort it could be useful to examine how providers engage these specific women in care that results in greater trust as compared to other medical providers giving PrEP care. However, it is important to consider that some of the women also considered family, friends, and/or significant others as trustworthy sources of information. Further, in the interviews, several women spoke about the importance of their significant others or family members and their reaction to starting PrEP. This supports the notion that women need to be seen as more than just an individual in addressing the appropriate approach to care. Their social and familial support systems should also be taken into account to better engage them in care. If providers listen to patients' concerns and respond to them accordingly, they might build trust with the patient.

In regard to PrEP messaging, the literature talked about meeting women where they were, especially in regard to injection drug use. Advertising PrEP in places such as "syringe exchange sites, naloxone distribution programs, opioid substitution therapy sites, and in emergency rooms or clinics" [McFarland et al., 2020, pg. 1292] would be beneficial. This was further supported by the interview analysis. The women spoke about not seeing themselves represented in PrEP commercials or billboards and therefore they did not think it was an option for them. The lack of representation of women in PrEP advertising has potential to contribute to misinformation about PrEP and HIV risk among women.

The most significant area of improvement for current interventions needs to be in HIV risk perception and knowledge of PrEP. This was highlighted in the form of doctor's recognizing and talking about risk, as well increasing HIV knowledge through education. Providers can identify patients at risk such as through the use of electronic health records [Krakower et al., 2019; Ridgway et al., 2018; Tomko et al., 2019] and further providers need to understand how changes in perceived risk by the person can influence their willingness to take PrEP [Lankowski et al., 2019]. These

articles highlight the opportunity for healthcare providers to continually assess and educate HIV risk because it can fluctuate with time. The model of care needs to be more flexible in order to continue to engage people in PrEP [Lankowski et al., 2019]. Other areas of the literature focused on the lack of knowledge surrounding HIV and PrEP, one finding that men had a higher initiation rate which was associated with previous knowledge [Kwakwa et al., 2018]. Another study found that women would be more willing or likely to take PrEP if they were informed about HIV epidemiology in their area [Kwakwa et al., 2016].

Lastly, the literature spoke about integrating PrEP counselling, education, and HIV risk awareness education into clinic appointments [O'Connell et al., 2020; Park et al., 2019; Taggart et al., 2020] and how this would increase HIV and PrEP knowledge. Each of these points were evident in the interview analysis. One woman spoke specifically about how she would take PrEP if HIV prevalence was higher in her community. Further, in the interview analysis, women talked about their lack of knowledge and exposure to information to PrEP, even from their doctors. Additionally, most women expressed low or no concern for HIV risk, which may not be accurately represent their risk of exposure to HIV. By implementing education for HIV and PrEP in clinics or doctors' offices, women will have more information and tools to support decision-making around HIV prevention and PrEP. While this type of education would ideally begin in high school, healthcare settings have great potential to serve as crucial sites for STI and HIV prevention and education.

A shortcoming of three out of the five intervention methods from the literature is that they were geared towards PWID. That is suboptimal because it illustrates that these interventions are not targeting those most at risk, as these people were in treatment already. These samples, therefore, may not be representative of those not ready for treatment for substance use disorder. This also

means the findings may not be as applicable to women who do not have substance use disorder. However, the important aspects of those three interventions are that educational videos can be effective, especially those that provide immediate feedback, and even further that interventions such as the CHRP-BB model can be implemented and be successful. These interventions should be applied to different at-risk populations and evaluated for effectiveness.

The other two interventions are the most directly relevant to the outcomes of the interview analysis. The first was the SMS platform [Pintye et al., 2020], which given the analysis of the interview and women being concerned about remembering to take the pill, would be potentially effective. As technology evolves and becomes an increasingly important part of our world, it needs to be part of PrEP prevention strategies. This would make confronting barriers and promoting facilitators of PrEP much easier if prevention specialists could do them in real time as they are presented to the user. Secondly was the PrEP messaging intervention with the creation of the palm card [Collier et al., 2018]. This would be useful as researchers suggest that providers should be having this conversation with women to help them understand their HIV risk and educating on PrEP. It can be used as a model to guide the creation of other palm cards or more educational materials that providers can use to facilitate productive conversations with women.

Clear gaps exist in the current care being provided to women in regard to PrEP. Several already existing interventions could be combined to create an effective approach, but the most important components of any future intervention are as follows: First, educating women about their HIV risk and PrEP any chance that is available. Whether in clinics, providers' offices, or treatment centers, providing information is key. The palm card would be an appropriate addition in this step to help providers get clear, concise information to women in an effective way. Additionally, listening to what women have to say about their own barriers and what would help them to stay adherent to

PrEP, whether that is through interviews or surveys, can be useful in continuing to improve these outreach attempts. Women are the experts in topics regarding their own needs and health. Further, providers should work alongside women to develop adherence strategies. PrEP navigators are crucial for this approach, as well as the development of the SMS platform. It is incredibly important to understand who they are in the bigger picture, what relationships they have that would make PrEP uptake and adherence more or less difficult. If they feel like their provider or navigator understands them and wants to help them navigate their particular barriers, they will be more willing to work through them and stay adherent to PrEP.

There were two limitations to this review. The first is that the interview analysis occurred in a small cohort of women, so that generalizing the results to women as a whole is not possible. The second limitation is that there was only one coder. This was due to the time constraints on the project.

While these are limitations exist, the strength of this study is that the interviews were done with women who would be logical targets for PrEP. The interview participants provided incredible insights on barriers, facilitators, attitudes, knowledge, and broadly decision-making influences on PrEP. Further, they showed in their answers ways in which public health practitioners can address some of the biggest failings in current HIV prevention interventions, as well as use some of the strengths of current interventions.

6.0 Conclusions

Women have largely been ignored in efforts for PrEP provision, although it has potential to be an ideal prevention strategy. While women represent 19% of new HIV cases, in 2018 only 7% of PrEP users were women. Despite there being nearly one million people who benefit from PrEP, uptake is low, especially in women. In order to better understand this problem, this thesis explored how women in Pittsburgh, Pennsylvania, describe their PrEP decision-making processes, barriers, and facilitators to PrEP use and what current interventions exist to engage women in PrEP care through a rapid review of the literature.

The result of the literature review and interview analysis suggest that women face many barriers to using PrEP and that addressing those concerns and providing effective solutions will take an individualized approach. Women have a lot to say about using PrEP, what they feel are barriers and facilitators, and ways in which PrEP providers can improve. It is imperative that we listen to what these women have to say if we want to increase PrEP use among this population. Women are diverse and sometimes different approaches will be needed, but it is clear that a one size fits all approach is not effective.

In summary, the most important aspects of a good PrEP intervention are educating women about their HIV risk and PrEP at any available moment, listening to what women have to say about their own barriers and facilitators to PrEP use, and creating adherence strategies with them. What seems to be lacking in current interventions is the incorporation of women in the design. In public health, there is often an approach to program planning where the researcher feels they know what is best. Those interventions are the ones that tend to not work because it did not consider the perspective

of the community. In short, including the community in which you are intending to impact in the design of the program, will likely make it more successful.

Appendix A Literature Review Search

Search line #	Search Query
1	Pre-Exposure Prophylaxis/
2	(prep or Pre-Exposure Prophylaxis or (preexposure adj1 prophylaxis)).ti,ab,kf,rn.
3	((emtricitabine and tenofovir) or DESCOVY or microbicide* or truvada or (vaginal adj1 ring)).ti,ab,kf,rn.
4	Emtricitabine, Tenofovir Disoproxil Fumarate Drug Combination/ or Emtricitabine/
5	1 or 2 or 3 or 4
6	HIV/
7	hiv infections/ or acquired immunodeficiency syndrome/
8	(((acquired or human) adj2 immunodeficiency) or aids or hiv).ti,ab,kf.
9	6 or 7 or 8
10	5 and 9
11	women/ or pregnant women/ or female/
12	(women or female* or girls).ti,ab,kf.
13	11 or 12
14	10 and 13
15	evaluation studies/ or "evaluation studies as topic".pt. or program evaluation/ or validation studies/ or "validation studies as topic".pt. or (effectiveness or

	intervention or (pre- adj5 post-) or (pretest adj5 posttest) or (program* adj6 (evaluate or evaluated or evaluates or evaluating or evaluation or evaluations or evaluator or evaluators))).ti,ab,kf.
16	Counseling/ or Directive Counseling/
17	counseling.ti,ab,kf.
18	health knowledge, attitudes, practice/ or "patient acceptance of health care"/ or patient compliance/ or medication adherence/ or treatment refusal/
19	Health Promotion/
20	15 or 16 or 17 or 18 or 19
21	14 and 20
22	21 not ((exp africa/ or exp asia/ or exp australia/ or exp canada/ or exp central america/ or exp europe/ or exp south america/) not ((exp africa/ or exp asia/ or exp australia/ or exp canada/ or exp central america/ or exp europe/ or exp south america/) and (north america/ or exp united states/)))
23	limit 22 to yr="2012 - 2021"
24	23 and english.la.
25	"systematic review".pt. or "Systematic Reviews as Topic"/ or (data adj2 (extract or extracting or extractings or extraction or extraction)).ti,ab,kf. or ((cochrane adj2 database adj2 systematic adj2 reviews) or (evidence adj2 technology adj2 assessment)).jn. or (((comprehensive* or integrative or mapping or rapid or scoping or systematic or systematical or systematically or systematicaly or systematicly or umbrella) adj3 (bibliographical or bibliographically or bibliographics or literature or review or reviews)) or (state

	adj3 art adj1 review) or (research adj2 synthesis) or ((data or information) adj3 synthesis)).ti,ab,kf. or ((review adj3 (rationale or evidence)).ti,ab. and "review".pt.) or (cinahl or (cochrane adj3 (trial or trials)) or embase or medline or psyclit or (psycinfo not (psycinfo adj1 database)) or pubmed or scopus or (sociological adj1 abstracts) or (web adj2 science)).ab. or "Meta-Analysis".pt. or "meta-analysis as topic"/ or "network meta-analysis"/ or ((meta adj2 (analyse or analyser or analyses or analysis or analytic or analytical or analytics or analyze or analyzed or analyzes)) or metaanalyse or Metaanalysen or metaanalyser or metaanalyses or metaanalysis* or metaanalytic or metaanalytical or metaanalytics or metaanalyze or metaanalyzed or metaanalyzes).ti,ab,kf.
26	10 and 20 and 25
27	26 not ((exp africa/ or exp asia/ or exp australia/ or exp canada/ or exp central america/ or exp europe/ or exp south america/) not ((exp africa/ or exp asia/ or exp australia/ or exp canada/ or exp central america/ or exp europe/ or exp south america/) and (north america/ or exp united states/)))
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Appendix B Grounded Theory Memo 1

Memo #1

2/27/21

The first round of open coding is done. I ended up with 28 codes. Below are the codes and their definitions:

1. ACHD Follow-up feelings: This was anytime that the person spoke about the phone call from the health department

2. Comfortability talking about PrEP: Situations in which the person described a situation where they would be comfortable talking about PrEP

3. HIV Knowledge: This is their knowledge of HIV

4. HIV risk: This is their understanding of what HIV risk looks like in other people

5. Intention to use PrEP: This is when they explicitly say that PrEP is right for them

6. Medication Interactions: This is when they ask questions or express concern about how PrEP interacts with other medications

7. Medication use: This is when they are talking about taking the pill every day and they express that they already use a daily medication

8. Other disease interactions: This is when they ask questions about or express concerns about how PrEP would affect their other illnesses

9. Places they have seen PrEP: Places where PrEP has been advertised

10. PrEP Knowledge: This is their knowledge about PrEP

11. PrEP Motivation: This is when they express something that would motivate them to take PrEP

12. PrEP Navigator: This is when they express that something like a PrEP navigator or peer navigator would be helpful in supporting their PrEP use or who they want to talk to about PrEP

13. PrEP Positives: This is when they talk about pros of using PrEP

14. PrEP Concerns: This is when they express concern about certain aspects of PrEP but they aren't outright refusing it

15. PrEP Refusal Reasons: This is when they express something that would make them not take PrEP at all

16. Prevention Methods: This is when they talk about prevention methods and also the difficulties of utilizing these methods

17. Providers not talking about PrEP: This is when they say that providers have never spoken to them about PrEP

18. Purpose of study: This is when they are curious about the study and how it will be used

19. Remembering to take pill: This is when they express that they will not remember to take the pill or that they have trouble taking the pills they already have

20. Risk perception: This is when they talk about how they perceive their own HIV or STI risk

21. STI Concerns: This is when they talk about concerns they have with STIs

22. Side effects: This is when they express concern with taking PrEP because of the side effects

23. Stigma: This is when they talk about stigma from people in their community or their friends and family when it comes to taking PrEP

24. Support from providers: This is when they talk about feeling supported by providers in relation to PrEP use or talking about PrEP

25. Support from family/friends/significant others: This is when they talk about feeling supported by family/friends/significant others in relation to PrEP use or talking about PrEP

26. Support in taking PrEP: This is ways in which they explicitly say what would support them in taking PrEP

27. Trusting friends and family: This is when they talk about trusting friends and family to receive medical information

28. Trusting health providers: This is when they talk about trusting providers to receive medical information

After my first initial round of coding, some concepts I see forming are barriers to PrEP use, facilitators to PrEP use, medical trust, HIV and PrEP knowledge, stigma, study reactions, and risk perception. During my next round of coding, I will be focusing in on these concepts to combine some of the 28 codes I have now. The way I am thinking about organizing them are as follows:

Category: Barriers to PrEP use

Codes: PrEP concerns, PrEP refusal reasons, Providers not talking about PrEP, Remembering to take the pill, Side effects, Medication use, Medication Interactions, Other disease interactions, Places they have seen PrEP

Category: Facilitators to PrEP use

Codes: PrEP motivation, PrEP navigator, comfortability talking about PrEP, PrEP positives, Support from providers, support from family/friends/significant others. Support in taking PrEP, Intention to use PrEP

Category: Medical Trust

Codes: trusting family and friends, trusting health providers

Category: HIV and PrEP Knowledge

Codes: HIV Knowledge, PrEP Knowledge, Prevention methods

Category: Stigma

Codes: Stigma, HIV risk

Category: Study Reactions

Codes: Purpose of study, ACHD follow-up feelings

Category: Risk Perception

Codes: Risk Perception, STI Concerns

Observations:

So far, what I am seeing is interesting. The barriers to PrEP use were pretty much what I had expected them to based on of the literature. The facilitators are also pretty on par with what the literature said, except for the idea of a PrEP navigator, which is something that already exists, however, a more normalized and widespread use of them would be beneficial. It seems that in terms of an intervention that would be useful from the literature it would the SMS platform that sent reminder texts to participants.

The other interesting trend I am seeing is that most of these participants have low HIV and PrEP knowledge which is skewing their idea of their risk perception. It is interesting because each of these participants has tested positive for 4 STIs at this point, but do not think they are at risk for HIV or they aren't concerned at all about HIV. Another intervention that could be beneficial is to increase HIV and PrEP knowledge. I think the most important place for this to happen is within doctor's offices and clinics, but even more importantly within sex education at school. That idea is definitely controversial, but it will never be possible to change risk perception and HIV knowledge and in turn PrEP knowledge without reaching them at an age that they are especially vulnerable to this disease.

Appendix C Grounded Theory Memo 2

Memo #2

3/2/21

The second round of coding or axial coding is done. In this stage I created categories for the 28 codes made in open coding to fit into. There are 7 categories. They are below along with their definitions:

1. Medical Trust- This category is when the woman describes trusting in healthcare providers or trusting in friends and family for medical/sexual health advice
2. Barriers to PrEP Use- This category is for discussion points that describe the difficulties in PrEP use or what would make them not use PrEP
3. Facilitators to PrEP Use- This category is for discussion points that talk about ways in which a woman might feel supported in taking PrEP or what would make it easier to take PrEP
4. HIV, PrEP, and STI Knowledge- This is when the woman describes what she knows about PrEP and HIV either explicitly or when she is talking about circumstances surrounding PrEP and HIV, this is also when she is talking about prevention methods relating to HIV and STI's
5. Risk Perception- This category is for when the woman describes her understanding of her own risk and when she talks about STI concerns as she is often describing her understanding of her risk for STI's
6. Stigma- This category is when the woman is describing stigma that they would experience if they used PrEP and when they are displaying stigma and talking about what they think HIV and STI risk look like
7. Study Reactions- This is when a woman talks about her feelings when ACHD reached out to her and when they speak about the purpose of the study/what they think would be helpful to study result

Each category had several codes from the first round of coding attached to them. They are as follows:

Category: Barriers to PrEP use

Codes: PrEP concerns, PrEP refusal reasons, Providers not talking about PrEP, Remembering to take the pill, Side effects, Medication use, Medication Interactions, Other disease interactions, Places they have seen PrEP

Category: Facilitators to PrEP use

Codes: PrEP motivation, PrEP navigator, comfortability talking about PrEP, PrEP positives, Support from providers, support from family/friends/significant others. Support in taking PrEP, Intention to use PrEP,

Category: Medical Trust

Codes: trusting family and friends, trusting health providers

Category: HIV, PrEP and STI Knowledge

Codes: HIV Knowledge, PrEP Knowledge, Prevention methods

Category: Stigma

Codes: Stigma, HIV risk

Category: Study Reactions

Codes: Purpose of study, ACHD follow-up feelings

Category: Risk Perception

Codes: Risk Perception, STI Concerns

Upon further examination of the codes, the third round of coding will entail further defining prevention methods. There are two parts to that code. The first is when the woman talks about the prevention methods she uses and the second is when she talks about the easiest and hardest situations associated with using the prevention method. In this case, I think that I would create two additional codes that would be entitled “Barriers to using prevention methods” and “Facilitators to using prevention methods” As far as how I would code those in categories, I would likely add the

barriers one to Risk Perception because that will affect how a person views their risk or it won't change it, but it probably should change it. I would add the facilitators one also to Risk Perception because this could affect how they view their risk of contracting STIs.

As far as condensing categories, I think that I am going to combine Medical Trust to facilitators of PrEP use, because these are people whom they trust to receive medical and sexual health advice from, this would facilitate PrEP use if they heard about PrEP from those people. I also think I am going to combine risk perception and stigma because when reviewing the interviews, those often occurred in tandem with each other.

The categories for the third round will look like this:

1. Barriers to PrEP Use
2. Facilitators to PrEP Use
3. HIV, PrEP, and STI Knowledge
4. Stigma and Risk Perception
5. Study Reactions

Observations:

On this second review of the interviews, it is still incredibly interesting to me how risk perception is so low considering the background of each of these women. They do not believe they are at risk for HIV. While the circumstances in which a person gets an STI vary and that can contribute to low risk perception, doctors need to make these women aware that just the actual getting of an STI can increase risk, no matter the manner in which you receive the STI.

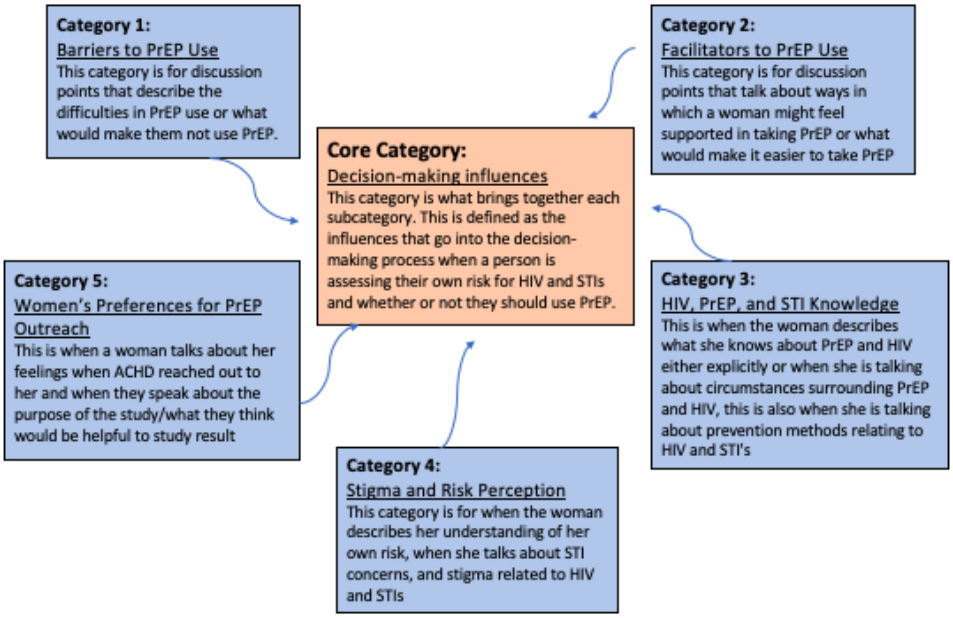
What is also interesting to me is the level of stigma that is associated with the behaviors that are considered risky. I didn't think that stigma would be so high. In short it seems that the actual risk in the situation is high, stigma related to risky behaviors is high, but their own perception of what their risk is, is incredibly low.

An intervention that could be useful in this circumstance is sort of what the pocket guide that was mentioned in the literature achieves; except I think it is even more important to highlight their own risk after seeing this disconnect. I would recommend some type of assessment that they can take to see what their actual risk score is rather than only a doctor assessing the risk because it may not get through to the patient that they are actually at risk. I also think once again that an important consideration for adoption would the SMS platform intervention. It is a recurring theme in the barriers to PrEP use category that remembering to take the pill and worrying about side effects are major barriers. This intervention would help to remind but also provide real-time assistance to those who are taking PrEP.

Appendix D Grounded Theory Memo 3

Memo #3
3/4/21

The third round of coding is done. In this stage I reduced the number of categories from 7 to 5. I have selected my core category which is decision-making influences. Below is a graphic that demonstrates how all codes and categories relate to the core category.



Each category has several codes within each. Those are as follows:

Category 1: Barriers to PrEP Use Codes
PrEP concerns, PrEP refusal reasons, Providers not talking about PrEP, Remembering to take the pill, Side effects, Medication use, Medication Interactions, Other disease interactions, Places they have seen PrEP

Category 2: Facilitators to PrEP Use Codes
PrEP motivation, PrEP navigator, comfortability talking about PrEP, PrEP positives, Support from providers, support from family/friends/significant others, Support in taking PrEP, Intention to use PrEP, Medical Trust, trusting family and friends, trusting health providers

Category 3: HIV, PrEP, and STI Knowledge Codes
HIV Knowledge, PrEP Knowledge, Prevention methods

Category 4: Stigma and Risk Perception Codes
Risk Perception, STI Concerns, Stigma, HIV risk, Barriers to Prevention Methods, Facilitators to Prevention Methods

Category 5: Women's Preferences for PrEP Outreach Codes
Purpose of study, ACHD follow-up feelings

Observations:

As I wrap up coding, it was nice to finally see a centralized theme arise. The idea that each of these categories plays into the decision-making process is a really important concept to understand. I feel as though often times, providers are not treating the patient as a whole, but rather they are treating their symptoms or disease and that is why so many people don't continue PrEP use or even start it. When you create an intervention, you have to continuously keep in mind how complex a person's circumstances are that will potentially keep them from properly taking a medicine but also how can you make what is going on in their life work for them, how can you change a barrier into a facilitator. Further, I think that while this interview data is not generalizable to the entire population or even to women, what it did show us is that you can learn a lot about what kind of decisions a person is going to make if you listen to them! These women were given the opportunity to talk and they shared valuable information on the obvious gaps in HIV, STI, and PrEP knowledge out there, as well as the disconnect between understanding what risky behaviors are (seen from comments made under the stigma or HIV risk code) and if they are at risk. You also see people giving suggestions on ways to fix these things if they are given the opportunity. In any future studies, the most important thing that a researcher or a provider can do is listen to what someone has to say. You can tailor any intervention if you know exactly what a person's barriers, facilitators, knowledge level, and understanding of their risk are.

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