Increasing Access to Pre-Exposure Prophylaxis (PrEP) Among Transgender Women and Trans Feminine Non-Binary Individuals in New York City

Augustus Klein

The Graduate Center, City University of New York

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INCREASING ACCESS TO PRE-EXPOSURE PROPHYLAXIS (PrEP) AMONG
TRANSGENDER WOMEN AND TRANS FEMININE NON-BINARY
INDIVIDUALS IN NEW YORK CITY

by

Augustus Klein

A dissertation submitted to the Graduate Faculty in Social Welfare in partial fulfillment of the
requirements for the degree of Doctor of Philosophy, The City University of New York

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Augustus Klein

This manuscript has been read and accepted for the Graduate Faculty in Social Welfare in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy.

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THE CITY UNIVERSITY OF NEW YORK
Abstract

Increasing Access to Pre-Exposure Prophylaxis (Prep) among Transgender Women and Trans Feminine Non-Binary Individuals in New York City

by

Augustus Klein

Advisor: Professor SJ Dodd

In the United States, transgender women (i.e., individuals born male whose gender identity is on the feminine spectrum) are a highly vulnerable and marginalized population at high risk for HIV. Substance use, survival sex work, depression, unstable housing, and high levels of victimization and violence are commonly reported by transgender women and trans feminine individuals, indicating the potential for multiple concurrent HIV risks and underlying vulnerabilities. Structural forms of discrimination may contribute to these risk factors, possibly leading to poor outcomes such as unemployment or underemployment, homelessness, and lack of access to gender affirming health care. Given this context, a biomedical intervention such as pre-exposure prophylaxis (PrEP), which can address risks from multiple types of exposure (i.e. sexual or parenteral) and be used effectively without negotiation between sexual partners, may be critical for effective HIV prevention packages that meet the needs of transgender women and trans feminine individuals. This dissertation was designed to identify the facilitators and barriers to PrEP access, uptake, and adherence among transgender women and trans feminine individuals at risk for HIV.

Thirty in-depth semi-structured interviews were conducted with two groups: a) transgender women and trans feminine individuals on PrEP (n=15) and b) transgender women
and trans feminine individuals not on PrEP. Participants were recruited throughout New York City using flyers, online social media postings, targeted emails to community-based organizations, and word of mouth. All interviews contained a core set of questions regarding factors at the individual, community, and systems level that might influence PrEP adoption, adherence, access, and willingness to use future biomedical PrEP interventions. Interviews were transcribed verbatim and coded thematically using Dedoose Qualitative Software.

The results of this dissertation suggest that to increase PrEP access, uptake, and adherence there is a need for the development and design of strategies and programs that contextualize HIV risk among transgender and non-binary women (TGNBW) as a social and psychological process rather than solely a byproduct of behavior. Situating HIV risk as a social and psychological process acknowledges that for TGNBW, risk factors are associated with multiple levels of social oppression (i.e., racism, transphobia, and sexism) (Sevelius, 2013; 2016). By recognizing that HIV risk is driven by social oppression, we begin to reframe the HIV prevention discussion to focus on the intersection of the structural, interpersonal, and individual level factors contributing to HIV risk, rather than focusing solely on individual behaviors. To do otherwise may contribute to the alarming rates of HIV infection among this community by creating barriers to PrEP.
Dedication

Be ashamed to die until you have won some victory for humanity."

—Horace Mann, First President of Antioch College

This dissertation is dedicated to my grandmother Matilda Zemsky who instilled in me a passion for and commitment to fighting for social, racial, and economic justice. Her love and support have been the guiding force behind my success.
Acknowledgements

Although my name appears on the front of this dissertation, so many people have contributed to its production. First and foremost, I would like to thank the thirty individuals who graciously gave their time to participate in this study. Their courage to live their authentic selves (in the face of pervasive stigma and discrimination) and to contribute to making the world a better place for themselves, their communities, and future generations of transgender and non-binary individuals is inspiring. I am eternally grateful to Olympia Perez and Charlie Solidum who each believed in my vision to create and engage in transgender health research that centers transgender and non-binary people. The success of this dissertation is due in large part to their decision to accept the position as my research assistants.

To my wife, Therine Youngblood your unwavering love and support provides me with the foundation to accomplish my dreams. None of my accomplishments would be possible without you. To Miles, the best dog in the world, you are my best friend and side kick who has taught me true unconditional love. Thank you to my in-laws, Anne and Stuart Youngblood, fifteen years ago you welcomed me into your family as if I was your own child. To my sister-in-law Abby Youngblood and her family Dan, Maya, and Leo Murphy, thank you for your love, support, and the meaningful and life changing role as uncle Gus.

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embarked on the journey to first get into a PhD program and then survive it. I am excited to see the ways in which our work grows together. Lastly, to the grandpas, Nathan, and Ben, thank you for holding space and providing me with copious amounts of support through texts, co-working dates, and much needed breaks for fun excursions to the upside down.

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CHAPTER 1: INTRODUCTION

Problem Formulation

Transgender, trans, non-binary or gender non-conforming are terms individuals use to describe a gender identity or expression that is different from their sex assigned at birth (Bornstein & Bergman, 2010; Lombardi, 2010; Namaste, 2000; NCTE, 2016). In the United States transgender women (i.e., individuals born male whose gender identity is on the feminine spectrum) are a highly vulnerable and marginalized population at high risk for HIV (Baral et al., 2013; Herbst et al., 2008). Despite a high prevalence of HIV, transgender women have historically been included under the behavioral risk group men who have sex with men (MSM), erasing their unique HIV risk and prevention needs and impeding understanding of accurate HIV prevalence and incidence rates (Sevelius et al., 2016). In HIV surveillance data and research, if included at all, transgender women represent a small number of individuals and are commonly referred to using the phrase ‘MSM and transgender women.’ When presenting results or implication of study findings, researchers do so without disaggregating transgender women from MSM. Thus, offering an inaccurate representation of the HIV prevalence and incidence among both groups.

In the early 1990’s, the introduction of the MSM category within HIV research aimed to describe behaviors rather than a complex set of sexual identities in an effort to acknowledge that behaviors, not identities placed people are risk for HIV infection (Young & Meyer, 2005). However, MSM as a behavioral risk category has been criticized for failing to account for sociocultural differences within this population that are seen as crucial to promoting sexual health and preventing HIV (Boellstorff, 2011; Young & Meyer, 2005). Universally applying the term MSM to a group of people may undermine the identities of sexual minorities, disregard
social meanings of sexuality, and ultimately fail in their aim to describe sexual behavior (Young & Meyer, 2005). The implication that MSM are a heterogeneous group is not devoid of cultural meaning. Young & Meyer (2005) assert that the way in which public health counts and categorizes people in research not only reveals a great deal about cultural attitudes and social constructions, it also shapes and perpetuates these attitudes and constructions. By incorporating transgender women within the category of MSM researchers convey several beliefs, including: 1) that transgender women are in fact men, 2) gender identity is not important in understanding sexual health and preventing HIV, and 3) transgender women's sexual practices and experiences are fundamentally the same as the men who are included in this category (Fiereck, 2015; Sevelius et al., 2016). While there is currently no literature on transgender women’s sexual health to support these beliefs, it is possible that devaluing and ignoring self-determined gender identity (by emphasizing biologically driven sexual behavior) within HIV research may exacerbate the HIV disparities experienced by transgender women (Sevelius et al., 2016). For example, research has demonstrated that gender affirmation (i.e., social and/or medical affirmation of one's gender identity) is a significant factor in both sexual risk-taking and health care seeking behaviors among transgender women (Colton-Meier, Fitzgerald, Pardo, & Babcock, 2011; Nuttbrock, Rosenblum, & Blumenstein, 2002; Nuttbrock et al., 2009; Sevelius, 2013; Sevelius et al., 2016). To fully characterize the disparities experienced by transgender women it is imperative to understand the psychosocial differences between transgender women and MSM. However, this cannot be explained from current research, which aggregates MSM and transgender women, privileging one group over the other (Fiereck, 2013; Sevelius et al., 2016).

Although transgender people are excluded from national data collection, research has consistently demonstrated that HIV disproportionately affects transgender women (Baral et al.,
A 2013 meta-analysis found that internationally transgender women have 49 times the odds of HIV infection compared to the general adult population (Baral et al., 2013). In the United States, transgender women have been identified as the group with the highest rates of new HIV diagnoses (2.1%) compared to cisgender men (1.2%) and cisgender women (0.4%) (CDC, 2013). Due to higher HIV rates among transgender women compared to MSM, it is possible that transgender women may increase perceived prevalence among MSM in studies that aggregate transgender women with MSM (Deutsch et al., 2015; Sevelius et al., 2016). Based on these aggregated HIV rates, funding for HIV prevention efforts are made available, yet the program and prevention strategies developed are designed solely for those who were assigned male at birth. Transgender women's unique social, emotional, sexual, and physical health needs and contexts of risk are not considered or addressed in prevention programming for MSM. For example, while some MSM do engage in sex work, research has consistently documented that due to pervasive economic disenfranchisement transgender women, in particular, those living in urban areas have higher rates of lifetime engagement in transactional sex (Nadal, Davidoff, & Fujii-Doe, 2014; Sevelius et al., 2016). Furthermore, transgender women sex workers have higher rates of HIV than cisgender male sex workers (Operario, Soma, & Underhill, 2008). Thus, it is imperative that HIV prevention programming for transgender women address sex work.

Substantial attention has been paid to pre-exposure prophylaxis (PrEP), the newest and most promising biomedical HIV prevention intervention to be developed and tested (Grant et al.; 2010; Golub et al., 2013; Liu et al., 2014). The first clinical trial of PrEP (the Chemoprophylaxis for HIV Prevention in Men (iPrex), which included high-risk MSM and transgender women found that PrEP reduced the risk of HIV acquisition by 44% (Grant et al., 2010). Although a
subanalysis of the iPrex data found no efficacy among the small subgroup of transgender women in the study (Mascolini, 2011). Further analysis of the transgender women in iPrex found unequal drug levels between MSM and transgender women, where lower levels of uptake and adherence were reported among transgender women, which most likely contributed to the disparate rates of efficacy (Deustsch et al., 2015). However, researchers and clinicians state that interactions between PrEP and hormones cannot be ruled out due to a lack of pharmacokinetic studies (Deutsch et al., 2015). Lastly, of the seven clinical trials of PrEP for HIV prevention, iPrex is the only study with a confirmed enrollment of transgender women (Escudero et al., 2014).

There are currently no guidelines for PrEP that provide specific considerations for PrEP dissemination to transgender women (Escudero, et al., 2014; Sevelius, et al., 2016). PrEP guidelines from the World Health Organization mentions transgender women yet does not specifically address their needs (World Health Organization, 2012). Furthermore, in the Centers for Disease Control's clinical PrEP guidelines, transgender women are not included at all (CDC, 2011). To date, PrEP demonstration projects have reported low or unclear levels of enrollment of transgender women (Liu et al., 2014). Inaccurate data collection and tracking of transgender individuals allows for miscategorization of participants who may identify as transgender, non-binary, or gender non-conforming. In addition, transgender women face barriers to study participation such as, fear of stigma and marginalization associated with gender diversity, lack of cultural competency training for research staff, fear of participation due to lack of scientific knowledge regarding medication interaction with hormones, mistrust of the scientific community, and discomfort with visitor IDs and complications related to name change (Women & PrEP Working Group, 2015). Furthermore, a recently published study examined levels of
knowledge, indications, and willingness to take PrEP among a sample of 233 transgender women in San Francisco (Wilson, Jin, Liu, & Raymond, 2015). Only 13.7% of participants had heard of PrEP, despite the fact that San Francisco was a participating site in the three-city PrEP demonstration project (Wilson, Jin, Liu, & Raymond, 2015). Given the lack of trans-specific recruitment and retention strategies or data to guide trans-inclusive PrEP implementation this finding is not surprising. Results from this study underscore the fact that transgender women are not reached by the same information and social networks as MSM and do not benefit from HIV prevention programming designed for MSM (Sevelius et al., 2016). The lack of attention to both the barriers to PrEP uptake and adherence among transgender women and the sociocultural contexts that contribute to HIV risk, highlights how privileging sex assigned at birth over contextual factors of sexual risk in HIV prevention strategies perpetuates HIV related disparities (Fiereck, 2013; Sevelius et al., 2016).

The invisibility of transgender women in studies of MSM has significant consequences for informing the policy, programming, and access to PrEP. HIV prevention and treatment research has consistently demonstrated that transgender women have been left behind (Baral et al., 2013; Herbst et al., 2008; Poteat, Reisner, & Radix, 2014; Sevelius, Keatley, & Gutierrez-Mock, 2011), with higher rates of HIV than any group as well as higher rates of morbidity and mortality (Baral et al., 2013; CDC, 2008; Feldman, et al., 2016; Herbst et al., 2008). To date, PrEP research continues to repeat this pattern.

**Statement of Research**

PrEP researchers have called for trans-specific research on PrEP knowledge and acceptability (Escudero et al., 2014; Golub et al., 2013; Sevelius et al., 2016). To date, there have been two studies examining the specific facilitators and barriers to PrEP uptake among
transgender women (Sevelius et al., 2016; Wilson, Jin, Liu, & Raymond, 2015). However, we still need to know more about the specific facilitators and barriers to PrEP adoption, adherence, and access among transgender women at risk for HIV acquisition. This dissertation is designed to answer the following four research questions:

1. What are the structural, interpersonal, and individual level factors impacting transgender women’s willingness to utilize PrEP as an HIV prevention tool?

2. To what extent do these factors impede the integration of PrEP into the lives of transgender women?

3. What are best practices for integrating PrEP into health care for transgender women?

4. To what extent does need for and access to gender affirmation influence engagement in HIV risk behaviors among transgender women?
CHAPTER 2: CONTEXTUALIZING TRANSGENDER IDENTITIES

Introduction

Little historical information on transgender individuals exists outside of the medical and psychological literature. During the late nineteenth and early twentieth century, writing on transgender identities first appeared in Europe. In the United States, doctors and scientists did not begin to address transgender issues until the late 1940's (Meyerowitz, 2002; Stryker, 2007). Echoed throughout the literature is the debate as to whether sex and gender are essential and biologically based or socially constructed. Predominant theories on transgender individuals throughout much of the twentieth century were predicated on the belief that to be transgender was a form of mental illness or medical disorder (Benjamin, 1953; Cauldwell, 1949; Hirschfeld, 1910; Money & Schwartz, 1969; Stoller, 1964; 1968). In opposition to these ideas, new theoretical perspectives on transgender identities emerged during the late twentieth century influenced by community activism, academia, and the belief that to be transgender was not a mental illness or physical condition (Feinberg, 1992; Stone, 1991; Whilcins, 1997). The historical perspectives on transgender identities are linked to the current structural, interpersonal, and individual level factors that may influence transgender women's HIV risk and willingness to adopt and adhere to PrEP. This chapter will present historical and contemporary ideologies on transgender identities.

Historical Perspectives on Transgender Identities

Early European Medical Perspectives

In the late nineteenth and early twentieth century, beliefs about sexuality and gender identity were rooted in biological essentialism (DeCecco, Elia, 1993; Meyerowitz, 2002; Stryker, 2007). Sex not only signified female and male, but the traits, attitudes, and behaviors associated
with masculinity and femininity (DeCecco, Elia, 1993). Sex and gender were anchored in anatomy, physiology, and the belief that "nature" intended gender and sexuality as a biological imperative for reproduction.

Because sex and gender were believed to be interconnected, same-sex attraction was associated with femininity in men and masculinity in women. In turn, cross-gender identification was thought to be a form of homosexuality (Krafft-Ebing, 1877; Meyerowitz, 2002; Stryker, 2007). Within the medical literature, cross-gender identification first appeared in the landmark study, *Psychopathia Sexualis* (Krafft-Ebing, 1877). Krafft-Ebing (1877) proposed that individuals who actively identified as members of the opposite sex were profoundly disturbed and that the desire to physically alter one’s body was a form of psychosis.

In 1910, physician Magnus Hirschfeld an early advocate for transgender individuals challenged the notion that cross-gender identification was a form of homosexuality and psychopathy (Hirschfeld, 1910; Meyerowitz, 2002; Stryker, 2006; Stryker, 2007). He proposed that cross-gender identification was a complex phenomenon independent from homosexuality. Hirschfeld (1910) coined the term transvestites (trans=cross over; vesti=dress) to describe individuals who identified with and dressed as the opposite sex. He believed that sex was rooted in biology and promoted a theory of sexual intermediaries, which was the idea that biologically, men and women embodied a unique combination of male and female sex characteristics, traits, attitudes, and desires (Hirschfeld, 1910).

At the same time Hirschfeld (1910) promoted his theory of sexual intermediaries, two significant medical advances occurred. First, the new field of endocrinology discovered and created a chemical test to measure female and male sex hormones (Hausman, 1995). This discovery transformed the study of sex differentiation, which was previously solely reliant on the external
genitalia and reproductive organs. Sex hormones helped to explain sexual development, contributing to a new vision of sex that believed no individual was one hundred percent man or woman (Benjamin, 1945). Second, European scientists began to undertake experiments, first to transform the sex of animals and then humans (Meyerowitz, 2002). In Austria, physiologist Eugen Steinach took the lead in changing the sex of animals (Steinach, 1940). In Germany, during the 1920s and early 1930s, doctors working with Hirschfeld began to perform and publicize sex change surgeries on persons labeled transvestites (Meyerowitz, 2002; Stryker, 2007). The practice of sex-change surgery coupled with the discovery of sex hormones provided scientific evidence to promote the idea that male and female were not mutually exclusive categories.

The Emergence of the Transsexual

In the United States, the issue of cross-gender identification first appeared in the medical literature during the mid-twentieth century (Benjamin, 1953; Cauldwell, 1949). In 1949, physician David O. Cauldwell wrote *Psychopathia Transexualis* published in the Journal of Sexology. *Psychopathia Transexualis* (1949) is considered the first scholarly paper to use the term transsexual to describe individuals wishing to become the opposite sex (Meyerowitz, 2002; Stryker, 2006; Stryker, 2007). According to Cauldwell (1949), transsexuality was a psychological disorder caused by a genetic predisposition, an unfavorable childhood, and overbearing parents. Echoing the earlier writing of Krafft-Ebbing (1877), Cauldwell (1949) believed that individuals afflicted with wanting to live as the opposite sex were severely mentally disturbed. He promoted the belief that masculinity and femininity were social and psychological attributing gender differences to social factors (Cauldwell, 1950, 1951). While he acknowledged that sex change operations were possible, he strongly opposed physicians performing such
medical interventions, considering it a crime to remove healthy tissue and glands. He professed that treatment must focus on rehabilitation through social re-education by discouraging cross-gender behaviors (Cauldwell, 1949). Cauldwell's theory on the origins of and treatment to correct cross-gender identification was the foundation for the pathologization of the transsexual.

In stark contrast to Cauldwell, endocrinologist Harry Benjamin emerged as a proponent of the use of hormones to treat individuals wishing to change their sex. Benjamin (1953; 1966) challenged the emerging psychological and psychoanalytic cures, stating that hormone treatment rather than psychological care was more appropriate for treating individuals who wished to change their sex. While he did not discount the psychological origins of transsexualism, Benjamin (1953; 1966) believed that transsexuality was primarily a physical condition influenced by hormones and genetics. Given the physical nature of transsexualism, he posited that attempts to discourage transsexuality through psychotherapeutic interventions were useless and would not alleviate a person's desire to change their sex. Benjamin (1966) supported the theory of universal bisexuality popularized in Europe during the early twentieth century, which suggested that no individual was exclusively male or female and that each person was both parts male and female. Benjamin's clinical practice, scholarly publications, and advocacy for the rights of transsexuals determined much of the modern medical approach for transgender individuals.

Early Psychological Perspectives on Transsexuality

Following World War II, psychiatrists and psychologists gained legitimacy as an authority within American medicine and society (Hale, 1995; Starr, 1982). Because the field played a crucial role in screening recruits for military service during the war and providing treatment to soldiers in distress, the federal government acknowledged their growing influence by passing the Mental Health Act of 1946, which established the National Institute of Mental
Health (Hale, 1995). As their authority grew, psychiatrists and psychologists increasingly supported environmental causes to psychological conditions, rejecting biological explanations. It was in this context that psychologists and psychiatrists began to promote that transsexuality was psychological and not a medical condition. During much of the 1950's and 1960's, the recommended treatment for transsexuals was psychoanalysis and other forms of psychotherapeutic treatment that tried to eliminate the desire to live as the opposite sex (Meyerowitz, 2002).

In the 1960's, psychoanalyst Robert Stoller (1964; 1968) developed an influential model distinguishing biological sex from gender, gender identity and gender role. Although a proponent of the psychological etiology of transsexuality, he did not discount the influences biology had on the psychological development of a person's sex. Stoller's model (1964) attempted to bridge the gap between the biological and environmental "causes" of cross-gender identification. He proposed that biological sex, which was determined by physical conditions, such as chromosomes, external and internal genitalia, hormones, and secondary sex characteristics, was separate from the psychological and cultural process of gender (Stoller, 1964). Gender referred to the amount of masculinity or femininity found in a person, where sex was termed male and female, gender was masculine and feminine. While Stoller (1964) believed that a "normal" male was mostly masculine and a "normal" female mostly feminine, gender identity was the subjective sense of being a particular sex, which over time might develop in opposition to biological sex. Gender role was defined as the display of overt behaviors that helped others determine a person's gender. Stoller's work remains influential and to a large extent responsible for the expanded sex/gender distinction underlying much of the research on transgender individuals.
The field of psychology used this new conceptualization of sex and gender to further the belief that cross-gender identification could be changed through therapeutic interventions that discouraged cross-gender behaviors. By applying the concept of gender identity, psychologists and psychiatrists professed that appropriate treatment of transsexuality was to monitor gender in early childhood (Stoller, 1967). Since early cross-gender behaviors were seen as a symptom of transsexualism, a preventative intervention was needed to treat this process before gender identification was complete (Burke, 1996). If gender did not necessarily come from biological sex, then training was required to ensure that transsexuality did not occur. To further the preventative model of treatment, Stoller and his colleagues at UCLA established a Gender Identity Research Clinic (Meyerowitz, 2002), which allowed for research on the development of gender identity with the explicit goal of preventing transsexuality in adults (Stoller, 1966). This preventative model urged the preservation of societal gender norms built on the heteronormative assumption that men and women exist solely to reproduce to ensure the continuation of the production of labor (Stoller, 1966).

**Legitimizing Treatment for Transsexuality**

In the 1950's and 1960's as doctors and scientists debated the meanings of sex and gender, individuals armed with growing information from the medical literature on transsexuality contacted doctors to inquire about sex-change treatment (Meyerowitz, 2002). As they urged their doctors to engage in this new form of medical treatment, most experienced barriers related to unwillingness on the part of the physician, prohibitive costs, and limits of technology. In the history of transsexuality, few doctors emerged as pioneers willing to assist patients determined to change their bodies and lives.
In the United States, Dr. Harry Benjamin emerged as an expert on transsexualism during this period. After the publication of his seminal work, *The Transsexual Phenomenon* (1966), his notoriety increased and would be patients traveled to his offices in New York City and San Francisco (Meyerowitz, 2002). Patients introduced their friends and acquaintances to Benjamin as he became known as both a pioneer and advocate for the medical treatment of transsexuality (Meyerowitz, 2002; Stryker & Whittle, 2006; Stryker, 2007). In their initial consultations with Benjamin, patients conveyed a sense of hopelessness and despair (Benjamin, 1966). Previous attempts to seek medical treatment for sex change were often met with offers for psychotherapy, shock treatments, lobotomies, or commitment to a mental institution (Stryker & Whittle, 2006). Some individuals had spent years in psychoanalysis or institutions to rid themselves of their desire to live as the opposite sex (Benjamin, 1966). Additionally, stories of arrests for cross-dressing, loss of employment or fear of being found out to be an imposter were common (Benjamin, 1966). Medical treatment was not just a strategy for self-protection, but an active form of self-expression where the desire to change sex reflected the assertion of an inner self.

In the mid-1960's, the Erickson Educational Foundation (EEF) a non-profit organization, began to fund medical research outside of the mainstream (Erickson Educational Foundation, 1970). Reed Erickson, its founder, was a female to male transsexual who after undergoing sex-change surgery and hormone therapy, felt compelled to further research on and services for transsexuality by providing grants to the doctors who helped him (Devor, 2002; Erickson, 1969; Meyerowitz, 2002). Benjamin and John Hopkins Hospital were two of EEF's funding recipients (Devor, 2002; Meyerowitz, 2002). The support EEF provided for research, treatment, and advocacy helped transform transsexuality into an acknowledged medical specialty and social issue (Meyerowitz, 2002).
During the late 1960s, the first clinic to perform sex reassignment surgery (SRS) was started at John Hopkins Hospital in Baltimore, which solidified a professional legitimacy to the practice of SRS (Money & Schwartz, 1969). The program at John Hopkins also cleared the way for other medical centers to start similar clinics (Meyerowitz, 2002). At the same time, Harry Benjamin began to move towards creating a formal program with a network of psychologists and doctors willing to recommend and arrange surgery, forming the Harry Benjamin Foundation (Meyerowitz, 2002). With support from the EEF, an anthology on transsexualism entitled *Transsexualism and Sex Reassignment* (1969) was published, of the thirty-two articles published more than half came from researchers affiliated with Johns Hopkins Gender Identity Clinic, the Harry Benjamin Foundation, and the UCLA Gender Identity Research Clinic (Green and Money, 1969; Meyerowitz, 2002). The anthology served as a handbook for doctors who chose to treat transsexual patients, providing a detailed outline of how to treat patients with hormones and surgery (Green and Money, 1969).

As sex reassignment surgery received institutional backing and gained more legitimacy doctors began to formulate criteria for assessing patients that were appropriate for hormone therapy and surgery (Green, 1969). Individuals wishing to live as the opposite sex were first required to undergo a psychological evaluation to determine whether they had a longstanding cross-gender identification and no severe mental illness. Before undergoing surgery, doctors expected patients to live as the opposite sex and take hormones for several months and in some cases years, all at the discretion of the physician (Baker & Green, 1970; Edgerton, Knorr, & Callison, 1970; Hunt & Hampson, 1980). Physicians were careful to choose patients with the capacity to understand what treatment would and would not do (Benjamin, 1966; Pauly, 1969). This group of physicians, psychiatrists, and researchers that endorsed medical intervention set up
a gatekeeping system that allowed them to control access to treatment based on their subjective belief as to who was worthy and a "true" transsexual. Preference was given to individuals whom the doctor believed could "pass" as the opposite sex. It was important that these individuals both looked and behaved like conventional women or men (Benjamin, 1966; Green & Money, 1969). In some cases, doctors required training in traditional gender stereotypes (Meyerowitz, 2002). Additionally, doctors expected their patients to live as heterosexuals, and if possible marry after surgery. A male to female individual who had sex with women before treatment would not qualify for treatment as readily as a male to female person who had sex with men (Meyerowitz, 2002). Doctors rejected candidates who after treatment would not conform to the dominant standards of gender and sexuality.

In the 1970's, to further legitimate doctor's authority in this growing medical field, a new diagnostic category was adopted, gender identity disorder was an umbrella term covering a broad range of cross-gender behaviors deemed appropriate for medical intervention (Meyerowitz, 2002). During the International Symposium on Gender Identity at Stanford University in 1975, a committee was appointed to draft guidelines to serve as medical standards for the diagnosis and treatment of transsexuals (Meyerowitz, 2002). At the next conference in 1977, the guidelines were approved. In 1979, professional recognition of transsexualism and guidelines for its treatment had culminated in the formation of the Harry Benjamin International Gender Dysphoria Association (HBIGDA) (Meyerowitz, 2002). The international organization further standardized criteria for diagnosis and treatment, which authorized medical treatment under certain conditions, but disavowed surgery on demand, and required recommendations from two licensed psychologists or psychiatrists before medical intervention (SOC, HBIGDA, 1981).
At the same time, HBIGDA formed, psychiatrist Richard Green began to draft a section on transsexualism for the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (Meyerowitz, 2002). In 1980, transsexualism first appeared in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM, 1980), and was officially recognized as a gender identity disorder. The inclusion of transsexualism provided further legitimation and medical authority to doctors providing medical and surgical treatment to transsexuals, however, it unearthed a growing divide between doctors and the individuals who needed them.

Building on the legitimacy provided by university-based clinics offering transsexual surgeries, private psychologists, psychiatrists, and physicians began to treat transsexual patients (Meyerowitz, 2002). Additionally, starting in the 1970s, the privatization of medical treatment began to play an integral role in the practice of transsexual surgery, as doctors in private practice discovered the lucrative nature of offering transsexual surgery (EEF, 1972). The privatization of transsexual surgery created access to those individuals who had the money to afford such treatment. For individuals who could pay for access to care, they no longer had to settle for any doctor they could find. Furthermore, private psychologists and psychiatrists began to recommend surgery for individuals who would not have met the surgical criteria required at the more restrictive university research and treatment programs. By the 1980's and 1990's, transsexuals increasingly turned to private doctors for sex reassignment surgery (Stryker, 1998). The original doctors who had led the field of transsexual medicine were no longer at the forefront. A new group of doctors began to fill this role coupled with a growing transgender movement that emerged in the 1990's.
The Building of a Movement

In the early 1990's, a wave of transgender activist organizations emerged, including Transgender Nation, Transsexual Menace, and the American Educational Gender Information Services (AEGIS) (Wilchins, 1997). These activists pressured the HBIGDA to revise its standards of care and include transsexuals in its deliberation process, as well as convince non-profit organizations fighting for gay rights (such as the National Gay and Lesbian Taskforce) to fight for the rights of transgender people in their political efforts (Meyerowitz, 2002). They brought attention to the violence and brutality targeted towards the transgender community advocating for the inclusion of the rights of transsexuals and transgender people into anti-discrimination legislation (Meyerowitz, 2002; Stryker, 2007).

To build community and disseminate information magazines, newsletters, and conferences for and by transgender individuals began to emerge calling for free expression of gender variance. For example, this included magazines and newsletters such as TransSisters: The Journal of Transsexual Feminism, Transsexual News Telegraph, Gender Euphoria (Meyerowitz, 2002). The creation of the Internet provided a new opportunity to organize, and connect with people who were otherwise isolated, join public protests, and find a community of peers that they could connect with, without leaving their home (Wilchins, 1997).

that identities and desires were diverse and complex (Stone, 1991). Stone's (1991) manifesto ushered in a renewed interest in redefining gender, which came from a new movement of transsexual scholars and activists seeking to contribute to a discourse that had been previously dominated by the medical field.

In 1992, Leslie Feinberg published *Transgender Liberation: A Movement Whose Time Has Come* (Feinberg, 1992). Feinberg's book was a call to action for social, political, and economic justice, bringing together all individuals who were marginalized and oppressed for a gender expression that was different from societal gender norms. Feinberg's (1992) definition of transgender encompassed transsexuals, drag queens, butches, cross-dressers, masculine women, effeminate men, and anyone else not accounted for by the dominant binary sex/gender dichotomy. Feinberg's call to arms was a catalyst for the transgender liberation movement, mobilizing a community of individuals who began to fight for civil and human rights for transgender people, which continues to fuel the current public debate on transgender issues (Feinberg, 1992; Stryker, 2006). For example, during the 1990's some states began to recognize the legal change of sex on birth certificates, change of name and gender on driver's licenses, and the rights of postoperative transsexuals to marry in their preferred gender (Stryker, 2007).

As Feinberg (1992) called for a political revolution, scholars such as Judith Butler (1990) influenced by Michel Foucault began to publish new theoretical perspectives on gender and sexuality.

In *Gender Trouble: Feminism and the Subversion of Identity* (Butler, 1990), Butler proposed a concept of gender performativity, which became central to the understanding of a predominantly White and well-educated group regarding their gender expression and transgender identity (Namaste, 2000). For transgender people who were the targets of violence,
discrimination and rejection for actualizing their transgender identity the idea that gender was a

game, where one could put on and take off one's gender identity at will was infuriating

(Wilchins, 2004; Namaste, 2000). Butler extends her arguments on gender in Bodies That

Matter: On the Discursive Limits of Sex (1993), embracing the social constructionist views of

biological sex, gender, gender identity, and gender role which were popularized in psychiatry

and psychology during the 1950's and 1960's. Butler (1993) proposes a "new" theoretical

framework, which suggests that sociocultural contexts influence how we understand and
"perform" gender. For scholars within the new transgender movement, Butler's explanations

provided a new understanding of the transgender experience.

A National Transgender Movement

The visibility of the transgender community grew exponentially during the 1990's,

however much of this growth was situated in large cities such as San Francisco, New York, and

the District of Columbia (Stryker, 2007). In 1991, the expulsion of a transwoman from the

Michigan Womyn's Music Festival sparked off the debate of policies within queer women-only

spaces as to whether transwomen were welcomed because they were not born women (Styker,
2007). In direct response, transgender activists and allies organized a "Camp Trans" near the

festival protesting the anti-trans policy and providing educational outreach, community

discussions and action to combat transphobia (Meyerowitz, 2002, Styker, 2007). Another

milestone in transgender activism also occurred in 1991, when the first transgender conference,

Southern Comfort took place in Atlanta (Styker, 2007), which included guest speakers,

workshops, support/discussion groups, entertainment, and socializing. Southern Comfort is still

one of the largest gatherings of transgender individuals.
In 1994, activist Riki Wilchins launched the political action group Transsexual Menace, which was known by their trademark image of the group's name in blood-dripping red letters on the backdrop of a black t-shirt. Wilchins and Transsexual Menace gained national media coverage by sponsoring vigils outside of courthouses where cases involving anti-transgender crimes were being held, most notably was their ongoing protests during the trial of the 1993 rape and murder of Brandon Teena in Nebraska (Stryker, 2007). In 1995, Wilchins went on to form the first national political organization (Gender Public Advocacy Coalition) devoted to and representing the rights of the transgender community (Wilchins, 1997). GenderPac was instrumental in bringing Congress’ attention to transgender issues, specifically those related to individual, community, and structural levels of violence and discrimination (Wilchins, 1997). GenderPac, closed in 2009, citing the growth of several organizations working to further the rights of the transgender community.

In San Francisco, transgender activists worked with the city’s Human Rights Commission in 1993 and 1994 to create a landmark report documenting the unprecedented levels of human rights abuses against the transgender community (Green, 1994). The report provided the framework for San Francisco's 1995 transgender anti-discrimination ordinance (Stryker, 2007). Over the next decade, San Francisco built upon this foundation by offering transgender individuals greater legal protections against discrimination and becoming the first city to offer its transgender employee’s health care benefits that covered the cost of their gender transition (Stryker, 2007).

The Transgender Day of Remembrance was started by Gwendolyn Ann Smith in 1999 to honor those who have lost their lives to violence (https://tdor.info/) and to highlight the disproportionately high rates of anti-transgender violence and murder cases. The event started as
a small candlelight vigil in San Francisco and has grown to an International day of remembrance held each November, to raise public awareness of the hate crimes against transgender people through honoring all transgender individuals who have lost their lives.

Lastly, as the Internet became more accessible to the masses in the late 1990’s, it provided an additional avenue for the growing transgender movement. The Internet helped connect transgender people nationally and internationally and provided fertile ground for the expansion of the transgender movement into the twenty-first century. The transgender activism of the 1990's built communities brought awareness to transgender-related violence and discrimination and created a transgender narrative separate from the dominant medical and psychological paradigm.

**Contemporary Perspectives on Transgender Identities**

The twenty-first century has seen a rise in visibility among the transgender and gender non-conforming communities. An estimated .03% percent of adults in the US, or almost 700,000 people between the ages of 18 and 64, identify as transgender (Gates, 2011). However, the total number is unknown, due in part to a lack of data collection on gender identity in population-based surveys (e.g., US Census and the National Health and Nutrition Examination Survey; NHANES). The following presents, current medical, psychological, social, and political perspectives on transgender identities to contextualize the environment transgender and non-binary individuals navigate to exist in the world.

**Current Medical and Psychological Perspectives**

Given the nascent field of transgender health, current medical and psychological perspectives are continually evolving. No scientific evidence exists as to the etiology of the transgender phenomena. Current guidelines and recommendations for the medical and
psychological treatment of transgender individuals contain the same core recommendations from the 1979 initial recommendations (Berger, Green, Laub et al., 1979), which were based solely on anecdotal experiences of the pioneers in the field not scientific evidence. No studies have been conducted to test the current criteria's impact on post-treatment satisfaction outcomes, or complications (Deutsch, 2016). Transgender and gender non-conforming individuals must fulfill certain procedure specific criteria as described by the current guidelines in order to receive gender affirming care, including hormone therapy and surgery. Yet, there is no consensus as to who is a “qualified” candidate and no formal training exists (Deutsch, 2016). This leaves transgender and gender non-conforming individuals in a powerless position, whose care lies solely on the subjective expertise of medical and mental health practitioners who determine who is “deserving” or “worthy” enough for treatment. Furthermore, this dynamic shifts the focus of the doctor/patient relationship to gatekeeper rather than health care partner.

To address the barriers to transgender affirming care, LGBT specific medical and mental health providers are developing new models of care (Callen-Lorde Community Health Clinic, 2012; Reisner et al., 2015). However, none of these models have been evaluated or tested. The most common practice addressed in these new models regards access to cross-sex hormone where an informed consent model is being adopted, which removes the need for prolonged mental health evaluations and “real life tests” (i.e., living full-time in one’s self-identified gender) to obtain hormone therapy. For example, in this model, individuals wishing to initiate hormones would meet with medical staff first who would discuss the medical effects of cross-sex hormones, present the risks and benefits, as well as inform patients based on clinical knowledge and limited research the types of physical changes that will occur. Referrals for counseling are offered to provide support for navigating the psychological and social impact of transitioning.
By addressing the medical aspects first, the hope is to depathologize the transitioning experience for transgender and gender non-conforming individuals. These practitioners view gender affirming care as a holistic practice one that should not start off by forcing transgender and gender non-conforming individuals to prove that their biological sex and internal sense of gender are different.

**Gender Dysphoria**

During the preparation of the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), a contentious debate arose as to whether the new edition should continue to include and categorize gender identity disorder (GID) as a mental illness (Vance et al., 2010). Before this new edition, the core indicators of GID were the combination of identification with the other gender, and a sense of inappropriateness, or outright rejection, of one’s sex assigned at birth (American Psychiatric Association, 1994).

Some scholars have drawn similar parallels between the debates of GID and the DSM and those, which led to the removal of homosexuality from the DSM in 1973 (Meyer-Bahlburg, 2010). Before the DSM-III, homosexuality was believed to be a pervasive mental illness (Bayer, 1981). The lack of scientific evidence for homosexuality as psychopathology launched a protest movement against its classification as a mental disorder (Meyer-Bahlburg, 2010). Psychiatrists declared that homosexuality was a “normal variant” of sexual identity and that individuals who were gay or lesbian were both high functioning and satisfied with their sexual orientation (Bayer, 1981). Given that "impairment" and "distress" were defining features of a "mental disorder," these insights provided the foundation for resolution approved by the American Psychiatric Association to remove homosexuality from the DSM in December 1973 (Bayer, 1981).
Historically, cross-gender identification has been seen as a pervasive mental illness (Siomopoulos, 1974). Over the past twenty years, there has been growing recognition that transgender individuals are not mentally ill (Meyer-Bahlburg, 2010). A prominent activist movement has emerged, which includes a growing school of mental health professionals (some of whom are transgender) who view gender as fluid and do not consider cross-gender identification a form of mental illness (Brill & Pepper, 2008; Hill et al., 2007; Lev, 2005; Moser & Kleinplatz, 2005; Perrin, 2002). Also, recognition that lesbian, gay, bisexual, transgender and gender non-conforming individuals experience extensive societal stigma, which in many cases may increase psychological distress (Alanko, et al., 2009; Lombardi, Whilchins, Priesing, & Malouf, 2001; Meyer & Northridge, 2007; Nuttbrock et al., 2009; Ryan, Huebner, Diaz & Sanchez, 2009; Winter, 2009) has helped to contextual the social, emotional, and cultural factors impacting this community’s mental health.

Unlike individuals who are gay, lesbian, or bisexual, transgender and gender non-conforming individuals may wish to change their legal gender status to the other desired gender, as well as align their body with their desired gender by the use of cross-gender hormones or surgery. In the United States, legal regulation for government action and insurance coverage require the recognition of a clinical or psychopathological condition that is attested to by a professional specialist (Currah, Juang, & Minter, 2006; Currah, Green, & Stryker, 2009; Khan, 2011). In the arguments for and against the inclusion of GID some key issues came to light, including 1) whether or not gender variance is a pathological condition or "natural" variation? 2) how are the criteria for GID as a mental disorder defined? 3) is the psychological distress associated with gender variance primarily a function of social stigma or is it inherent to gender variance itself? 4) does the label of mental disorder serve as an additional source of stigma? 5) is
the use of hormones and surgery a psychiatric treatment? 6) how can gender affirming mental health and medical care be justified if “GID” is removed from the DSM and gender non-conformity considered a normal variation? (American Psychological Association Task Force on Gender Identity and Gender Variance, 2008; Ault & Brzuzy, 2009; Meyer-Bahlburg, 2010).

These questions address essential areas for researchers, clinicians, and policy advocates investigate with the goal of enhancing access to health care for transgender and gender non-conforming individuals as well as reducing the pervasive impact of stigma and discrimination.

While, GID was removed from the DSM-V (American Psychiatric Association, 2013) it was replaced by Gender Dysphoria. The American Psychiatric Association (2013), stated that while the DSM is used to define and diagnosis mental disorders, it also impacts how people see themselves and others. Furthermore, while diagnostic terms facilitate care and access to insurance coverage that supports mental health, the APA (2013) also acknowledged how terms have a stigmatizing effect. The hope in replacing the term disorder with dysphoria was to also remove the stigma associated with being disordered. What is clear from the APA’s statement is that the decision to include gender dysphoria was for the need to protect transgender individuals access to care, given that many treatment options including cross-sex hormones, gender reassignment surgery, and social and legal transition to one’s desired gender are currently contingent on obtaining a diagnosis.

**Models of Transgender Identity Development**

Scholars attempting to articulate a coherent model of transgender and/or transsexual identity development almost exclusively draw from literature on the gay and lesbian “coming out” process (Coleman, 1982; Cass, 1979, 1990, 1996; Troiden, 1988, 1989). Within these models an assumption is made that transgender and/or transsexual identities are formed through
a predetermined series of stages that begin in adolescence or early adulthood and culminate in a healthy and integrated transgender/transsexual identity (Eliason & Schope, 2007 & Devor, 2004; Nuttbrock et al., 2002). Although no developmental model applies to every individual, most stage models of transgender identity development aim to explain transgender identity development of all or most transgender individuals (Devor, 2004; Eliason & Schope, 2007; Gagne, Tewksbury, & McGaughey, 1997). Most stage models include at least three broad stages: 1) awareness and confusion about gender identity, 2) exploration and testing, and 3) integration of transgender and/or transsexual identity (‘coming out’) (Bockting & Coleman, 2007). According to these models, transgender individuals should be able to transition successfully to the opposite gender, most often via medical intervention, ‘come out’ to family and friends, and integrate their “new” gender identity with other aspects of their identities (Bockting & Coleman, 2007; Devor, 2004). These outcomes are considered markers of a successful gender transition and, once they are achieved, the resulting identity is largely resistant to change. Although stage models provide important insights they cannot account for differences in transgender identity development across race, ethnicity, age, social class and gender. The reliance on a linear sequential account of a developmental process that can be fluid does not attend to the development of intersecting identities that may be inseparable from one’s transgender identity.

There is a small but growing body of research and theory development offering alternative understandings of transgender identity based on the claim that this developmental process has no universal endpoint, interacts with, and is influenced by contextual factors. For example, Bilodeau and Renn (2005) in a study of transgender identity formation among college students adapt D’Augelli’s (1994) lifespan approach to sexual identity development, which suggests that sexual orientation can be fluid at certain times in the lifespan or more fixed at
others. Suggesting that human growth is intimately connected to and shaped by environmental and biological factors. Another conceptual model developed by Denny et al. (2004) attempts to deemphasize the rigid gender binary that characterizes conventional models of gender identity development, and instead presumes the existence of parallel gender continuums inclusive of male and female dimensions. According to this model, individuals can strongly identify with both male and female dimensions or with neither (Denny et al., 2004). In addition, rather than positing a single modal developmental pathway, it posits the existence of multiple, individualized trajectories. A third approach emphasizes the fluidity and malleability of transgender identity (Diamond, Pardo, Butterworth, 2011). The researchers propose applying dynamic systems theory (Thelen & Smith, 1994) to transgender identity development which is characterized by non-linear changes and view identity development as a process which is continually constructed and reconstructed over time, rather than achieved with an absolute finality (Diamond, Pardo, Butterworth, 2011). These recent additions to conceptualizing transgender identity development have attempted to improve upon traditional stage models. However, they ignore how transgender identity development intersects with other aspects of social and developmental experience such as culture, race, ethnicity, sexuality, and socioeconomic status. These contextual factors are important to understanding the sociocultural lives of transgender women and in particular, transgender women of color.

**Cisgenderism**

The term cisgender was first used as a descriptive category to distinguish non-transgender people from transgender and gender non-conforming individuals (Edelman, 2009; Serano, 2007). More recently, a new conceptualization of cisgender termed cisgenderism has emerged. Cisgenderism (Ansara and Hegarty, 2012; Ansara and Hegarty, 2014; Lennon and Mistler, 2014)
refers to the cultural and institutional ideologies that deny, pathologize, or delegitimize gender variance by refusing to acknowledge or accept that natal sex can differ from one’s social and psychological gender. Thus, cisgenderism endorses and perpetuates the belief and practice that people’s biological sex, psychological, social, and legal genders are connected and binary, and that any deviation from this is abnormal (Lennon & Mistler, 2014; Lombardi, 2007). For example, sex segregation by sex assigned at birth within the prison or shelter system is a form of cisgenderism, which prioritizes natal sex over self-identified gender identity. The very nature of cisgenderism is to create systems that contribute to the erasure of transgender identities and bodies. By systematically rendering transgender and non-binary individuals invisible, they not only do not exist, but are unable to access basic life necessities (e.g., access to public bathrooms, housing, employment, education) cisgender individuals take for granted.

Transgender-Related Stigma and Discrimination

A growing body of evidence points to the multitude of challenges affecting the quality of life of gender minority populations, including poverty, violence, incarceration and routine discrimination in housing, employment, educational, health care and social service settings (Grant et al., 2011; Khan, 2011; Lombardi, Wilchins, Priesing, & Malouf, 2001; Nemoto, Bödeker, & Iwamoto, 2011; Reisner, Bailey, & Sevelius, 2014; Testa et al., 2012). For example, the National Transgender Discrimination Survey (Grant et al., 2011), the first comprehensive survey in the US examining the pervasiveness of transgender discrimination found that sixty-three percent (63%; \(N=6,456\)) of respondents reported experiencing a severe act of discrimination, which was defined as an event that would have a significant impact on a person's quality of life and ability to sustain themselves financially or emotionally. Examples of discrimination included loss of job due to bias, eviction due to bias, school bullying/harassment,
teacher bullying, physical and sexual assault due to bias, homelessness because of gender identity/expression, and loss of relationship with a partner or child due to gender identity/expression. Furthermore, twenty-three percent (23%) of participants stated that they had experienced at least three of the major life events in their lifetime. While pervasive discrimination was reported throughout the sample, particularly devastating were the combined effects of anti-transgender bias and structural racism. People of color, reported higher rates of discrimination compared to White participants, with African-American respondents experiencing the highest incidents of discrimination.

Research has demonstrated that many risks to the physical, emotional, and social health of transgender and gender non-conforming individuals are related to social stigma and negative societal response towards gender non-conformity (Bradford, Reisner, Honnold, & Xavier, 2013; Clements-Nolle, Marx, Guzman, & Katz, 2001; Clements-Nolle, Marx, & Katz, 2006; Grant et al., 2011; Herbst et al., 2008; Nuttbrock et al., 2012; Testa et al., 2012; Wilson et al., 2009; Xavier, Bobbin, Singer, & Budd, 2008). Much of this research has focused on stigma and discrimination at the structural level (i.e., policies, social norms and behaviors within institutions and social structures that are unjust towards transgender people). For example, several studies have documented stigma and discrimination against transgender individuals in healthcare settings, and its impact on the community's ability to access safe and supportive health services (Bradford, Reisner, Honnold, & Xavier, 2013; Goldblum et al., 2012; Grant et al., 2011; Operario, Yang, Reisner, Iwamoto, & Nemoto, 2014; Testa et al., 2012).

Data consistently suggests that transgender and gender non-conforming individuals are at unusually high risk for a host of adverse health outcomes, including HIV infection, substance misuse, depression, and suicide (Baral et al., 2013; Benotsch et al., 2013; Clements-Nolle, Marx,
Guzman, & Katz, 2001; Clements-Nolle, Marx, & Katz, 2006; Goldblum et al., 2012; Haas & Rodgers, 2014; Herbst et al., 2008; Neilands, & Sevelius, 2013; Keuroghlian, Reisner, White, & Weiss, 2015; Reisner, Gamarel, Nemoto, & Operario, 2014; Resiner, Pardo, Gameral, Pardee, Keo-Meier, 2015). For example, in the general population, the rate of suicide is between 1-6% (Kessler, Borges, & Walters, 1999; Nock & Kessler, 2006; Nock et al., 2008). These rates are higher among lesbian, gay, and bisexual (10-20%) individuals (Paul et al., 2002). Increased risk for suicide among the LGB community has been linked to the social stigma, prejudice, and discrimination associated with being a sexual minority (Haas et al., 2011; Suicide Prevention Resource Center, 2008). LGB persons commonly experience discrimination at both the individual-level (e.g., interpersonal rejection, including family rejection, harassment, and physical violence) (Meyer, 2003; Meyer et al., 2007; Ryan, Huebner, Diaz, & Sanchez, 2009) and the institutional-level (e.g., laws and public policies that create inequities or fail to provide protections for sexual minorities) (Buchmueller & Carpenter, 2010; Hatzenbuehler, 2010; Heck, Sell, & Gorin, 2006; Ponce, Cochran, Pizer, & Mays, 2010).

Among transgender populations, these rates of suicide are even higher, estimated to be between 25% and 43%) (Clements-Nolle et al., 2006; Goldblum et al., 2012; J. L. Haas & Rodgers, 2014b; Moody & Smith, 2013; Xavier et al., 2008). Clements-Nolle, Marx, and Katz (2006) conducted a study of a non-random sample of transgender-identified individuals living in San Francisco. The study assessed whether the discrimination and victimization transgender individuals experience were independently associated with attempted suicide after controlling for known risk factors such as substance abuse, physical and sexual abuse, and depression. Thirty-two percent (32%) of participants reported having ever attempted suicide, with equal rates between MTF and FTM respondents. The study found that younger age, unemployment,
depression, substance abuse, and a history of forced sex were individual risk factors significantly associated with suicide (Clements-Nolle et al., 2006). Additionally, societal risk factors such as gender-based discrimination and victimization were independently associated with attempted suicide.

Goldblum and colleagues (2012) examined the relationship between gender-based victimization and suicide attempts among a sample of transgender individuals in Virginia. Of the total sample (N=290), 28.5% reported a history of suicide attempts. Among these respondents, 32.5% reported having made one attempt, 28.6% reported a history of two attempts, and 39% reported having made three or more attempts. Transgender men reported the highest rates of suicide attempts (32.1%), while transgender women reported a suicide attempt rate of 26.5%. Additionally, 33% of participants under the age of 45 reported a history of suicide attempt, compared to older respondents who reported significantly lower rates (19%; 45-54 and 6.9% 55 and older). Furthermore, of the total sample, those who reported experiencing gender-based discrimination or violence (44.8%) were almost four times as likely to endorse making a suicide attempt as those who had not experience gender-based discrimination or violence.

Lastly, a needs assessment of transgender people of color living in Washington D.C., conducted by Xavier, Bobbin, Singer, and Budd (2008) highlighted how transgender people of color are at increased risk for suicidality, substance abuse, and HIV risk behaviors. Of the total sample (N=248), 38% reported suicidal ideation, and 16% had made a suicide attempt (Xavier et al., 2008). Among those reporting suicidal ideation, 63% of these individuals attributed it to their transgender status (Xavier et al., 2008). Although transgender men were more likely to report suicidal ideation, transgender women were more likely to attribute suicidal ideation to their gender identity (Xavier et al., 2008).
Furthermore, the few existing studies demonstrate that transgender people have a significantly elevated prevalence of alcohol and illicit drug use compared to the general population, and that misuse is associated with experiences of gender-based violence and discrimination (Benotsch et al., 2013; Testa et al., 2012). Benotsch and colleagues (2013) recruited 155 transgender individuals from a transgender health clinic in Virginia. Overall, 26.5% of the sample reported lifetime non-medical prescription drug use, including opiate painkillers (23.9%), benzodiazepines (17.4%), stimulants (13.5%), and sleeping aids, such as Ambien (8.4%) (Benotsch et al., 2013). Participants who reported lifetime non-medical prescription drug use were significantly more likely to report recent use of recreational drugs, including alcohol (72.5%), marijuana (62.5%), poppers (15.4%), ecstasy (20.5%), cocaine (15.4%), methamphetamine (10.3%), and heroin (10.3%). Additionally, participants who reported experiencing transgender-related discrimination were significantly more likely to report non-medical prescription drug use (Benotsch et al., 2013).

Testa and colleagues (2012), examined whether there was a relationship between exposure to physical and sexual violence and substance abuse in a sample of transgender individuals. Participants were recruited through transgender service organizations and over the Internet. Overall, a substantial portion of the sample reported being victims of past physical (38%) or sexual (26.6%) violence. The study found that a history of experiencing sexual violence was associated with a history of alcohol abuse in transgender women and transgender men. Additionally, transgender women who experienced sexual violence were significantly more likely to report past illicit substance use as compared to those who had not experienced past violence.
Lastly, studies have linked minority stress theory (Meyer, Schwartz, & Frost, 2008; Meyer, 2003) with adverse health-related outcomes in transgender and gender non-conforming adults, including HIV infection, suicide (Clements-Nolle et al., 2006; Goldblum et al., 2012; Haas & Rodgers, 2014; Moody & Smith, 2013; Testa, Jimenez, & Rankin, 2014), substance misuse (Keuroghlian, Reisner, White, & Weiss, 2015; Operario et al., 2014; Reisner, Gamarel, Nemoto, & Operario, 2014; Xavier et al., 2008), depression, and experiencing transgender-related violence (Bauer et al., 2009; Grant et al., 2011; Khan, 2011; Lombardi, 2007, 2009; Lombardi, Wilchins, Priesing, & Malouf, 2001; L. Nuttbrock et al., 2012; Reisner, Bailey, et al., 2014). The most commonly documented experiences of gender minority related stress for transgender and gender non-conforming individuals surround external events that occur in the person’s environment and are related to either knowledge or perception of their transgender or gender non-conforming status (Testa et al., 2012). Surveys have consistently documented that transgender individuals report high levels of both physical and sexual violence related to transphobia, with 43% to 60% of transgender individuals having experienced physical violence and between 43% and 46% reporting having experienced sexual violence (Clements-Nolle, Marx, & Katz, 2006; Kenagy & Bostwick, 2005; Lombardi, Wilchins, Priesing, & Malouf, 2001; Xavier, Bobbin, Singer, & Budd, 2005).

Transgender as a Social Problem

Criminalization of Transgender Identities

Until the mid-1970’s and 1980’s, policing gender took the form of enforcement of laws, which required individuals to wear at least three articles of clothing associated with their sex assigned at birth or risk incarceration for impersonating the opposite gender (Craig, 2007). During the late nineteenth century, municipalities in the United States began enacting cross-
dressing laws (Capers, 2008; Franke, 1995; Stryker, 2007). However, little historical research exists surrounding the origins of such laws. Scholars have drawn parallels between the formations of the gay and lesbian community, which emerged with the rise of industrialization and the migration of mostly single men to cities where an industrial economy had created wage-paying jobs (D'Emilio, 1998; Meyerwitz, 2002; Stryker, 2007). The anonymity of city living coupled with an independence from one’s family provided the social environment for gay communities to develop (Stryker, 2007). At a time when sexual orientation and gender variance fell under the same broad category, cities might have been prompted to create laws to regulate and control gender and sexual deviance (Capers, 2007; Mogul, Ritchie, & Whitlock, 2011). Cross-dressing laws did not just affect effeminate men and masculine women, it signaled to everyone the type of dress and behavior that was appropriate. Men and women must both behave and dress in a manner that was congruent to their biological sex. The division between men and women must be readily visible and maintained.

In the United States, crossdressing laws were overturned beginning in the 1970’s through the 1980’s (Meyerwitz, 2002; Mogul, Ritchie, & Whitlock, 2011; Stryker, 2007). However, these laws have contributed to the lasting image that transgender and gender transgressive individuals are inherently criminal (Capers, 2007). Individuals whose appearance, dress, or behavior conflicts with cisgender expectations of sex and gender continue to be punished by law enforcement under a set of unwritten laws which when violated, signal disorder or fraud (Mogul, Ritchie & Whitlock, 2011). Today, gender is often policed by arbitrary and violent arrests of transgender and gender non-conforming people for using the "wrong" restroom. Most recently, anti-transgender bathroom legislation has either been passed (North Carolina, Mississippi, Kansas) or proposed (Michigan, Washington, Texas), these laws would or do make it illegal for
transgender and gender non-conforming people to use a bathroom that is different from their sex assigned at birth (NCTE, 2016). These laws are punishable by imprisonment if an individual is presumed to be transgender or gender non-conforming.

**From Individual Problem to Public Issue**

Due to increased media coverage on transgender issues, including the public transition of several prominent celebrities, the success of the television show Transparent, and most recently the political and economic response to the anti-transgender bathroom laws, there has been a shift in the public discourse as to whether or not the social, psychological, health, and economic issues transgender and gender non-conforming individuals face are a significant issue in need of government response. Without political and social capital, transgender communities are often not in the position to garner support for themselves, which is particularly true for transgender and non-binary people of color, and those dealing with multiple levels of oppression. The current political climate regarding transgender issues provides a real-time example of how a social problem moves from personal trouble to a public issue (Wright Mills, 1959). Manning (1987) states that when an individual problem becomes a typical experience for many, it moves into the realm of a public problem rather than solely an issue located within the person. Simply put, everyone can relate to needing to use the restroom, and this is precisely why the "bathroom issue" has resonated with the American public.

Size and responsibility are at the heart of any discussion on social problems, the use of the word “social” implies something larger than individual experience (Manning, 1987). While the current discourse on bathrooms is important, the movement towards “transgender” as a social issue rather than an individual problem is evident in the historical and contemporary perspectives discussed above. From the dominant medical and psychological theories on cross-gender
identification, which viewed gender variance as an individual problem that was either biologically based or a result of one’s inability to conform to societal gender norms. To the increased medical authority and power to regulate who is truly deserving of changing their sex; the criminalization of gender non-conformity, which sought to uncover those who were masquerading or worse deceiving unknowing “normal” individuals into believing they were a gender they were not; and to the rise of the politicized and visible transgender movement of late twentieth century, which not only challenged the predominant medical and psychological theories but brought attention to the social, emotional, and economic issues faced by this community. These combined efforts contribute to the national attention transgender, and gender non-conforming people are receiving today.

Furthermore, increased visibility has raised awareness to the persistent and often severe forms of discrimination and violence the transgender and gender non-conforming community face on the individual, community, and structural level. Public discourse for and against transgender rights has grown exponentially, due in part to the creation of federal, state, and local anti-discrimination legislation that attempt to address the social, emotional, physical, and economic needs of the transgender and gender non-conforming community (Transgender Law Center, 2016). While there is currently no federal comprehensive civil rights bill protecting transgender and gender non-conforming community, anti-discrimination policies are being enacted to protect transgender individuals in employment settings, when accessing public accommodations, identification documents, health care, housing, credit, education, and federally funded programs (Transgender Law Center, 2016). These policies seek to address, the economic loss associated with a lack of job protection, the psychological effects of being a stigmatized and marginalized community living without equal rights, and the health of transgender and non-
binary individuals who are more likely to be uninsured or underinsured due to discriminatory policies and practice in the health care system (NCTE, 2016). Current government response has legitimated transgender and gender non-conforming people as deserving of equal protection. Despite, a growing anti-transgender social, economic, and political movement that wishes to uphold conventional ideas about gender and sex.

**Conclusion**

The historical ideologies on cross-gender identification continue to influence contemporary beliefs regarding the transgender and gender non-conforming community. Current societal beliefs still view biological sex and gender as connected, binary, and immutable. A person is either male or female, and individuals whose gender identity is different from their biological sex or those whose gender representation does not align with societal gender norms are often punished for failing to present their gender in a socially appropriate manner. Those who fall outside or between the gender binary, are expected to conform or risk being stigmatized, ostracized, and socially rejected. Within this context, transgender and gender non-conforming individuals must navigate significant obstacles to live. The rise of a transgender movement has propelled the social, emotional, economic, and political needs of this community forward. While the magnitude of the transgender community is unknown, the experiences of violence and discrimination are well documented, and national public discourse has begun to discuss how to best address these issues. Contextualizing the historical and contemporary perspectives on transgender identities situates the facilitators and barriers to PrEP among transgender women at risk for HIV within a broader context. The following chapter presents the theoretical concepts guiding the design of this dissertation.
CHAPTER 3: THEORETICAL CONCEPTS OF STIGMA AND DISCRIMINATION AND GENDER AFFIRMATION

Introduction

This dissertation integrates theories of stigma and discrimination (Link and Phelan, 2001) and the Gender Affirmation Framework (Sevelius, 2013) to examine the facilitators and barriers to pre-exposure prophylaxis (PrEP) access, adoption, and adherence among transgender women at risk for HIV acquisition. First, I apply theories of stigma and discrimination to a socio-ecological model (Baral et al., 2013; Link and Phelan, 2001), which conceptualizes structural, interpersonal, and individual level barriers to health care access and utilization among transgender and gender non-conforming individuals as an outcome of transgender-related stigma and discrimination. This model posits that access to gender-affirming health care, which includes PrEP is necessary to facilitate PrEP access, adoption and adherence among transgender women. Second, I utilize the gender affirmation framework to contextualize HIV risk as a social and psychological process rather than solely a byproduct of behavior. The gender affirmation framework (Sevelius, 2013) proposes that HIV risk among transgender women is a consequence of social oppression, whereby transgender women find themselves in high-risk contexts where HIV risk increases due to the social and emotional impact of stigma and discrimination at the individual, community, and institutional level. To understand potential facilitators and barriers to PrEP for transgender women it is imperative to examine the contextual factors that contribute to HIV risk for this community.

Stigma and Discrimination

Stigma refers to the negative regard, inferior status, and relative powerlessness that society collectively assigns to individuals and groups that are associated with various conditions,
statuses, and attributes (Link & Phelan, 2001). As discussed above, transgender and gender non-binary people routinely face stigma and discrimination due in part to their gender non-conformity and these experiences are associated with adverse health outcomes. Due to stigma and discrimination at the structural, interpersonal, and individual level, transgender and non-binary individuals experience barriers to health care - whether they seek preventive routine, or emergency care, mental health and social services; or transition-related care (Bauer et al., 2009; Feinberg, 2001; Grant et. al, 2011; Lombardi, 2007, 2011). Transgender and non-binary people are regularly denied access to health care and social services and must navigate serious obstacles when accessing care (Bauer et al., 2009; Clements-Nolle et al., 2001; GLBT Health Access, 2000; Kenagy, 2005; Lombardi, 2001, 2011; Grant et al., 2011; Shipherd et al., 2010; Snelgrove, Jasudavisius, Rowe, Head, & Bauer, 2012). For example, transgender and gender non-binary individuals report experiences of discrimination from staff and medical providers, including misgendering, refusal to use or even ask a person's gender pronoun or name, insurance practices which do not cover transition-related care, and a lack of providers who are willing and competent to provide services to this community. While, many of these barriers can be traced to transgender-based stigma, for individuals who claim multiple identities experiences of stigma and discrimination due to race/ethnicity, socioeconomic status, age, and immigration status create additional barriers to accessing vital health care services. Additionally, a lack of research on provider side barriers to transgender care fails to view health care providers as integral to the success of creating a safe and inclusive health care system.

**Structural Stigma**

Structural or institutional stigma is the manifestation of stigma within the institutions of society (Link & Phelan, 2001). Within the healthcare system structural stigma against
transgender and gender non-conforming individual’s manifests as cisgenderism (Ansara and Hegarty, 2012; Ansara and Hegarty, 2014; Lennon and Mistler, 2014), which is the cultural ideology embedded in institutional practices that refuse to acknowledge self-identified gender identity. It is important to note that structural stigma can occur in the absence of individual prejudice or discrimination (Link & Phelan, 2001). The healthcare system justifies and perpetuates cisgenderism in two ways. First, is the assumption that gender and biological sex are connected, binary, and immutable. We are either male or female. One's sex (gender) determination is based on external genitalia. This belief renders transgender and non-binary people invisible within a two-gender healthcare system. When gender nonconformity becomes visible, transgender and non-binary people are often labeled or diagnosed with a psychological or psychiatric disorder. Within a health care system predicated on cisgenderism, structural barriers include: health insurance practices that limit the types of care covered for transgender and gender non-conforming individuals (e.g., insurance companies view gender reassignment surgery as cosmetic will often not cover it); the cost of gender confirming procedures (e.g. gender reassignment surgery, hormones); lack of training for providers in transgender health; and institutional policies and practices that create unsafe environments for transgender and gender non-conforming individuals to receive care (Bauer et al., 2009; Lombardi, 2001, 2007; Snelgrove et al., 2012).

**Informational Systems**

A lack of consistent information on the social, emotional, and physical health needs of transgender and non-binary individuals dramatically affects the community’s access to health care services (Bauer et al., 2009; GLBT Health Access, 2000; Kenagy, 2005; Lombardi, 2001, 2007, 2011). When information is produced, it is often not incorporated into textbooks and
educational curricula for individuals in the medical and psychology field (Bauer et al., 2009; Lombardi, 2001, 2007, 2011; Snelgrove et al., 2012). Furthermore, the specific needs of transgender people are often omitted or incorrectly equated with the needs of the lesbian, gay, and bisexual community (Bauer et al., 2009; Lombardi, 2001, 2007). For example, research on PrEP has consistently lumped transgender women and cisgender men who have sex with cisgender men (MSM) together (Sevelius et al., 2016). This process not only contributes to the erasure of the social, emotional, physical and sexual health needs of transgender women it conflates gender identity with sexual orientation.

**Locating a knowledgeable provider.** Finding a health care provider who is knowledgeable of the psychosocial and health care needs of the transgender and gender non-conforming community is the most commonly reported barrier to care (GLBT Health Access, 2000; Kenagy, 2005; Lombardi, 2001, 2007, 2011; Grant et al., 2011; Sanchez et al., 2009). Once an individual locates a provider, they often find themselves in the role of the educator (Bauer et al., 2009; GLBT Health Access, 2000; Kenagy, 2005; Lombardi, 2001, 2007). A limited number of providers are able and willing to treat transgender and gender non-conforming people, which makes it difficult to secure appointments for both transition-related and routine medical care. Studies have found that gender affirming providers are located primarily within urban areas, which creates an enormous barrier to care for individuals living in rural areas (Bauer et al., 2009; GLBT Health Access, 2000; Kenagy, 2005; Lombardi, 2007; Snelgrove et al., 2012). Due to geographic location, individuals may need to travel far distances to find an accommodating provider. Further, due to a scarcity of providers, transgender and gender non-binary people are limited in the number of providers to choose from (Bauer et al., 2009; GLBT Health Access, 2000; Kenagy, 2005; Khan, 2013; Lombardi, 2001, 2007; Snelgrove et al., 2012).
The lack of trained healthcare providers is due in part to the failure of most medical schools and health care institutions to prepare their students and staff on transgender care (Makadon, 2008; Obedin-Maliver et al.; Solursh et al., 2003). For example, Obedin-Maliver, et al. (2011), distributed an internet-based survey to administrators of medical education at 148 allopathic medical schools (17 Canada, 131 United States) and all 28 osteopathic medical schools in the United States to assess the number of hours of LGBT-related content hours in the medical curricula. Of the 176 medical schools, 132 (75%) completed the entire questionnaire. The median number of curriculum hours dedicated to LGBT related care was five.

**Physician barriers.** The absence of transgender-related medical education is the barrier most often cited by providers who report that insufficient training and exposure to transgender patients impacts their ability to provide appropriate medical care to transgender individuals (Lurie, 2005; Poteat et al., 2013; Snelgrove et al., 2012). Despite internationally recognized standards of care published by the World Professional Association for Transgender Health (WPATH), providers are often not aware of available and reliable sources to assist them in providing care. Snelgrove et al. (2012) found that providers reported a need for readily accessible information whether through the Internet, academic journals, Internet sites endorsed by a professional medical organization, and Continuing Medical Education (CME) conferences. Finding “trans-friendly” colleagues for referral outside of one’s scope of practice is also difficult for many providers (Snelgrove et al., 2012), and, if a provider is located, there are concerns about a colleague’s lack of knowledge, sensitivity, and availability. The lack of qualified and affirming medical care is particularly evident for gender-affirming surgeries given the highly specialized skill set required for these procedures. For example, studies have found that depending on the specific procedure; a significant barrier exists when trying to locate a surgeon
capable of performing gender-affirming surgeries within a specific geographic location (Poteat, 2013; Snelgrove et al., 2012).

**Institutional Barriers**

Institutional barriers to health care are policies and procedures that do not accommodate and acknowledge transgender identities and bodies. Studies have posited that health care barriers at the structural level are an outcome of a two-gender medical system (Lombardi, 2009; Poteat, 2013; Snelgrove, 2012; White, Reisner, & Pachankis, 2015). At the institutional level these barriers manifest as systemic failures in recognizing and accommodating the health care needs of transgender patients. Sex-specific eligibility criteria for certain procedures, screening tests, or therapies often prevent adequate healthcare for transgender patients. Health system level barriers occur when providers are unable to order a test or offer treatment to a patient because of sex-specific eligibility criteria (Snelgrove, 2012). Additionally, billing systems and health insurance providers will only allow sex-specific procedures to be paid when an individual is designated that sex (GLBT Health Access, 2000; Khan, 2011; Sanchez et al., 2009; Snelgrove et al., 2012, White-Hughto, Reisner, & Pachankis, 2015). Examples include the inability to bill for a hysterectomy for a male patient or a prostate related procedure for a female patient.

**Health Insurance.** Lack of health insurance is a major structural barrier to healthcare for many Americans and for transgender and gender non-conforming people in particular. The National Transgender Discrimination Study (2011) found that study participants were less likely than the general population to have health insurance or be insured by an employer and more likely to be covered by public programs such as Medicare or Medicaid. Economic disenfranchisement, employment discrimination, underemployment, and non-recognition of marriages result in a disproportionate number of transgender and gender non-conforming people
who are uninsured (Conron et al., 2012; Grant et al., 2011; Lombardi, 2011). If an individual is insured, most are denied insurance coverage for transgender-specific health care, such as hormone therapy or gender reassignment surgery (Bauer et al., 2009; GLBT Health Access, 2000; Kenagy, 2005; Khan, 2011). Most private and public insurance plans contain explicit exclusions for transgender-related care (Khan, 2011). Additionally, in the event that an insurance company is aware of a person’s transgender identity, non-transition related care has been denied and attributed to a symptom of their gender transition (GLBT Health Access, 2000; Khan, 2011; Lombardi, 2007, 2011). Transgender and gender non-conforming individuals who do not have access to insurance are forced to pay out of pocket for gender-affirming procedures, which are often cost prohibitive (Khan, 2011). From the perspective of the insurer, transgender and gender non-conforming individuals do not have an insurable interest (Khan, 2011).

Transgender and non-binary individuals are often seeking coverage for what is termed "a pre-existing" condition that is believed to be expensive to treat. Since gender non-conformity or transgender individuals have historically have little social and political power, health care for transgender individuals does not provoke the popular sympathy or support that common medical conditions garner. Insurers can deem gender-affirming care as medically unnecessary without experiencing public or political backlash (Khan, 2011). Within this context, transgender and non-binary individuals unable to afford medically necessary care, resort to the use of street hormones or illegal silicone injections, acquired through friends or online (Grossman & D'augelli, 2006; Sanchez et al., 2009). Due to a lack of regulation, there is little known information as to the contaminants that are found in street hormones (Coleman et al., 2012; Nemoto, et al., 1999; Williamson, 2010). Furthermore, the use of street hormones can pose a serious health risk if taken in excess of the recommended dose or if clean syringes are not used.
Interpersonal and Individual Stigma

Interpersonal and individual level barriers reflect the attitudes, beliefs, and behaviors of both providers and patients within the health care system (IOM, 2010). Indirect and direct forms of transgender-based stigma create substantial barriers when attempting to access health care. Three essential expressions of stigma will be discussed to understand the interpersonal and individual manifestation of gender-based stigma, enacted, felt, and internalized stigma (Herek, 2007; Scambler & Hopkins, 1986).

Enacted stigma

Societal norms and beliefs of gender often translate into enacted stigma at the interpersonal level. Enacted stigma are instances of discrimination against individuals on the grounds of their perceived unacceptability or inferiority (Scambler & Hopkins, 1986). Enacted transgender based stigma refers to overt acts of transphobia, through slurs, rejection, ostracism, or explicit forms of discrimination and violence. An example of enacted transgender based stigma is evident in a qualitative study (n=40) conducted in Boston, Massachusetts, which uncovered that transgender and gender non-conforming individuals encountered significant barriers when accessing health care (GLBT Health Care Access, 2000). Comprised of four focus groups (MTF adults, FTM adults, MTF youth, and FTM youth) the study addressed several areas related to health care access. Focus group participants were recruited from local community organizations serving the transgender community and by transgender identified outreach workers who approached community members they felt might be willing to participate. The group members provided examples of discrimination ranging, from outright refusal by health care providers to treat them, to the refusal to use an individual's correct pronoun or name, to providers showing shock or disbelief when a person disclosed their transgender or gender non-conforming
status. Additionally, several participants raised the issue that a health care experience included interactions with both one's provider and the other medical and office staff, leaving the potential for enacted stigma to occur at several points during a visit.

The National Transgender Discrimination Survey (N=6,456) (2011) was the first large-scale national survey of transgender and gender non-conforming individuals. In 2008, The National Center for Transgender Equality (NCTE) and the National Gay and Lesbian Taskforce (NGLTF) partnered to conduct a cross-sectional survey of transgender discrimination. The NTDS used convenience sampling methods, including community/venue based and snowball sampling to recruit participants. To ensure broad participation in the survey, “transgender” was defined to include individuals who have transitioned or are transitioning from one gender to another, whether medically, socially, and/or legally, as well as individuals who cross-dress, identify as genderqueer or androgynous, or whose gender nonconformity is a part of their identity. Individuals from all 50 states, as well as the District of Columbia, Puerto Rico, Guam, and the U.S. Virgin Islands, were included in the sample. The overall sample was predominantly White (76%), identified along the transfeminine spectrum (60%), had some college or more (88%), reported a salary <$20,000 (74%), and were currently in the workforce (82%).

When asked to report on experiences of discrimination within the health care system, respondents reported being denied equal treatment in doctor's offices and hospitals (24%), emergency rooms (13%), mental health clinics (11%), by EMTs (5%) and in drug treatment programs (3%) (Grant et al., 2011). Furthermore, female to male respondents reported higher rates of unequal treatment than male to female respondents. Latinx participants reported the highest rate of unequal treatment (32% by a doctor or hospital and 19% in both emergency rooms and mental health clinics). When participants were asked if they have been denied service
altogether by doctors and other providers, 19% reported being refused treatment because of their transgender or gender non-conforming status. Twenty-eight percent (28%) of respondents experienced harassment in medical settings, and 2% were subjected to violence in a doctor's office. Twenty-four percent (24%) of transgender women and 20% of transgender men reported having been refused treatment altogether.

The findings of this survey make a powerful statement. However, it leaves many questions unanswered. To understand how stigma and discrimination are enacted within the health care system more information is needed to place these findings within a broader context. The authors of the survey acknowledge that this analysis is only a first step and encourage researchers to utilize this data for further investigation. One area that is addressed in the NTDS is how resilient transgender and gender non-conforming people are despite encountering stigma and discrimination in every major life area.

**Felt Stigma**

Felt stigma is the fear of enacted stigma, in addition to the feelings of shame associated with being transgender or gender non-conforming (Scambler & Hopkins, 1986). Because people wish to avoid being targets of enacted stigma, felt stigma often affects behavior. Transgender and gender non-conforming individuals may modify or adapt their behavior in a variety of ways to avoid stigma in various aspects of their lives, including healthcare settings. For example, a person may choose not to disclose their transgender or gender non-conforming status to their medical provider. They may even change their appearance to match their biological sex. To this extent, felt stigma can be adaptive because it protects an individual from enacted stigma (Cruz, 2014; Dewey, 2008; Mizock and Mueser, 2014). However, fear of stigmatization or previous negative experiences within the health care system may lead transgender and gender non-
confoming individuals to postpone or forgo care altogether. The National Transgender Discrimination Survey (2011) found that 28% of respondents delayed medical care when they were sick or injured due to discrimination. Other studies have found that participants did not have to experience direct discrimination from a provider to postpone or not get care. Reports of discrimination from other communities members were enough to encourage them to stay away from health providers (GLBT Health Access, 2000).

**Internalized stigma**

The third way an individual manifests stigma is by accepting the legitimacy of society’s negative regard for the stigmatized group. The individual manifestation of stigma and discrimination towards transgender and non-binary individuals are referred to as transphobia or the acceptance that those who transgress societal gender norms need to be feared and shunned (Herek, 2007). Transphobia on the part of healthcare providers often underlies enactments of stigma. There is a lack of literature examining provider attitudes towards transgender and gender non-conforming individuals.

Internalized stigma, internalized transphobia, or self-stigma may cause transgender and gender non-conforming individuals to feel that they do not deserve respect from their health care provider. They may not feel that they deserve access to health care as those who are cisgender (IOM, 2011). As a result, they may not disclose key information to their provider, may avoid seeking treatment, or refrain from challenging discrimination and other forms of enacted stigma. Dewey (2008) conducted a qualitative study with 22 self-identified transgender people. Participants were recruited through three transgender organizations in a large Midwestern city in the US. All participants were White with a mean age of 48. Through participant observation and interviews the researcher observed that in order to ensure quality care, maintain credibility and
receive particular treatments, each subject spent considerable energy deciding how they would approach a doctor. Patients chose what to disclose to doctors, depending on the type of medical treatment they needed and what they believed was the best way to receive these services (Dewey, 2008). Some participants were careful with what they revealed to their doctor, because they feared being denied quality medical attention for “cisgender” medical issues. While others, either because they had already fully transitioned or because they did not want treatments related to transitioning, chose to conceal their transgender identity, because they wanted to be seen as real men or women. Those who were gender non-conforming would attempt to keep their identity protected by lying to their doctors (Dewey, 2008).

Dewey (2008) asserts that concealment of a person's transgender identity may be a protective factor used to prevent conflict within a relationship where the doctor, as a gatekeeper, has considerable power. Furthermore, participants wanted to be seen as authentic in their representation and thus deserving of appropriate treatment. The qualitative observation and the author's presentations of the findings provide concrete examples of how some transgender and non-binary individuals approach health care interactions with the goal of minimizing stigma and discrimination. Whether these actions affect a person's health care experience needs further examination.

While enacted stigma refers to acts that are done to someone, the distinction between felt and internalized stigma is less clear. Many of how transgender and gender non-conforming individuals attempt to minimize the effects of stigma and discrimination can be protective. However, having to plan out every step for fear of potential discrimination may impact the physical, psychological, and social health of transgender and gender non-conforming individuals over time. Further research in is needed to identify protective factors and interventions that seek
to reduce adverse healthcare experiences associated with experiences of stigma and discrimination.

**Gender Affirmation Framework**

Gender affirmation refers to the social process by which individuals are recognized and supported in their gender identity and expression (Bockting et al. 2006; Melendez and Pinto, 2007; Nuttbrock et al., 2009; Sevelius, 2013). The need for gender affirmation is not unique to transgender individuals. However, due to their gender minority status, gender affirmation may take on a more prominent role in the lives of transgender, and non-binary individuals. Even cisgender people whose gender identity and expression align with their sex assigned at birth may find themselves at odds with societal pressures to conform to rigid notions of masculinity and femininity, which are pervasive and often unattainable for many (Sevelius, Keatley, and Gutierrez-Mock, 2011). For transgender individuals, gender affirmation is a vital component of their sense of self, a validation of their gender identity and expression. Gender affirmation can include the use of one's correct name and pronoun, to the active acceptance of the range of gender expressions transgender and gender non-conforming individuals claim. Studies have observed the importance of and need for gender affirmation among transgender individuals specifically related to the process of disclosing one's transgender identity (Melendez and Pinto, 2007; Nuttbrock et al., 2009). Despite the importance of gender affirmation in the lives of transgender individuals, the relationship between the need for gender affirmation and high-risk behavior has not been thoroughly investigated (Reisner et al., 2015; Sevelius, 2013).

The Gender Affirmation Framework (Sevelius, 2013) was developed from an intersectional perspective (Warner, 2008) and integrates objectification theory (Fredrickson and Roberts, 1997; Moradi and Huang, 2008) and the Identity Threat Model of Stigma (Major and
O'Brien, 2005). Fundamental to an intersectional approach is understanding that identity is informed by institutional, political, and societal structures (Warner, 2008). Objectification theory proposes that experiences associated with gender socialization and sexual objectification may create environments where women's bodies and appearance are both defined by others as well as themselves (Moradi, 2010). The second theory that informs the gender affirmation framework is the Identity Threat Model of Stigma, a social psychological theory which suggests that when persons with a stigmatized identity perceives a threat to one's identity and that person lacks the necessary coping skills to address such a threat, the individual will either attempt to decrease their exposure to the threat or increase one's coping skills and ability (Major and O'Brien, 2005).

Lastly, the gender affirmation framework draws from HIV related research with Latino gay and bisexual men, which examines sexual risk and psychological distress as outcomes of social oppression (Diaz et al., 2001, 2004).

![Figure 1. Gender affirmation framework for conceptualizing risk behavior among transgender women (Sevelius, 2013)](image)

Sevelius (2013) suggests that for transgender women of color the intersection of multiple oppressions (i.e., racism, transphobia and sexism) results in extreme marginalization where a high need for gender affirmation often goes unmet. Transgender women of color often report
early childhood experiences of harassment (Mallon and De Crescenzo, 2006) and family rejection (Koken et al., 2009) due to gender non-conformity. Research has found that transgender women often receive affirmation for their gender identity and expression from friends rather than family (Nuttbrock et al., 2009). For transgender women rejection from family members at a young age has been associated with homelessness, school dropout, and unemployment, often leading to a cycle of sex work, substance misuse, incarceration, and poverty (Cochran et al., 2002; Koken, et al., 2009; Reisner et al., 2015; Wilson, et al., 2009). This cycle is intensified for transgender women of color, in particular, African-American transgender women (Lombardi, 2009; Reisner et al., 2015), highlighting the relationship between racism, transphobia, poverty, and violence (Sevelius, 2013). Furthermore, studies have demonstrated a relationship between experiences of transphobia and self-reported depression, anxiety, and low self-esteem (Lombardi, 2009; Melendez and Pinto, 2007; Nuttbrock et al. 2010).

Research has found that transgender women also report experiences of sexual objectification starting at a young age (Garofalo et al. 2006). Sevelius (2013) posits that for transgender women experiences of sexual objectification may represent an environment in which they receive some form of gender affirmation; this is particularly salient within the context of sex work where gender affirmation is often perceived as readily accessible. Sexual objectification refers to experiences that reduce women to their appearance or the function of their body/body parts (Fredrickson and Roberts 1997). This includes experiences of objectifying stares from men, public evaluations of a woman’s appearance (i.e., catcalls), and other sexual gestures and comments, all of which are commonly reported by transgender women (Sevelius, 2013). Objectification theory also proposes that experiences of sexual objectification may lead to self-objectification, which is defined as a process in which women internalize themselves as sexual
objects, which may cause them to consistently monitor and measure their bodies against the dominant societal standards of beauty (Moradi, 2010). The self-objectification process can lead to body shame and increased anxiety, which has been commonly reported among transgender women (Algars et al., 2010; Kraemer et al., 2008; Moradi, 2010).

Self-objectification and body shame have been associated with lower body esteem, lower self-esteem, and less health-promoting behaviors (Bockting et al., 1998; Lowery et al., 2005; Sevelius, 2013). McKinley and Hyde (1996) propose that body control beliefs are associated with self-objectification and body shame. These beliefs perpetuate the idea that one's physical appearance can and should be controlled to comply with cultural standards of beauty and attractiveness (i.e., through medical intervention). Body control beliefs represent an internalization of societal expectations of beauty and may be associated with both a sense of agency over a person's health and risky body modification behaviors (McKinley and Hyde, 1996). For transgender and non-binary women, body control may be a protective factor and include seeing a doctor for feminizing hormones and gender-affirming health care. However, it may also result in the unsafe practice of using feminizing hormones obtained on the street or taking additional doses of hormones than prescribed by a physician in hopes that they will produce feminizing results quicker (Sevelius, 2013).

The Identity Threat Model of Stigma states that anxiety and maladaptive coping strategies can result from stigma-related stressors that threaten one's identity and exceed one's coping skills (Major and O'Brien, 2005). Thus, when the need for gender affirmation is high (due to psychological distress), and access to gender affirmation is low (due to social oppression), identity threat may result. For transgender women, stigma, social rejection, and body shame create a high need for gender affirmation while stigma and discrimination can prevent access to
gender affirmation (Sevelius, 2013). This discrepancy creates identity threat, resulting in anxiety and depression in addition to attempts to reduce the threat. For example, transgender women may attempt to reduce identity threat by either attempting to increase their access to gender affirmation or decrease their need for gender affirmation. Evidence suggests that transgender women may seek to fulfill unmet needs for gender affirmation in ways that increase risk for HIV and other negative health outcomes (i.e., engaging in sex work, pursuing dangerous silicone injections, having sex to obtain gender affirmation) (Bockting, et al., 1998; Glynn et al., 2016; Sausa et al., 2007; Sevelius, 2013; Weiessing et al., 1999). According to the identity threat model of stigma, those with the highest need for and the lowest access to gender affirmation will be at the highest risk for negative health outcomes (Sevelius, 2013).

Research with Latino men who have sex with men has found that self-reported experiences of discrimination were highly associated with psychological distress and risky sex practices (Diaz, 1998; Diaz et al., 2004). Diaz (2004) proposed a framework for understanding how oppression may influence sexual risk behaviors among marginalized populations. He proposed that the psychological distress (i.e., anxiety, depression) associated with stigma and discrimination may increase engagement in high-risk contexts, such as sex under the influence of drugs or alcohol. Moreover, it is within these contexts that HIV risk increases (Diaz et al., 2004).

Transgender women consistently report condomless receptive anal sex with multiple partners and sex under the influence of drugs and alcohol (Kenagy, 2002; Nemoto et al., 2004; Operario et al., 2011; Sausa et al., 2007). Studies have also shown that experiences of stigma and discrimination increase transgender women's need for gender affirmation from their male sexual partners. The need for gender affirmation has been associated with a willingness to engage in risky sexual behavior, the inability to negotiate condom use and substance use during sex
(Bockting et al., 1998; Melendez and Pinto, 2007; Reisner et al., 2009; Rodriguez-Madera and Toro-Alfonso, 2005; Sausa et al., 2007; Sevelius, 2013; Sugano et al., 2006). One meta-analysis found that 44% of transgender women reported unprotected receptive anal sex, with the highest rates being reported with sex work clients (39%) and primary partners (37%) (Herbst et al., 2008). Further, sex under the influence of drugs or alcohol is one of the most commonly cited sexual risk factors associated with condomless sex among transgender women and is often used as a way of coping with stigma, loneliness, or the demands of sex work (Nemoto et al., 2004; Xavier et al., 2005).

**Conclusion**

The theories presented in this chapter situate HIV risk and the facilitators and barriers to PrEP among transgender women on a macro, mezzo, and micro level. If the structural barriers to health care prevent transgender women from both awareness of and access to PrEP, uptake, and adherence cannot occur. By contextualizing HIV risk as a social and psychological process that is driven by social oppression, we begin to reframe the HIV prevention discussion to focus on the intersection of the structural, interpersonal, and individual level factors, which contribute to HIV risk, rather than focusing solely on individual behaviors. Research has examined the contextual factors that contribute to the increased rates of HIV among this group. The following chapter presents a review of research on HIV risk among transgender women.
CHAPTER 4: LITERATURE REVIEW

Introduction

Historically, research on transgender communities has predominantly focused on HIV risk among transgender women. The literature review below presents a historical overview of the recognition of HIV risk among transgender women, the emergence of transgender women as an HIV risk category, current HIV burden and vulnerabilities, and available HIV prevention strategies.

HIV and Transgender Women

Recognition of HIV Risk among Transgender Women

During the late 1980's, early 1990's a small body of research began to emerge on HIV risk among transsexual and transvestite female sex workers (Boles and Elfison, 1994, Castello-Branco, et al., 1988, Elfison, et al., 1993, Gattari, et al., 1991, Gattari, et al., 1992, Modan et al., 1992, Tirelli, et al., 1991). It is not clear from these studies whether participants were asked about their gender identification or sexual orientation. Thus, it is possible that participants did not identify with the group they were assigned by researchers. Transsexual and transvestite female sex workers were identified as a specific subgroup of sex workers, often found living in major urban cities. Studies found, when compared to cisgender female and male sex workers, transsexual and transvestite females had higher HIV prevalence rates (Boles and Elfison, 1993, 1994; Modan et al., 1992). Several factors were identified as increasing risk for HIV among this population, including, multiple sexual partners, sexual behavior (frequent receptive anal sex), illicit drug use, and the interaction between sexual and drug using/injecting behavior (Boles & Elfison, 1994; Elfison et al., 1993; Galli et al., 1991; Gattari et al., 1991; 1992; Modan et al., 1992; Tirelli et al, 1988; 1991). The research found that condom use was more frequent with
partners who paid for sex than with non-paying partners (Boles & Elifson, 1994; Elifson et al., 1993; Tirelli et al., 1991). One study (Modan et al., 1992) found that 'male to female transsexual' sex workers had an HIV prevalence rate of 11.1% compared to cisgender female sex workers (1.1%). Another study demonstrated that 68% of the sample were HIV-positive and that HIV seroprevalence rates were higher among ‘transvestites' who engaged in receptive anal sex and used crack than those who did not (Elifson et al., 1993). Furthermore, Boles & Elifson (1994) found that a strong commitment to transvestism, defined as using female names, wearing feminine clothing, and identifying as female, was associated with social and/or physical isolation, experiences of discrimination, feelings of hopelessness, participation in risky sexual behavior, and higher rates of HIV infection.

**Emergence of a Risk Category**

A 2008 meta-analysis found that in the United States a small number \(N=29\) of studies on transgender women and HIV risk took place from 1996-2003 (Herbst et al., 2008). The majority of these studies were conducted in urban areas such as, San Francisco (Clements-Nolle et al., 2001a; Clements-Nolle, 2001b; Kellogg et al., 2001; Nemoto et al., 1999; Nemoto et al., 2004, 2006; Operario and Nemoto, 2005; Sugano et al., 2006; Weinberg et al., 1999), New York City (Lombardi et al., 2001; McGowan, 1999; Wilchins et al., 1997), Philadelphia (Kenagy, 2002; Kenagy, 2005; Kenagy and Hsieh, 2005) and Los Angeles (Reback et al., 2001; Reback et al., 2004, 2005; Simon et al., 2000). Unlike earlier studies, a definition of "transgender," as well as specific eligibility criteria for recruitment and enrollment of transgender individuals, began to emerge, with several standard gender identity markers used across each study. Of the twenty-nine research studies, sample size ranged from 19 – 515, with nearly half of the samples having 100 participants or less (Herbst et al., 2008). Seventy-two (72%) percent of the studies were
comprised of predominantly transgender women of color (Herbst et al., 2008). Transgender women were found to engage in risk behaviors, such as drug use, having multiple sex partners, condomless sex, and participating in sex work (Kenagy, 2002; Kenagy, 2005; Nemoto et al., 2006; Reback & Simon, 2004; Simon, Reback, & Bemis, 2000). In addition to sexual risk behaviors, individual (e.g., substance use, suicidality, depression, and anxiety), interpersonal (e.g., physical and sexual violence, discomfort in public settings), and structural (e.g., discrimination in employment, housing, and social services, incarceration, lack of transgender specific health care) level factors commonly reported by transgender women (Lombardi, 1999; Lombardi & van Servellen, 2000; Lombardi et al., 2001; Nemoto, et al., 1999; Nemoto, et al., 2004).

**HIV Burden**

The Center for Disease Control (CDC) identifies transgender women as a group at high risk for HIV infection, but for whom no efficacious interventions exist (CDC, 2013). It is unclear as to when the CDC officially designated transgender women as a group at high risk for HIV, which is due in large part to the lack of uniform HIV surveillance data on transgender individuals collected at the federal level, state, and local level. While data on HIV prevalence and incidence among transgender women remain unreliable and underestimated, research indicates high HIV rates. HIV prevalence among transgender women is estimated at 27.7% among transgender women, higher than the 19% prevalence among men who have sex with men and STI prevalence among transgender women is estimated at 21%, with a range of 12-79% (Herbst et al., 2008). The highest HIV prevalence is found among African American transgender women, averaging 56.3% (Herbst et al., 2008). Additionally, findings from a 2013 meta-analysis indicate that
transgender women had more than 49 times the odds of HIV infection compared to cisgender adults (Baral et al., 2013).

Research has demonstrated that transgender women engage in a variety of HIV risk behaviors. For example, on average, 44.1% of transgender women report unprotected receptive anal sex, 27.4% unprotected insertive anal sex, and 39.3% sex while under the influence of drugs and alcohol (Herbst et al., 2008). Increased sexual risk behaviors are associated with sex work among transgender women (Clements-Nolle et al., 2001; Clements-Nolle et al., 2006; Poteat, Reisner, & Radix, 2014; Sevelius, 2013) On average, 41.5% of transgender women report sex work, and the highest rates of unprotected sex are with clients (Herbst et al., 2008). Studies have found that transgender women who exchanged sex for money, drugs, housing, and other services were a population at high risk for HIV acquisition and transmission (Baral, et al., 2013; Clements-Nolle et al., 2001; Clements-Nolle et al., 2006; Herbst, et al., 2008; Poteat, Reisner, & Radix, 2014; Sevelius, 2009; 2013). Inconsistent condom use, often coupled with offers of more money for condomless sex (Herbst et al., 2008; Sevelius, 2009; 2013) is commonly reported among this population. In one study, a majority of participants reported engaging in unprotected anal sex with transactional male sex partners whose HIV status was either unknown or different serostatus in the past 12 months (Sevelius et al., 2009). Studies have found that financial need, gender-based discrimination, lack of access to education and jobs, drug/alcohol misuse were central reasons for transgender women to engage in sex work (Clements-Nolle et al., 2001; Herbst et al., 2008; Sevelius et al., 2009; 2013). Lastly, research has found that transgender women significantly underestimate their level of HIV risk; on average 71.6% of transgender women perceived low or no chance of being HIV+, and 83.9% felt they had little or no chance of becoming HIV+ (Herbst et al., 2008).
HIV Vulnerability

A body of research examining the relationship between individual, interpersonal, and structural level factors and HIV risk has emerged, acknowledging that sexual risk behaviors are not the sole indicator for HIV risk (Operario et al., 2014; Sevelius, Reznick, Hart, & Schwarcz, 2009). These syndemic factors contribute to increased HIV risk for transgender women. A syndemic represents multiple co-occurring health and social problems that contribute to the exacerbation of additional health problems within disadvantaged communities (Singer & Clair, 2003). Research demonstrates that experiences of stigma and discrimination towards one's gender identity and gender expression are associated with severe health disparities, including HIV (Operario et al., 2014; Sevelius et al., 2009; Bradford et al., 2013; Sevelius, 2013). Transgender women experience pervasive discrimination and stigmatization, including high rates of violence and sexual assault (Lombardi et al., 2001; Nemoto et al., 2011; Testa et al., 2012). Herbst et al. (2008) found that of transgender women 42.9% reported physical abuse, 20.6% sexual assault, and 57.9% partner violence. Research has demonstrated that transgender women reporting sexual violence had triple the odds of inconsistent condom use (Clements-Nolle et al., 2001; Herbst et al., 2008). A prospective study in New York City found that transgender-related discrimination and violence was associated with sexual risk behavior and HIV and STI incidence among young transgender women (Nuttbrock et al., 2013). Lack of parental support has also been associated with HIV risk. A study among young transgender women in Los Angeles and Chicago found that sex without condoms was reported by individuals without parental support while having at least one supportive parent was associated with consistent condom use (Wilson et al., 2012).
Studies have found the accumulative effects of low self-esteem, depression, anxiety, substance use, and victimization related to one's transgender identity, and intimate partner violence has been associated with HIV infection and sexual risk (Brennan et al., 2012; Jefferson et al., 2013; Nuttbrock et al., 2009; Operario et al., 2014; Sevelius et al., 2009; Sevelius, 2013). Kenagy & Bostwick (2005) found that transgender women reporting low self-esteem had triple the odds of inconsistent condom use. Rates of depression among transgender women are high, exceeding 61% (Clements-Nolle et al., 2001; Jefferson et al., 2013; Nuttbrock et al., 2012; Nuttbrock et al., 2010). Suicidal ideation and attempts are common among transgender women (Clements-Nolle et al., 2006; Goldblum et al., 2012; Grant et al., 2011; Klein & Golub, 2016; Xavier et al., 2008); on average 53.8% report suicidal thoughts (Clements-Nolle et al., 2006; Goldblum et al., 2012; Grant et al., 2011) and 31.4%-48% report suicide attempts (Clements-Nolle et al., 2006; Goldblum et al., 2012; Grant et al., 2011; Klein & Golub, 2016; Xavier et al., 2008).

Transgender women often report substance use as a way to cope with the stigma and discrimination associated with gender non-conformity (Benotsch et al., 2013; Grant et al., 2011; Keuroghlian et al., 2015; Klein & Golub, 2016; Xavier et al., 2008). Studies have demonstrated that substance use among transgender women is associated with unprotected sex (Nemoto et al., 2011; Operario et al., 2014) and that unprotected sex under the influence of polysubstance is common (Nemoto, et al., 2004; Operario, et al., 2014; Risser, et al., 2005), thus magnifying the risk for HIV and other STIs. Furthermore, discrimination in housing, employment, and healthcare settings are identified as factors that may increase transgender women’s risk for HIV infection (Bradford et al., 2013; Grant et al., 2011; Khan, 2011; Nemoto et al., 2011; Sevelius et al., 2009; Sevelius, 2013; Strousma, 2014).
Evidenced in current studies are the multilevel vulnerabilities contributing to HIV risk among transgender women. Stigma and discrimination, including the intersection of multiple stigmatized identities, lack of social and legal recognition of self-identified gender identity, and lack of employment and educational opportunities are well documented as central drivers of HIV risk in transgender women (Baral et al., 2013; Poteat, Reisner, & Radix, 2013; Sevelius, et al., 2009; Sevelius, 2013). Studies have identified that barriers to health care access, including stigma and discrimination, and a lack of trans-specific and trans-sensitive health care providers contribute to low HIV testing rates among transgender women (Bradford et al., 2013; Baral et al., 2013; Grant et al., 2011; Poteat, Reisner, & Radix, 2013). Furthermore, lack of access to gender-affirming health care may also influence the development of and access to transgender-specific HIV prevention and treatment services.

**HIV Prevention for Transgender Women**

Despite the existing body of research on HIV risk among transgender women, no efficacious interventions exist (Garofalo et al., 2012; Poteat, Reisner, & Radix, 2013; Reisner et al., 2016). Interventions sensitive to the numerous vulnerabilities faced by transgender women are needed, not just for alleviating HIV burden, but also because the marginalization of transgender women leads to a variety of adverse health and psychosocial outcomes (Sevelius et al., 2009). For many transgender women, HIV prevention may become an afterthought given the day-to-day necessities of food, shelter, and safety. Data suggest that programs that integrate HIV prevention into broader concerns of vulnerable groups are more acceptable and more likely to retain participants and have better outcomes (Garofalo et al., 2012; Melendez & Pinto, 2009; Poteat, Reisner, & Radix, 2013; Sevelius et al., 2009; Sevelius, 2013). Melendez and Pinto (2009) found that building HIV prevention services into existing gender affirming (i.e., hormone
therapy) care at a community – based health clinic increased HIV/STI screening and engagement in HIV treatment among a sample of transgender women in New York City. Leveraging the experience of community settings in identifying community health needs and implementing context specific and culturally appropriate health promotion and HIV prevention is paramount. Given this context, a biomedical intervention such as pre-exposure prophylaxis (PrEP), may be critical for effective HIV prevention packages that meet the unique needs of transgender women (Escudero et al., 2015).

Pre-exposure prophylaxis (PrEP) refers to a daily or intermittent oral administration of antiretroviral drugs designed to protect high-risk HIV-negative individuals from infection (CDC, 2015). PrEP has been found to be efficacious in preventing HIV acquisition among several high-risk populations, including men who have sex with men (MSM) (Grant et al., 2010), serodiscordant heterosexual couples (Baeten, et al., 2012) and people who inject drugs (Choopanya et al., 2013). Although, results from clinical trials have spurred recommendations for PrEP among these high-risk groups, (CDC, 2011; CDC, 2012; CDC, 2015) research involving (and specific recommendations for) transgender women have mostly been absent, despite the substantially elevated risk for HIV within this community. To date, few studies include transgender people and those that do often conflate transgender women with MSM (Buchbinder et al., 2014; Liu et al., 2014; Grant et al., 2014). Additionally, inaccurate data collection and tracking of transgender individuals allows for miscategorization of participants who may identify as transgender or gender non-conforming. Transgender women face barriers to study participation such as, fear of stigma and marginalization associated with gender non-conformity, lack of cultural competency training for research staff, fear of participation due to lack of scientific knowledge regarding medication interaction with hormones, mistrust of the
scientific community, and discomfort with visitor IDs and complications related to name change (U.S. Women & PrEP Working Group, 2015). A 2015 meta-analysis, found that of the seven trials that analyzed the efficacy of oral PrEP for HIV prevention, only one (iPrex) confirmed enrollment of transgender women (Escudero et al., 2015). Of the 2,499 participants enrolled in this trial, 29 (1.2%) self-identified as transgender at baseline (Escudero et al., 2015).

Deutsch et al. (2015) conducted a subgroup analysis of the iPrex clinical trial, which initially reported the participation of 29 transgender women. This secondary analysis of the iPrex study is the first study to disaggregate transgender women from MSM, thus providing valuable information regarding the efficacy of PrEP as an HIV prevention intervention for this population. Of the 2499 enrolled participants, 296 (12%) identified as transgender and 29 (1%) as a woman. An additional 14 (1%) male-identified participants reported female hormone use. The total number of combined participants from each of the three groups was 339 (14%). This analysis found that the distribution of transgender women participants including those with sub-identities did not differ between the intervention and placebo group. Compared with MSM, transgender women were more likely to report transactional sex, receptive anal intercourse without a condom, or 5 or more partners in the past three months. Among transgender women in the study, there were 11 HIV infections in the PrEP group and ten in the placebo group. In the PrEP group, no drug was detected in any of the transgender women who seroconverted. The findings suggest that PrEP appears to be effective in preventing HIV acquisition in transgender women when taken, of the women in the PrEP group who became infected none had detectable drug levels at the time of seroconversion. The lack of protection from PrEP seems to be primarily a result of low adherence leading to low drug exposure, yet due to a lack of studies on drug interactions between PrEP and hormones, this factor cannot be ruled out.
Lastly, a recent study (Sevelius et al., 2016), examined trans-specific barriers and facilitators to PrEP acceptability among transgender women in San Francisco. The study conducted three focus groups and nine individual interviews ($N=30$). Participants ranged in age from 21 to 51, with a mean age of 36. The majority of ($n=22, 74\%$) self-identified as a person of color (Sevelius et al., 2016). Sevelius et al. (2016) found that knowledge of PrEP was low, yet once participants were given information regarding PrEP interest was relatively high. Participants expressed that due to past negative experiences with health care providers, the need for trans-competent providers was an essential component to PrEP uptake and adherence. Additionally, participants felt that PrEP could be used to promote self-efficacy and empowerment in sexual situations where transgender women encountered reduced power to negotiate condom use, especially within the context of sex work. Lastly, trans-specific barriers included lack of trans-inclusive social marketing campaigns of PrEP, overall prioritization of hormone use over taking a medication that little information is known about with regards to hormone interactions, and general medical mistrust due to experiences of transphobia (Sevelius et al., 2016).

**Conclusion**

Despite decades of research, HIV surveillance and monitoring of transgender women at the federal, state, and local level has not been required. A lack of research and HIV surveillance and monitoring are due in large part because the Centers for Disease Control (CDC), does not collect nor require that specific data on an individual’s current gender identity and sex assigned at birth be collected. A lack of governmental response to the HIV crisis among transgender women has created a situation in which researchers and clinicians must continually fight to receive funding for research and HIV prevention and treatment programs that are trans-specific.
Until population-based data is collected at the federal level funding will continue to be funneled to the groups for which there is data that is viewed as legitimate. The next chapter will present the research design and methodology for this dissertation.
CHAPTER 5: RESEARCH DESIGN AND METHODOLOGY

Introduction

The purpose of this dissertation was to identify the facilitators and barriers to pre-exposure prophylaxis (PrEP) adoption, adherence, and access to transgender women. This study was designed to answer the following four research questions: 1) what are the structural, interpersonal, and individual level factors impacting transgender women's willingness to utilize PrEP as an HIV prevention tool? 2) to what extent do these factors impede the integration of PrEP into the lives of transgender women? 3) what are best practices for integrating PrEP into health care for transgender women? 4) to what extent does need for and access to gender affirmation influence engagement in HIV risk behaviors among transgender women?

Research Design and Methodology

Identification of Facilitators and Barriers to PrEP Adoption, Adherence, and Access

Utilizing qualitative research methodology (i.e., in-depth semi-structured interviews) this dissertation: a) identified social and behavioral factors that are likely to influence PrEP acceptance, uptake and adherence among transgender women in New York City, including factors at the structural, interpersonal, and individual level; and b) examined social and behavioral factors associated with disparities in access to gender-affirming - transgender-sensitive prevention and care services among transgender women in NYC that might directly impact PrEP adoption and adherence.

Sampling and Recruitment. A series of in-depth semi-structured interviews were conducted with a total of thirty participants from the following two groups: a) transgender women currently taking PrEP \( (n=15) \), and b) transgender women currently not using PrEP \( (n=15) \). To be eligible for participation individuals had to meet the following criteria: 1) 18 years
of age or older; 2) assigned male at birth; 3) identify with a gender different from sex assigned at birth; 4) in the past six months had receptive anal or vaginal sex with a cisgender man or transgender woman or meet at least one criteria for PrEP eligibility; 5) live in the NY tri-state area; and 6) self-report a negative HIV status. Also, to be eligible for the PrEP group, individuals had to self-report current PrEP use. People of color were oversampled to facilitate understanding of specific issues related to disparities in access and acceptability among this group deemed at high risk for HIV acquisition. Sample size was chosen based on recommendations for similar qualitative inquiries to ensure thematic saturation (Reisner, Perkovich, & Mimiaga, 2010; Sevelius, 2009; Sevelius, 2013; Sevelius et al., 2016) as well as feasibility concerns.

Recruitment flyers were posted at the following community-based health centers, which provide medical and social services to transgender women in New York City: Callen-Lorde Community Health Center, APICHA Community Health Center, CKLife at Bronx Lebanon Hospital, and Community Health Network. Emails were sent to transgender community leaders and advocates throughout New York City to assist with recruitment through their social networks. Lastly, online recruitment consisted of online flyers and text postings via Facebook, Twitter, and transgender-inclusive and specific listservs.

**Procedures.** Potential participants contacted the Hunter HIV/AIDS Research Team (HART) via telephone to be screened for eligibility. If eligible, participants were scheduled for an in-person semi-structured interview that took place at the HART office at Hunter College at 68th Street and Lexington Ave. Trained research staff took participants through the informed consent process, including the audio recording of the interview. Interviews lasted between an hour to an hour, and a half and participants were compensated $40 for their time. Interviews were transcribed by members of the study's research team and a transcription service (Transcript
Divas). Any identifying information was redacted immediately from the transcripts to ensure the confidentiality of interview participants. Interviews contained a core set of questions regarding factors at the structural, interpersonal, and individual level that might influence PrEP adoption, adherence, access, and willingness to use future biomedical PrEP interventions.

**Interview Topics** (see appendix - interview guide). **Participants on PrEP** were asked to discuss any contributing factors that led to their PrEP use and any benefits and challenges experienced since initiating PrEP, including issues around access and adherence. **Participants not on PrEP** were asked to discuss their knowledge of and attitudes towards PrEP, and any factors that contributed to their decision-making around whether to take PrEP. Participants in both groups were asked to discuss factors that would be most important to facilitate broad interest and participation in PrEP. Input was also solicited on intervention components that would ensure cultural competence and acceptability.

**Qualitative Data Analysis**

After interviews were transcribed and verified for accuracy, thematic coding was used, following procedures outlined by Miles and Huberman and Patton (Miles & Huberman, 1994; Patton, 1999). For thematic analyses, data were indexed and coded using open and axial coding (Patton, 1999). Axial coding procedures allowed the data to be coded to address research questions 1-4. Open coding procedures were used to identify emerging themes and factors associated with each research question. Following the development of the codebook, data were coded in Dedoose qualitative software. Reliability was maintained through the use of multiple coders, including two research assistants and the principal investigator. Inconsistent application of codes was discussed and revised until coders maintained 90% agreement. Once the coding scheme captured the themes arising from the transcripts, the synthetic and analytic features of
Dedoose were used to facilitate theory building by permitting the examination of overlap between codes to conceptualize and assess hypotheses about the co-occurrence of themes.
CHAPTER 6: RESULTS

Introduction

The purpose of this dissertation is to identify the facilitators and barriers to pre-exposure prophylaxis (PrEP) adoption, adherence, and access among transgender and non-binary women (TGNBW). The following chapter presents results from thirty semi-structured interviews with two groups: 1) TGNBW not on PrEP (n=15) and 2) TGNBW on PrEP (n=15). Each interview contained a series of open-ended questions addressing the study’s four main research questions: 1) what are the structural, interpersonal, and individual level factors impacting TGNBW’s willingness to utilize PrEP as an HIV prevention tool? 2) To what extent do these factors impede the integration of PrEP into the lives of TGNBW? 3) What are best practices for integrating PrEP into health care for TGNBW? And, 4) to what extent does need for and access to gender affirmation influence HIV risk among TGNBW?

Description of Study Sample

Demographic Characteristics

In New York City (NYC) between 2012-2016, transgender people represented 2% of individuals newly diagnosed with HIV (NYC DOHMH, 2017). Among transgender people newly diagnosed with HIV in NYC the majority were transgender women (99%) between the ages of 20-29 (60%), who were either Black (44%) or Latinx (48%) (NYC DOHMH, 2017). As such, the overall sample for this dissertation is comprised of thirty transgender and non-binary women (TGNBW) living in (NYC) who reflect these demographics and are disproportionately at risk for HIV. Participants represent a cross section of the NYC TGNBW community for whom PrEP has the potential to greatly reduce the disparate rates of HIV infection.
Presented in Table 1, the vast majority of the sample were under the age of 30 (60%, n=18) ($M=28.00$, $SD=6.91$; age range 21-49), identified as a person of color (73%, n=22), claimed a binary gender identity (i.e., identified as female, woman, or trans woman) (93%, n=23), identified as heterosexual/straight (57%, n=17), reported an income of less than $12,000 (87%, n=26), were currently not in the workforce (90%, n=27), and were publicly insured (87%, n=26).

Overall, 60% (n=18) of the total sample represented individuals under the age of 30. Participants under 30 were more likely to be on PrEP (73%, n=11) compared to non-PrEP users (47%, n=7). Far fewer non-PrEP users identified as white (13%, n=2) compared to PrEP-users 40% (n=6). Sixty-seven (67%, n=10) percent of non-PrEP users identified as heterosexual/straight compared to 47% (n=7) of participants on PrEP who identified as heterosexual/straight. Finally, all participants not on PrEP (n=15) reported an annual income of less than $12,000, were currently not in the workforce, and were publicly insured compared to participants on PrEP (73%, 80%, and 73%, respectively).

**PrEP Eligibility and Indications**

Table 2 presents PrEP eligibility criteria and indications by group. Overall, the majority of participants met at least one of the following PrEP eligibility criteria (CDC, 2014): a) condomless anal sex in the past 6 months (93%, n=28), b) STI diagnosis in the past 6 months (3%, n=1), and/or c) have an HIV-positive sex partner (20%, n=6). Among PrEP-users, 100% (n=15) reported condomless anal sex in the past 6 months compared to 87% (n=12) of participants not on PrEP. Participants on PrEP were more likely to report having an HIV-positive sex partner in the past 6 months (27%, n=4) compared to 13% (n=2) of non-PrEP users.
In addition to meeting PrEP eligibility criteria, participants also reported three key factors that increased risk for HIV infection where PrEP use would be beneficial, including engaging in sexual activity with a) multiple sex partners (33%, n=10), b) a partner with multiple sex partners (30%, n=9), and c) a partner whose HIV status is unknown (53%, n=16). Among the total sample, PrEP users were more likely to report at least one of the three indicators: a) multiple sex partners (40%, n=6), b) a partner with multiple sex partners (40%, n=6), and c) a partner whose HIV status is unknown (60%, n=9) compared to non-PrEP users (27%, 20%, and 47% respectively). Lastly, participants on PrEP (27%, n=4) were more likely to report all three indicators compared to participants not on PrEP (20%, n=3).

**Structural, Interpersonal, and Individual Level Factors Impacting PrEP Use (RQ 1, 2)**

Several facilitators and barriers emerged as factors that synergistically interact at the structural, interpersonal, and individual levels to impact willingness to use PrEP among transgender and non-binary women. The following sections present the study’s findings at each level. First, at the structural level, participants identified several facilitators that increased awareness, knowledge, and uptake, including access to PrEP messaging and information and active provider engagement and active provider assistance with PrEP. Further, participants identified two related structural barriers influencing PrEP dissemination and uptake, which included the conflation of TGNBW with men who have sex with men and a lack of trans-inclusive gender affirming sexual health messaging and program.

Next, at the interpersonal level, participants identified two important facilitators influencing PrEP uptake - personal relationships and community connectedness and transphobia and HIV-related stigma as a potential barrier. Finally, at the individual level participants identified having a realistic perception and understanding of personal HIV risk, reduced
psychological distress and increased self-esteem as facilitators to PrEP use. While participants discussed two interrelated barriers at the individual level, including hesitation around taking PrEP due to the fear that it would negatively interact with the feminizing hormones used for gender transition and not wanting to take any additional medication than what they are already being prescribed.

**Structural Level Factors Impacting PrEP Use**

**PrEP Awareness and Knowledge**

Nearly all of the participants (97%, n=29) reported ever having heard of PrEP. Participants identified three factors that impacted willingness to take PrEP: a) types of PrEP information, b) how this information was received (e.g., public health campaign; doctor, friend), and c) trust in the information source. Key differences emerged between participants on PrEP and those not on PrEP with regards to willingness to take PrEP and levels of PrEP awareness and knowledge. For example, among non-PrEP users the majority (93%, n=14) had a high-level of PrEP awareness. Awareness was operationalized as: a) having ever heard of PrEP and b) demonstrating basic knowledge of PrEP (e.g. why PrEP is used and by whom and how effective it is).

I heard about PrEP it’s like 98-99% that you don’t contract HIV. PrEP is Truvada when you are on PrEP it’s what you use when you are negative.

- No PrEP Participant 3, 24, TW, Binary, African – American

This participant demonstrates a basic understanding of PrEP, its effectiveness, who uses it and what it does. However, in addition to a basic understanding of PrEP, participants on PrEP illustrated greater PrEP knowledge, which included: a) how often PrEP is taken, b) potential side effects associated with the medication, and c) how PrEP protects against HIV. All PrEP users
reported knowing that PrEP is an HIV antiretroviral drug that is also used to treat individuals who are HIV positive.

I know is that you take it every day, and if you take it every day it’s like 98, 99 percent effectiveness at stopping the transmission of HIV. My understanding of the way that it works is that it’s basically an antiretroviral drug that is part of the normal course of treatment for HIV for people who actually have the infection. And when you build up enough of it in your blood, there’s enough of the chemical floating around in there such that if you come in contact and some of the viruses get into you they won’t survive long enough to take hold and to take over the white blood cells, etc. I also know that if you take it 4 times a week it’s still effective just not as effective so it’s good to take it every day.

– On PrEP Participant 15, 38, Binary TW White

In the statement above, the participant demonstrates a high-level of PrEP knowledge, including the drug’s efficacy if taken every day and how PrEP works to prevent HIV infection. She also shares her understanding of PrEP research, which has found that PrEP is still effective if taken four times a week (Grant et al., 2010; Grohskopf et al., 2013). Thus, demonstrating how access to more specific PrEP information may positively assist in the decision-making process around whether to take PrEP (i.e., participant taking PrEP has more information).

Next, these results indicate that sources of PrEP information differed between groups. The majority of participants not on PrEP (73%, n=11) attributed their PrEP awareness to a recent New York City public health campaign, which included subway ads and health information pamphlets about PrEP.

I learned about PrEP from the ads on the subway. I heard two things: one is PrEP, and one is PEP. PrEP is something you can take to stop you from getting HIV, PEP is something to take after you have been exposed to HIV. That’s all I know about PrEP. I don’t know if there are side effects, or where to get it if I want to take it.

- No PrEP Participant 9, 38, Non-Binary, Asian/Pacific Islander
Despite a high-level of awareness, this participant demonstrates how basic PrEP information does not include two key factors associated with the potential use of PrEP: a) where to get PrEP from and b) information on side effects. Further, several participants not on PrEP (60%, n=9) echoed the above quotation by reporting that they did not know where to get PrEP and wanted more information about the potential side effects associated with PrEP. These results demonstrate a major structural barrier to PrEP access and uptake, if participants are interested in PrEP but need more information (e.g., potential side effects) yet are unable to access that information because they do not know where to get PrEP, potential uptake may not occur.

Among the small percentage of participants not on PrEP that had not learned about PrEP from a public health campaign (27%, n=4), their PrEP awareness was attributed to a one-time conversation (often a quick mention of PrEP) where their health care provider talked to them about PrEP.

He (doctor) smoothed it in there. He said, I know you’re a wild card and you be out there doing your thing, if you want to try it (PrEP) or get on it just let me know. I told him that now I know it’s an option I’ll let him know.

-  No PrEP Participant 6 – 28, Binary TW, African-American

She acknowledges that while her provider made her aware of PrEP it did not increase her willingness to take it despite her provider’s implication that she is high-risk. It is possible that the providers explicit judgement (i.e., you’re a wild card) about the participant’s sexual activity negatively influenced her willingness to take PrEP. Further, the providers approach also illustrates the lack of training providers receive in conducting sexual health assessments overall, and specifically with TGNBW.

In contrast, participants on PrEP learned about PrEP from a number of different sources, crediting their knowledge to: a) the internet and social media, b) working in the HIV prevention field, c) word of mouth from friends, and d) interactions with health care providers. Several PrEP
users (53%, n=8) mentioned a series of YouTube videos on PrEP starring Bob the Drag Queen from Rupaul’s Drag Race as one of their first introductions to PrEP.

I heard about PrEP through the RuPaul’s Drag Race and stuff like when I watch them on YouTube and they were talking about PrEP and I was like what are they talking about.

- On PrEP Participant 1, 27, TW, Binary, African-American

Twenty (20%, n=3) percent of PrEP users reported that working as an HIV prevention outreach worker or PrEP navigator gave them access to providers and information that greatly increased their knowledge of and willingness to take PrEP.

I heard about it [PrEP], I feel like mostly just word of mouth, so I knew there was this thing called PrEP. But it wasn’t until I started working at an LGBT health center and I started learning a lot more about PrEP and I was like oh my god not only do I want to get on PrEP ASAP, but I want everyone to know the things that I’ve just learned because I felt that they were really game changing.

- On PrEP Participant 2, 29, Non-Binary, Latinx

This participant talks about how being exposed to more information about PrEP increased their willingness to use it as well as their desire to educate others. Furthermore, they indicate that there is important information that is not being made accessible to all persons who might benefit from PrEP, thus highlighting a barrier to how PrEP information is generated and disseminated.

Lastly, all of the participants on PrEP discussed three factors that worked together to increase PrEP knowledge and uptake, this included having: a) a friend talk to them about PrEP, b) knowing someone on PrEP (especially other TGNBW), and c) a provider who actively engaged them around taking PrEP.

When I first heard about it I wasn’t sure what it was and then maybe a year or two ago one of my friends brought it up and said there was PEP and PrEP and I was like what’s PEP and PrEP. So, I asked more questions and she told me about it and that’s when I got curious and did some research myself and then my provider told me about it too and then I got on it about a year ago.

- On PrEP Participant 4, 28, TW, Binary, API
Her quotation illustrates how having a personal connection to the source of PrEP information and a friend on PrEP sparked her interest and willingness to seek out more information about PrEP. In addition to her connection to others on PrEP and a motivation to learn more about PrEP, active provider engagement also aided in her PrEP uptake.

These results demonstrate that PrEP messaging may be working but awareness is not the sole indicator of PrEP uptake. Despite a high-level of PrEP awareness only 20% (n=3) of participants not on PrEP stated that they want to take or would consider taking PrEP. While the majority of non-PrEP users (93%, n=14) had heard of PrEP, these results demonstrate a disconnect between having heard of PrEP and possessing information on PrEP that is integral to the decision-making process around whether to take it or not. Among participants on PrEP, awareness was an important facilitator to PrEP uptake, however it was the source of PrEP information coupled with the types of information that influenced willingness to take PrEP.

**Active Provider Engagement and Assistance**

Overall, less than half of the total sample (40%, PrEP n=7, No PrEP n=5) reported that a provider had ever initiated a conversation with them about PrEP. In contrast, participants on PrEP (60%, n=8) who reported not having a provider start a conversation about PrEP indicated that they had initially asked their provider about starting PrEP. Participants who had a provider actively discuss and/or help with accessing PrEP said that these interactions increased their knowledge, access, and uptake. Providers, who had an ongoing dialogue with patients about PrEP rather than a one-time discussion, appear to positively influence participant’s willingness to use PrEP. Participants on PrEP reported that active provider engagement entailed ongoing conversations about PrEP, which included information about the medication’s efficacy and side effects as well as how to pay for PrEP. These ongoing conversations provided participants with
the opportunity to ask questions and integrate PrEP knowledge, which assisted in the decision-making process around PrEP uptake.

He (doctor) brought it (PrEP) up almost every other time we would meet. He would say hey this is available to you it’s covered by your insurance in case you want to go on it.

- **On PrEP Participant 4 – 28, Binary TW, Asian Pacific Islander**

This participant illustrates that having her provider talk about PrEP at almost every appointment and emphasizing that it is covered by was an important facilitator to her PrEP use.

Further, a third of participants on PrEP (33%, n=5) identified active provider engagement and active assistance as two major facilitators to PrEP uptake at the structural level.

PrEP was offered to me so frequently in the few interactions I had with my health clinic initially they made it so easy to get on. Plus, they helped me get on insurance that covered PrEP, that’s exactly the way to do it.

- **On PrEP Participant 7 – 29, Binary TW, White**

Active provider assistance included not only educating and offering PrEP but navigating the process of insurance and payment assistance for obtaining PrEP.

They (health center) have a person, a case organizer almost. They’ll make sure everything you’re doing with the social worker, the doctor – they also double as the PrEP coordinator to get people on PrEP.

- **On PrEP Participant 9 – 25, Binary TW, White**

She indicates that having a dedicated staff member within a health center whose role is to assist patients in facilitating a range of health care services, including PrEP, encourages PrEP uptake by integrating this practice into overall health care.

**Conflation of Transgender Women with MSM**

Another theme that emerged is the extent to which the conflation of TGNBW with men who have sex with men (MSM) is a barrier to PrEP access and uptake. Forty (40%, n=6) percent of PrEP users expressed frustration with being categorized as MSM within HIV and other STI...
prevention services. Participants identified this as a barrier to not only PrEP uptake but also HIV and STI testing.

Yeah, like when you put man or trans woman, then you're already off the bat saying that these two things are comparable. But if you just say do you have sex with a person with a penis or a vagina then it's more open to interpretation, I think they'll have a lot more luck with getting the answers that they need from people. And I feel they'll make a lot more people comfortable.

- On PrEP Participant 12 – 26, Binary TW, Latina

This participant expresses her frustration with being compared to a man and how this practice both renders TGNBW invisible and affects the types of information a provider might need to accurately assess a person’s sexual behavior and risk. She also recommends that during a sexual health risk assessment, providers separate a person’s gender from their anatomy (i.e., asking if you have sex with a person with a penis or vagina), which acknowledges that TGNBW have sex with partners of multiple genders with varying genitalia. The conflation of transgender and non-binary women with MSM reinforces the societal belief that natal sex and gender identity are immutable by refusing to acknowledge and support TGNBW and accurately describe the factors associated with HIV risk among this community.

Lack of Trans/Gender Affirming Sexual Health Messaging and Programs

As discussed above the categorization of TGNBW with cisgender gay men renders TGNBW and the HIV disparities among this population invisible. Participants stated that the practice of lumping TGNBW with MSM contributes to a lack of transgender-inclusive and gender-affirming sexual health messaging and programs (which include PrEP). This off-putting PrEP messaging, which lacked a transgender inclusive and gender affirming lens was identified as a major barrier to PrEP uptake. Ninety (90%, No PrEP = 12, PrEP=15) percent of the total sample said that low PrEP uptake among TGNBW was due in part to a lack of trans-inclusive/gender affirming messaging. Participants felt that this factor directly contributed to the
community’s belief that PrEP was not right for them. Overall, participants stated that current PrEP messaging did not reflect their lives as transgender and non-binary individuals.

I don’t ever see any information that is about trans women or sex workers, if you’re putting yourself at risk every day, is it a benefit to take it, will it help you? The pamphlets I see are really specific to lovers or partners but what if that’s not who you’re having sex with.

- No PrEP Participant 1 – 37, Binary TW, Latina

As this participant highlights, the confusion around whether PrEP was for TGNBW is not a byproduct of poor risk perception but rather a structural barrier perpetuated throughout PrEP messaging and programs that refuse to acknowledge and address the socio-cultural experiences of TGNBW. This participant states that PrEP messaging and programs need to be more specific and not gloss over the unique needs of the TGNBW community.

Another issue raised by all participants not on PrEP was whether PrEP protects against HIV with multiple partners. The following participant echoes the previous statement, highlighting a specific high-risk context in which PrEP would be beneficial for TGNBW.

I’ve basically heard it protects you if you have one partner. But in the trans community there are a lot of trans women who are sex workers, and we don’t know if it (PrEP) protects with multiple partners. Because we get paid more if we don’t use condoms. So most of the girls don’t use condoms. So, I don’t know if it’s true that PrEP will protect us against HIV with multiple partners.

- No PrEP Participant 3 – 24, Binary TW, African-American

This participant identified engagement in survival sex work as a potential risk for HIV. However, due to the terminology used in PrEP messaging, which emphasizes sexual partner(s) and does not address sex with multiple partners, participants expressed hesitation as to whether PrEP was right for them because they did not consider their clients sexual partners.

Participants also articulated a need for PrEP messaging campaigns to include images of the diverse gender presentations within the TGNBW community. A common thread throughout interviews was that many of the transgender women pictured in PrEP and HIV prevention
marketing campaigns do not represent the range of gender identities and expressions within the TGNBW community. Furthermore, the majority of participants (83%, n=25) stated that unless you had some personal connection to the transgender women in PrEP marketing ads you would otherwise never know that they were TGNBW.

A lot of the trans people that they’ve been using in a lot of these campaigns and stuff have been… Quote, unquote, for lack of a better term, more passable. And that’s not always the reality with our community, and that’s not always what our community looks like. So, you need people out there to show the diversity, and diversity of presentations.

- On PrEP Participant 6 – 34, Binary TW, Multiracial

She implies that prioritizing TGNBW who “pass” both sends an explicit message that this is the group that would most benefit from and are appropriate candidates for PrEP, while at the same time devaluing those who do not.

Lastly, participants discussed a lack of provider engagement around their overall sexual health. Almost everyone, (90%, n=27) stated that their health care provider rarely engaged them in discussions around their sexual health outside of standard risk assessment questions (i.e., are you currently sexually active? Have you had unprotected anal sex in the past 6 months?)

Participants discussed how current sexual risk questions, “do you have sex with men, women or both?” do not accurately reflect their sexual activity.

Like no doctor has ever really asked me if my dick still worked or if I could top with it, unless I brought something up about it.

- On PrEP Participant 8, 22, TW, Binary, White

In the event that a provider did discuss a participant’s genitals with them it surrounded whether or not they wanted to get them removed.

He’s only asked if I ever want to cut it off. I told him I don’t know if I want that. He’s never asked me anything else about it. This is fine with me, but I can see where it would be good for him to ask more questions.

- No PrEP Participant 3, 24, TW, Binary, African - American
As these two quotations indicate, if providers are not having conversations about the types of sexual activity TGNBW are engaging in or asking how this has or has not changed since starting hormones they are not adequately assessing risk, fully addressing the sexual health needs, or the sexual well-being or satisfaction of this community.

Overall, participants felt that providers perpetuated the belief that every TGNBW wanted to have bottom surgery and that genital health was unimportant because providers only acknowledged their genitalia when discussing surgery. Furthermore, participants identified a lack of diverse representation of TGNBW in PrEP messaging campaigns coupled with a lack of specific information for TGNBW sex workers around why PrEP would be beneficial and the dearth of providers willing to engage TGNBW in conversations about their overall sexual health created multiple structural barriers to PrEP uptake.

**Interpersonal Level Factors Impacting PrEP Use**

**Personal Relationships and Community Connectedness**

Themes of personal relationships and community connectedness emerged as important resiliency factors that participants on PrEP said impacted their willingness to integrate PrEP into their lives. On the one hand, the fact that few TGNBW are on PrEP was viewed as a vicious cycle – TGNBW don’t see/know others on PrEP, so they don’t go on PrEP themselves.

A lot of my trans friends are positive the vast majority of them, very few of them are negative and even fewer are negative and on PrEP.

- *On PrEP Participant 6 – 34, Binary TW, Multiracial*

In contrast, 60% (n=9) of women who did go on PrEP often reported that they had people in their social network who paved the way.
Within my friend group PrEP is something that people are often on. I definitely remember some of my friends being on Twitter and not just saying that they were on it but also saying that you should consider being on it too. Or at least you should consider if it’s right for you to get on it.

- On PrEP Participant 8 – 22, Binary TW, White

Further, close to 50% (n=7) of participants on PrEP talked about a societal responsibility to increase social norms around PrEP use in the transgender and non-binary community, viewing their PrEP use as not only an individual level protection but a contribution to the safety of the trans feminine community, their sexual partners, and society. PrEP users were not ashamed of their use, at times proselytizing the benefits and importance of being on PrEP to friends and sex partners.

I want my friends to be on PrEP too. I think it’s important that people are on it because it helps reduce and control HIV within, not only our community, but also every persons that are having sex. I talk to my sexual partners about it too because I want them to be safe as well and also know that they are safe with me as well.

- On PrEP Participant 4 – 28, Binary TW, Asian/Pacific Islander

Lastly, a third (33%, n=5) of women on PrEP reported that a key aspect to their PrEP uptake was a sense of altruism and the chance to be a part of history.

This is revolutionary I want to be one of the first people to do this. It took time, but I pretty much educated myself. To be a part of it is a big thing for me not just for myself, for future generations. Part of it is just for the history of it, just to be part of making the world a better place, for people, or a little bit of a safer place, for folks.

- On PrEP Participant 6 Participant – 34, Binary TW, Multiracial

In this quotation, the participant attributes her motivation to use PrEP with the opportunity to participate in a movement that will have a lasting impact on HIV infection among future generations of transgender women. She acknowledges that her PrEP use is not only benefiting her individually but also the community and society as a whole.
Transphobia and HIV Related Stigma

Over a quarter (27%, No PrEP=3, PrEP=5) of the total sample discussed how societal shame and stigmatization around being seen as HIV positive coupled with societal messaging describing transgender women as unclean, unsafe, or promiscuous may hinder PrEP uptake. A common example articulated by both groups dealt with the public shame and stigmatization associated with disclosure of PrEP status.

The worst thing about being on PrEP is actually letting people know you’re on PrEP because people assume that you have HIV.


As highlighted in this quotation, several participants stated that the worst part of being on PrEP is having someone think that you are HIV positive because you are taking PrEP. Participants stated that disclosing their PrEP status whether by choice or being found out (i.e., someone seeing a medication bottle for PrEP) was a barrier and negative aspect to PrEP use.

Additionally, participants were concerned that disclosing one’s PrEP use implied that they were whores or had a crazy sex life.

Like on BGC (sex/dating website), people will put negative on PrEP and then people start asking you got HIV, you HIV positive, that’s the first thing that comes even though you are saying PrEP. So, a lot of people don’t want to put that because that’s almost spooking, cause if you don’t have it, that’s almost like saying you have it. It’s like saying to who you want to have an encounter with that you have a crazy sex life.

- No PrEP Participant 3 – 24, Binary TW, African-American

In this quotation, PrEP use disclosure is viewed as an open invitation for people in the community to judge your sex life. Rather than a personal choice that promotes positive sexual health care and agency over TGNBW’s HIV risk.

A final barrier related to transphobia and HIV stigma deals with the negative stereotypes and representation of transgender women in the media.
It’s just this past knowledge, seeing transwomen on TV. So, they get freaked out. But then I’ll be like, no; actually, things are a lot safer, and that’s not me. So, it’s just this reeducation, reeducating people about our experience. It’s good. I enjoy doing it. It’s not a thing that we have to do, but for me it’s important. I don’t like being misunderstood.

- On PrEP Participant 9 – 25, Binary TW, White

To combat negative stereotypes of TGNBW this participant uses her PrEP use as a conversation starter with potential sex partners in an attempt to dismantle the preconceived notions that transgender women are unsafe or dirty. Actively disclosing her PrEP use to others acts as a buffer against the negative effects of stigma and discrimination.

**Individual Level Factors Impacting PrEP Use**

**Risk Perception**

The role of risk perception in women’s willingness to utilize PrEP as a prevention tool is a complicated one, sometimes acting as a facilitator and at other times acting as a barrier. On the one hand, risk perception is a facilitator, because women who perceive themselves to be at risk want PrEP. But on the other hand, it can be a barrier, if PrEP is not seen as addressing the type of risk that is most important to participants or in the event that they are not engaged in high-risk activity.

For all of the participants on PrEP, risk perception was a facilitator to PrEP uptake.

Since I’m having sex with a lot of people I think it would be different if I was in a monogamous committed relationship with someone else who is negative it would be a very different thought process about whether I wanted to take it or not.

- On PrEP Participant 8 – 22, Binary TW, White

In this quotation, the participant clearly articulates why they are on PrEP and how their use is associated with their actual risk. Furthermore, highlighted in this statement is the understanding that if her risk level changed she would reevaluate whether or not to continue to take PrEP.
Current engagement in transactional sex was identified as a motivating factor for taking PrEP among 60% (n=9) women on PrEP. Participants viewed HIV risk as an occupational hazard associated with transactional sex.

Sex work is something that I do because I’m unemployed. I don’t know the histories of any of these men I’m having sex with, so…this is why I considered and ended up taking PrEP.

- On PrEP Participant 13, 24, TW, Binary, White

In this quotation, PrEP is used to minimize the risk associated with having sex with individuals whose sexual histories are unknown. She is clear that this risk is not just associated with her behavior but the contextual factors (e.g., unemployment and sex work) that increase her HIV risk.

Close to 50% (n=7) of participants on PrEP reported that a major driver for taking PrEP was previous scares and experiences where potential exposure to HIV had occurred.

I had a scare and took PEP. After that I realized, maybe I should get on PrEP because it’s just preventative measures and just to keep me safe because what if I didn’t have access to something within those 72 hours. That's what really motivated me to get on PrEP and hopefully prevent any future mistakes.

- On PrEP Participant 5 – 24, Binary TW, Asian/Pacific Islander

This participant speaks to how PrEP is viewed as a form of harm reduction that is preventative especially in the event that PEP is not available. PrEP provides her the peace of mind that if a “mistake” happens again she safe and protected. With PrEP HIV is one less thing she has to worry about.

In contrast, for women not on PrEP risk perception was a barrier to PrEP uptake, 40% (n=6) of participants not on PrEP talked about being low-risk and how this impacted their willingness to use PrEP.
It might differ depending on the type of sexual life I have. Like I said my sexual life is very poor so in that way I don’t have to think about it (being on PrEP) but somebody who is having multiple partners or doing sex work. Their thoughts and perspectives would be different compared to mine.

- No PrEP Participant 13 – 37, Binary TW, Asian/Pacific Islander

This participant both understands why someone may use PrEP (i.e., having an active sex life) and why PrEP is not appropriate for her right now. She acknowledges that if she was having sex with multiple partners her thoughts and action about PrEP would be different.

Additionally, women not on PrEP viewed their risk on a continuum, for them current low-risk behavior was not an indicator of future need for or use of PrEP.

If I go back to my old ways being a hot mess and going outside of my boyfriend, that’s why I would do it [use PrEP].

- No PrEP Participant 6, 28, TW, Binary, African-American

This participant acknowledges that while her current risk level does not call for PrEP. She realizes that if her risk level were to change she would reevaluate whether to take PrEP. This example highlights that risk can change overtime, which speaks to the importance of having ongoing conversations about PrEP regardless of current risk.

A final barrier to PrEP uptake among participants not on PrEP (53%, n=8) is that it does not protect against other STIs.

It (PrEP) would help me if I was to be on it but at the end of the day HIV is not the only thing you can get.

- No PrEP Participant 3 – 24, Binary TW, African American

This participant knows that PrEP protects against HIV infection and that she would benefit from using it. However, this benefit is not enough of a motivation for her to take PrEP because it does not protect against other STIs, thus warranting the continued use of condoms.
Reduced Psychological Distress and Increased Self-Esteem

Participants identified increased psychological well-being and sexual enjoyment as a major facilitator to PrEP uptake. Forty-three (43%, n=13) percent of the total sample discussed how PrEP reduces anxiety and worry around contracting HIV.

The good part is that you are safer, so you do not have too much stress when you are having sex and you can be more open about sex and live a more freer life. Psychologically you are more-steady. You don’t have to worry all the time at every sexual encounter, OMG do I have HIV.

- No PrEP Participant 9 – 38, Non-Binary, Asian Pacific Islander

This participant speaks to the psychological and sexual impact associated with HIV rumination. Without PrEP sex can be stressful and not enjoyable. With PrEP sex might be/was more enjoyable without the constant worry around whether this encounter would be the one where you would get HIV. Fifty-three (53%, n=8) percent of the women on PrEP provided concrete examples of the stress-reducing effects associated with their PrEP use.

Actually, I think about it (HIV) less now that I’m on PrEP. Beforehand there were condoms involved, but you never know. Whereas now I feel like even if I get some sort of weird accidental exposure, it’s probably not going to take. So, I think about it (HIV) less.

- On PrEP Participant 15 – 38, TW Binary, White

For this participant, using PrEP has reduced her worry about HIV by offering a level of protection that condoms do not provide. In her statement there is both an acknowledgement that condoms are an important part of her HIV prevention practice and that there are situations where accidental exposure may occur. It is within this gray area that she no longer has to worry about HIV or blame herself if an accidental exposure occurs because she is on PrEP.

Finally, an overarching theme among women on PrEP was how their PrEP use is a form of resiliency against the stigma and discrimination TGNBW routinely experience. Among PrEP users, 60% (n=9) said that using PrEP reduced their sense of fatality around sex.
I consider it (being on PrEP) to be very positive because it is making people actually think about living and understanding ways of fighting for their lives and making them feel a lot more important.

- On PrEP Participant 14, 27, Binary TW, Latina

Rather than giving in to the constant messaging that TGNBW are high-risk, thus doomed to get HIV, PrEP is viewed as a strategy for increasing self-esteem and self-worth among TGNBW.

I was obsessed with the idea of not being another number. Like if I’m going to get some sort of disease or something, I’d rather it be… Whatever else, like cancer or something like that. Like let me not do HIV.

- On PrEP Participant 6, 34, TW, Binary, Multiracial

Her resolve to not be another number contributes to her motivation to ensure that she does all that she can to protect herself from contracting HIV, which includes taking PrEP. Becoming HIV-positive is no longer inevitable because these participants take PrEP. PrEP is a tool to fight for their life and control over her bodies. Within this context, PrEP is a buffer against ongoing experiences of stigma and discrimination faced by TGNBW.

Lack of Information on Interactions between PrEP and Feminizing Hormone and Managing Multiple Medications

A common theme expressed by participants was whether PrEP would negatively interact with their existing cross-gender hormone regimen by limiting the hormones effectiveness. For the vast majority of the women the number one health care priority was their gender transition. Any medication that would interfere with this process as well as add more physical burden to their bodies was viewed as a barrier to PrEP uptake.

I wanted to know if it was going to affect my hormones because I was also taking all these pills at the time and I was like what is my body going through all of this just to be who I am. I wanted to know if it was going to affect my body physically in anyway.

- On PrEP Participant 5 – 24, Binary TW, API
As the following non-PrEP user states, prior to PrEP initiation it would be important for her to know what if any impact PrEP would have on her gender transition.

If I was to take that (PrEP) I would want to know how it would react to my hormones would I be to take my hormones while I take this medication.

- No PrEP Participant 11, 34, TW, Binary, Multiracial

Both participants speak to the prioritization of their gender transition and the concern that PrEP would negatively affect this process. While both groups of participants had similar concerns about potential drug-to-drug interactions between PrEP and hormone interactions, additional information is needed to understand the types of information PrEP users received which positively influenced their willingness to take PrEP.

Another common barrier was not wanting to take additional medications. Sixty-seven (67%, n=10) of participants not on PrEP indicated that they did not want to add PrEP to their existing medication regimen.

I take so many pills, I take spironolactone, estrogen, plus my psych meds. I’m anti taking a pill it’s like popping tic tacs. I just don’t want to pop another pill which is why I wouldn’t take PrEP.

- No PrEP Participant 12 – 35, Binary TW, Multiracial

Another non-PrEP user reiterates the sentiment above.

I’m taking all this medication, pills to go to sleep, my hormone medication, and my antidepressant pills. That’s too much. My body is being through hell with all the medications I’m taking.

- No PrEP Participant 3 – 24, Binary TW, African-American

These women highlight that participants not on PrEP may prioritize their gender transition and mental health over HIV prevention, thus highlighting the need for PrEP to be integrated into overall health care for TGNBW. In addition, not wanting to take too many medications may also
be associated with pill fatigue. These participants may be more likely to take PrEP if it was available in other forms.

Finally, to address the potential barrier posed by taking an additional medication, a possible facilitator to PrEP uptake may be a new form of PrEP that is currently in Phase 3 clinical trials. Long-acting injectionable PrEP would potentially require users to receive a shot every 8 weeks, limiting the need for daily oral PrEP over time, thus, counteracting the barrier of managing multiple daily medications. Twenty-seven (27%, n=4) percent of participants not on PrEP stated that they would be interested in taking PrEP if it was in a long-acting injectable form.

I like shots they can last up to a month. That would be a lot easier because I’m not very consistent with taking pills. Shots are much better.  

- No PrEP Participant 4 – 22, Binary TW, African-American  

Long-acting injectable PrEP for some would be similar to their hormone shots, which was viewed as more favorable than a daily pill and would assist with adherence. For those taking hormone shots every week getting an injection was familiar and not seen as a burden. These participants preferred an injectable form of medication because it was perceived to have less physical impact on the body compared to a daily oral pill. In addition, participants felt that not having to remember to take a pill every day coupled with the length of the dosage would positively affect adherence.

**Summary**

The results above demonstrate key elements impacting TGNBW’s willingness to use and adhere to PrEP at the structural, interpersonal, and individual levels. The structural factors identified highlight areas in which institutional policies and practice impact willingness to use PrEP among TGNBW. Access to consistent PrEP information from a variety of different sources
indicated a high-level of PrEP knowledge and greater PrEP uptake among participants. PrEP users had more access to PrEP information from a variety of sources compared to non-PrEP users. Participants on PrEP identified active provider engagement and assistance with accessing PrEP as a major structural facilitator to PrEP uptake. Providers who had ongoing conversations with their patients about PrEP were credited with increasing participant’s PrEP knowledge and uptake. Furthermore, PrEP users who had help from a provider navigating insurance and payment for PrEP acknowledged the influence this practice had on their PrEP use. Two structural barriers to PrEP uptake emerged, the conflation of TGNBW with MSM and a lack of transgender/gender affirming sexual health messaging and programs. Participants across both groups stated that being categorized as a man/MSM in HIV prevention programming and policies rendered TGNBW invisible and inaccurately portrays HIV risk factors as solely due to individual behavior. Participants also identified how a lack of transgender and gender affirming messaging and programming specific to the HIV risk environments TGNBW are forced to engage in reinforces the conflation of TGNBW with MSM and erases the HIV prevention needs of this high-priority community.

At the interpersonal level, personal relationships and community connectedness represented facilitators to PrEP uptake. Participants stated that knowing friends who were on PrEP increased their PrEP awareness and uptake. Participants on PrEP expressed a sense of responsibility to affect social and cultural norms around PrEP use and the TGNBW community. PrEP was also viewed as a game changer in the fight against HIV and the majority of participants on PrEP felt that taking PrEP was an important step in the fight against HIV and offered the chance to be a part of this historical moment.
Finally, at the individual level participants identified several factors associated with PrEP uptake. Perception of HIV risk was both a facilitator and barrier to PrEP uptake, participants who perceived themselves to be at risk wanted PrEP. However, risk perception was a barrier to PrEP uptake for participants whose HIV risk was low or for whom PrEP did not address the type of risk most important to them. Participants in both groups identified increased psychological wellbeing and sexual enjoyment as major facilitators to PrEP uptake. Taking PrEP increased participants’ self-esteem by reducing the sense of fatalism around HIV commonly found within the TGNBW community. Two final individual level barriers were a lack of information on drug-to-drug interactions between PrEP and commonly used feminizing hormone treatment and managing multiple medications.
CHAPTER 7: SUGGESTIONS FOR BEST PRACTICE TO INCREASE PREP UPTAKE (RQ 3)

Participants in both groups were asked to provide suggestions for best practice to increase PrEP access, uptake, and adherence among TGNBW. Each section below addresses an important facet to providing transgender inclusive and gender affirming sexual health, which includes PrEP. Participants identified three main shifts in programming to increase willingness to take PrEP among TGNBW: a) transgender inclusive and gender affirming sexual health messaging and programs, 2) ongoing active provider engagement and assistance with PrEP, and 3) strategies which support community mobilization/activism around PrEP.

Transgender Inclusive and Gender Affirming Sexual Health Programs

As discussed above (see section on structural-level factors), participants across both groups identified the need for transgender inclusive and gender affirming HIV prevention and sexual health education literature and messaging. Participants consistently said that by conflating TGNBW and MSM HIV prevention policies and practice ignored the specific sociocultural experiences of their community.

We are human, so we need to have our own organization. I feel like we are entitled to a lot of things. But I feel like they single us out because they can’t tell if we’re part of the heterosexual community or men-fucking-men community and everything. They just want to place us in a community that’s just gay, and that’s not even the actual.

- On PrEP Participant 14, 27, TW, Binary, Latina

Here she implies that by categorizing TGNBW with MSM, HIV prevention policies and practice have ignored the specific HIV prevention needs of this community. She suggests that to best serve the community there is a need for transgender specific organizations that view TGNBW as people rather than trying to force them into a community they are not a part of.
Women in both groups indicated that messaging and programs must include images of diverse gender presentations, and not prioritize TGNBW who “pass”.

You put it out there front and center, so nobody’s mistaking it whatsoever. You need somebody that – I mean, for lack of a better term – isn’t afraid of getting spooked by the general public. Somebody who’s not afraid to come out and say, “I’m trans. Hi.” On the side of a bus. And I think it’d be great to show people at different stages of transition, and different presentations. I think that’d be a good thing to see.

- On PrEP Participant 6, 34, TW, Binary, Multiracial

This participant indicates that in order to reach all TGNBW, HIV prevention campaigns must include images of the range of gender presentations found within the community, including images of TGNBW at different stages of transition.

Another theme that emerged is the need for the development and design of sexual health assessment tools and health education literature that is transgender inclusive and gender affirming. Participants suggested that these assessment tools and literature must accurately represent the various genders and genitalia TGNBW are having sex with, openly address sex work, assess for experiences of sexual violence, and discuss the limited data about whether PrEP interferes with hormones.

Participants said that PrEP messaging for TGNBW must include language around sex with multiple partners and sex with clients/dates. Non-PrEP users who engaged in survival sex unequivocally said that they did not know if PrEP was right for them due to the language in PrEP health education pamphlets, which does not address engagement in transactional sex.

I don’t ever see any information that is about trans women or sex workers, if you’re putting yourself at risk every day, is it a benefit to take it, will it help you? The pamphlets I see are really specific to lovers or partners but what if that’s not who you’re having sex with.

- No PrEP Participant 1, 37, TW, Binary, Latina
This participant illustrates how messaging campaigns and health education literature, which negligence to directly discuss issues pertaining to TGNBW are ineffective at reaching those who would most benefit from PrEP.

Another area that needs to be addressed in assessment tools and health education literature are experiences of sexual violence. Overall, the majority of participants reported multiple experiences of sexual violence. Participants expressed the need for providers to address these experiences.

It’s absolutely astonishing. I don’t know a single trans woman who hasn’t been raped – myself included. It just kind of happens, and you just kind of have to deal with it, and that’s it. It’s amazing. So just right there – you’re going to be the victim of violence. You’re going to be discriminated against. You just kind of have to mentally get there, figure out ways of coping before it happens. And the doctor should be talking to trans patients about this, period. If a doctor’s not talking to them about this stuff, the doctor is not doing the job, in my opinion.

- On PrEP Participant 15, 38, TW, Binary, White

This participant identifies the stark reality of sexual violence experienced by TGNBW. Given the disproportionate rates of sexual violence experienced by this community, PrEP is viewed as an important protective factor. However, if health care providers are not addressing this with their TGNBW patients they are missing a critical point of contact to discuss HIV prevention and PrEP.

Finally, the following quotation outlines some of the main points PrEP messaging and health information campaigns should highlight to other TGNBW, including the creation of PrEP literature that emphasizes how and why PrEP is important.

I just need for them to really explain to people how this can really help you, especially if you’re doing sex work and stuff. I feel like they should emphasize how important this is and tell people that it’s not going to affect your hormones in any way.

- On PrEP Participant 5, 24, TW, Binary, API

This participant talks about reaching groups that are most likely to benefit from PrEP, such as
TGNBW sex workers. She emphasizes the importance of educating TGNBW about PrEP’s benefits overall as well as how it is specifically helpful and necessary within the context of sex work. Finally, she acknowledges that it is important for providers to address the drug-to-drug interactions between PrEP and feminizing hormones given that the gender transition process is often a top priority for TGNBW.

**Active Provider Engagement and Assistance**

Active provider engagement and assistance around PrEP emerged as key factors to increasing PrEP awareness, access, and uptake among the TGNBW community. Active engagement by health care providers referred to having an ongoing dialogue about PrEP rather than a one-time discussion. It is important to reiterate that 60% (PrEP=8, No PrEP=10) of the total sample had never had a provider discuss or offer PrEP, highlighting a missed opportunity to directly impact the HIV incidence rates among TGNBW. Active assistance was identified as PrEP navigation services that included help with obtaining insurance and/or other payment options.

I think it just should be proactively offered in whatever way possible. With as little cost as possible. And I know that there are… Even if you don’t qualify for Medicaid or something for whatever reason, or if… Like some people are still on their parents’ insurance, and their parents’ insurance doesn’t cover it, there are programs to relieve the financial burden of getting on PrEP for people who are at highest risk.

*On PrEP Participant 7, 29, TW, Binary, White*

This participant highlights that reducing the structural barrier of cost and payment coupled with ongoing offers for PrEP were important facilitators to both her willingness to take PrEP and actual PrEP uptake. Participants also identified specific suggestions to reach those deemed most at risk for HIV, which included PrEP-related outreach services to sex workers to increase awareness, knowledge, and uptake.
By going out and doing education, educate people, educate us girls. Educate, educate, educate. Even if you have to go out to the stroll. And ask you ever heard about this?

- **No PrEP Participant 1 – 37, Binary TW, Latina**

The following quotation echoes the sentiment above.

I really like seeing the outreach to cars in the areas, like in the village when they come by. Especially homeless trans women and they hang out on the pier and stuff, they’re not taking the time to get checkups. They’re focused on surviving first. So, going out to them and doing that outreach I think is an amazing way, because then they’re right there.

- **On PrEP Participant 5 – 24, Binary TW, API**

These participants explain that active engagement means going to street-based sex workers to provide PrEP education. As the participant above suggests, when surviving is your first priority TGNBW may not be access health care on a regular basis. Providers need to go out and literally ask have you heard of PrEP, instead of waiting for these women to come and ask for it. Both participants highlight the importance of low threshold services such as outreach teams and vans to increase awareness and acceptability towards PrEP, specifically among TGNBW engaging in survival sex.

Finally, active provider engagement is not just asking someone if they are interested in PrEP. Participants suggested that providers must actively engage in conversations around PrEP by explaining what PrEP is, how it works, dosage and adherence information, and potential side effects.

Encouraging doctors or medical providers to specifically ask about PrEP, and maybe even ask it with some information about what PrEP is. When I was asked – I mean I knew what PrEP was, I’d heard of it, but I was just asked if I was interested in PrEP. And so, if I didn’t know what it was, I would’ve just said no, not really knowing what I was being asked.

- **On PrEP Participant 8 – 22, Binary TW, White**
This participant talks about how a lack of provider engagement (i.e., providing PrEP information) was a potential barrier to PrEP uptake for her. She highlights the importance of providing PrEP information in conjunction with asking patients if they want PrEP. This suggests that providers move away from assessing sexual risk using closed ended questions to having more open-ended conversations about sexual health.

**Community Mobilization and Activism**

Strategies that explore community mobilization/activism emerged as important facilitators to increasing awareness and trust around PrEP. Participants talked about a need for role models within the community who were willing to openly discussed their PrEP use.

While I was considering if I wanted to take it or not – I was seeing people who were on it talk about it. Like friends of mine who were on it. So, encouraging people to talk about being on it [PrEP] is important.

*On PrEP Participant 8 – 22, Binary TW, White*

For this participant an influential factor to her PrEP use was having friends and others in her community openly talk about their use.

Furthermore, participants on PrEP acknowledged that in many cases their first information about PrEP came from friends and not a provider.

My friend told me about it. She used to do sex education classes for us [her friends]. She taught me about it. She was like, girl, you know, they’ve got that new PrEP. So, I did some research on it and started taking it from there.

*On PrEP Participant 11, 28, TW, Binary, African-American*

She talks about the impact her friend had on her willingness to use PrEP. She acknowledges the trust that comes from an established relationship with someone who is like you and how this opened the door for her seek out more information and ultimately get on PrEP.

Conversely, PrEP users also discussed a sense of responsibility to educate their friends about PrEP.
I tell my friends about PrEP, because I want them to know about it. I don’t want my friends to be walking around here, and they have the opportunity to be prevented from getting HIV – I want them to know about the PrEP, so it can prevent them, especially when you like to do it raw. You need to be on the PrEP. But I encourage them to use protection. But I prefer them to use the PrEP, because they can protect themselves from the HIV.


Regardless of whether they decide to take PrEP or not, she emphasizes the importance of providing her friends with the knowledge to make informed decisions around whether to take PrEP. This participant expresses a fear around not sharing this life saving information with friends. She feels that it is important to educate her friends because she does not want her friends to be at risk for HIV and potentially seroconvert because they did not know about PrEP.

Summary

Participants gave concrete examples for best practice to increase TGNBW’s willingness to use PrEP. To increase PrEP awareness and uptake, HIV prevention and sexual health programs need to be transgender inclusive and gender affirming. Participants said that stopping the practice of categorizing TGNBW with MSM was the first step to creating affirming HIV prevention programs. Sexual health campaigns must include images of people with diverse gender presentations and at different stages of gender transition, rather than prioritize TGNBW that “pass”. Participants stated that HIV prevention and PrEP programs need to develop transgender inclusive and gender affirming sexual health assessment tools and health education literature that accurately represent the persons TGNBW are having sex with, the high-risk contexts they are having sex in, and information on drug to drug interactions between PrEP and cross-gender hormones.

Participants also identified active provider engagement around PrEP and active assistance with getting insurance or payment for PrEP as key factors associated with willingness to take
PrEP and PrEP uptake. Participants stated that active provider engagement included giving patients information about PrEP when offering it to them and having ongoing conversations with patients about PrEP rather than mentioning it one-time. In addition, several women said that active provider engagement was about creating PrEP-related outreach services to reach TGNBW who would most benefit from PrEP, such as street-based sex workers.

Finally, participants on PrEP shared community mobilization/activism strategies to increase PrEP knowledge and uptake among TGNBW. Participants talked about the importance of having community members openly talk about their PrEP use. They also highlighted the need for providers to acknowledge and support the role of friends in the dissemination of PrEP information. Participants said that seeing and talking to friends on PrEP was instrumental to their willingness to take PrEP. Participants on PrEP also reported a sense of responsibility to share their PrEP knowledge with other friends and community members to increase knowledge and uptake.
CHAPTER 8: GENDER AFFIRMATION AND HIV RISK (RQ 4)

Themes of gender affirmation and high-risk contexts emerged as important factors associated with HIV risk among transgender and non-binary women. Participants discussed the community’s HIV risk in general, and their own risk specifically, as byproducts of societal oppression where a high need for and low access to gender affirmation led TGNBW to seek out gender affirmation in high-risk contexts where HIV transmission is more likely to occur, such as survival sex work and sexual encounters under the influence of drugs and/or alcohol. Embedded in participant’s narratives was the belief that systemic factors such as racism, transphobia and sexism were driving HIV risk among transgender women, not solely individual sexual behavior. For example, participants discussed how systemic racism, transphobia, and sexism were associated with housing and employment discrimination among TGNBW. The lack of housing and employment opportunities forced TGNBW into situations (e.g., survival sex work) where survival is intrinsically linked to HIV risk.

Participants stressed the relationship between needing to survive, sex work as a means for survival, experiences of sexual violence, and HIV risk. Several rejected the common narrative that health care, social service providers, researchers, and public health officials perpetuate, which asserts that TGNBW chose to put themselves in risky situations. Thus, placing blame on the individual rather than acknowledging the structural factors contributing to HIV risk.

A lot of us trans women of color are forced to do survival sex work. I’m not going to say we put ourselves in a risky life, but we’re forced to do this. It’s survival. PrEP is really important because it’s helping us minimize our risk when we do what we do to survive in this cruel world.

- On PrEP Participant 5, 24, TW, Binary, API
This participant sees HIV risk as something that is forced upon transgender women, rather than resulting from behavioral choice or agency. PrEP is seen as a type of harm reduction, minimizing the negative effects of behavior that is necessary for survival.

One participant spoke to the specific risk of sexual violence transgender and non-binary women face in order to survive. This 26-year-old participant on PrEP shares that when she first moved to New York City she was homeless, in an attempt to find a place to stay, she met up with a cisgender man on Grindr who offered her a place to stay for the night with no strings attached. However, once at his place the participant was sexually assaulted and ended up naked running through the streets in the middle of the night in search of help. It was after this experience that she got on PrEP.

There’s a lot of risk involved [in living/surviving]. A lot of risk. So, PrEP was basically a necessity, especially after what happened to me (being raped), is when I got it prescribed. It was like, you have to be on this, especially being so vulnerable, this can happen again, and if you’re going to survive you might have to do those things that you don’t like, and you don’t like to do, and they might not be as safe as you’d like them to be, you know?

- On PrEP Participant 12, 26, TW, Binary, Latina

This participant discusses the choices she is forced to make to survive. Risk is an ongoing part of survival for transgender and non-binary women and PrEP is viewed as necessary for survival.

Participants used the word vulnerable to describe both their physical and emotional state during sexual encounters, often stating they had to be careful or safe because they did not want to find themselves in dangerous situations when meeting up with a potential sexual partner or client.

Trans women are naturally vulnerable. A lot of us are rejected by our families and we are forced into situations where we are exposed to certain situations and clients who disregard our lives or our existence.

- No PrEP Participant 7, 26, TW, Binary, White
Vulnerability is attributed to a social and economic positioning, which comes from being rejected by friends, family, and society as a whole. The threat of danger associated with being forced into high-risk situations to survive and being regarded as less than human is viewed as larger than HIV risk or other threats.

Overall, participants mentioned personal experiences with sex work due to economic disenfranchisement, contextualizing HIV risk as an occupational hazard rather than a moral failure or behavioral issue. Several participants talked about how clients offered financial incentives for condomless sex.

I just feel like it’s (PrEP) a good safety tool. I’m gonna be honest with you, I have my routine base, I have my procedures it’s always safe, safe, safe, but even in my work there are guys that request or they are offering something that would benefit me in exchange for something raw. It’s more of a safety thing to have.

- No PrEP Participant 7, 26, TW, Binary, White

In this way, PrEP is viewed as a life-saving precaution that should be available to all TGNBW. Again, HIV risk is talked about as something that is forced on transgender and non-binary women in order to survive, rather than individual sexual behavior or poor risk perception.

Experiences of sexual violence/sexual assault emerged as another high-risk context in which HIV risk is externally generated for transgender and non-binary women. Participants said that experiences of sexual assault were not an if but a when. Seventy percent (70%, n=21) of the total sample, stated that they had been sexually assaulted or raped.

Not every time I have had sex have a been a willing participant. I’ve been sexually assaulted a few times. I mean, definitely when it happened, one of the first things I worried about was HIV. Now, at least I’m taking PrEP, if, god forbid, it [being sexually assaulted] were to happen again, at least it’s one less thing for me to really worry about. You know, because the chance is so miniscule [of getting HIV], if you’re taking your PrEP.

- On PrEP Participant 6, 34, TW, Binary, Multiracial
This participant expresses a relief in knowing that she is protected and does not have to worry about HIV if she is ever in another situation where she is forced to have sex. PrEP is seen once again as a form of harm reduction in a context where HIV risk is not a result of individual behavior or a lack of agency.

While research has consistently documented the increased rates of sexual and physical violence among TGNBW, the conflation of TGNBW and MSM within HIV prevention and PrEP related literature has neglected to examine the relationship between experiences of sexual violence among women and HIV risk. The following participant not on PrEP expresses how women cannot trust men when it comes to their sexual health.

I have a girlfriend who trusted a guy to come over and he raped her. She went to a clinic because she was scared that she had caught something. PrEP definitely needs to be readily available because any woman could have some guy be like no I don’t want to use a condom or he could put something in my drink.

- No PrEP Participant 7, 26, TW, Binary, White

This participant does not distinguish or separate out transgender and non-binary women from cisgender women, acknowledging that sexual violence and assault is a women’s issue. By saying “any woman” this participant is affirming her own gender as a woman, while also acknowledging that sexism puts her at risk from men. Within this context, PrEP can be a means for women to have agency over their sexual health and bodies in a world that views them as objects to be used and assaulted for men’s pleasure.

Lastly, sexual experiences under the influence of drugs and/or alcohol emerged as a final high-risk context in which PrEP would be beneficial for transgender and non-binary women. Research has consistently documented that TGNBW are more likely to engage in condomless anal sex when using drugs and/or alcohol (Nemoto, et al., 2004; 2011; Operario, et al., 2014;
Risser, et al., 2005) thus increasing their risk for HIV. Participants stated that PrEP would be or was beneficial in situations where someone got too drunk or risked being drugged.

Like when I get too drunk I’ll do stupid things and when I wake up in the morning and I feel better because at least I know that this (PrEP) is protecting me. Because before I would be like shit I have to worry about this.

- **On PrEP Participant 9, 25, TW, Binary, White**

This participant highlights her understanding of the factors which increase her risk for HIV and the role PrEP plays within this context. PrEP becomes a strategy for safety, reducing both risk for HIV and the psychological distress around potential HIV exposure due to having condomless sex when intoxicated.

Finally, the following participant touches on the various social, psychological, and structural factors associated with gender affirmation and HIV risk among TGBNW.

Trans women are treated as non-people and fetish objects (emphasis added throughout). If you’re going to try to date a guy, which if you don’t pass, or you’re not quite full-time yet, there’s no guys that are dating you. They’re coming over to have sex with you and leave. And if you have a thing for straight guys on top of that, you’re entering a world of bad things. So basically, you’re being treated like a disposable sex toy. So, people just … they might just not wear a condom even if you want them to. And there are definitely plenty of trans girls out there who just don’t have the – whatever it is – that you need to kick a guy off of you or tell them no way even before they get there. Because you need to be validated and you need to feel like you’re attractive and all that stuff. So, I mean there’s that much that goes on. And then also economic opportunities for women like myself are limited. And there’s plenty of women from all backgrounds that just wind up homeless and addicted to methamphetamine or heroin and need money for that. They just wind up in a bad spot fast, so fast. There’s a lot of women who don’t want to be sex workers who are because of their circumstances. And then your customers … you may think that your clients deserve whatever they want for the money. You feel like you don’t have it (agency over your circumstances) because society looks down on you. You’re at the lowest rung now. So, you have no right to ask for anything. You’re lucky you don’t get killed walking down the street.

- **On PrEP Participant 15, 38, TW, Binary, White**
She articulates the relationship between HIV risk, gender affirmation, and high-risk contexts. She talks about the extreme marginalization TGNBW experience due to transphobia and how stigma and discrimination force this community into environments where HIV risk is associated with sexual violence, engagement in sex work, and drug and/or alcohol use. She goes on to talk about the psychological and behavioral impact consistent messaging of worthlessness have on TGNBW. And how these messages silence TGNBW and reinforce a sense of gratitude TGNBW must express for being allowed to live in the world and not killed because they are viewed as less than human.

**Summary**

Throughout each interview, participants consistently discussed various high-risk contexts (e.g., survival sex work) where HIV risk is associated with racism, sexism, and transphobia (e.g., housing and employment discrimination). Participants viewed their HIV risk as a complex multilayer process driven by stigma and discrimination at the structural, interpersonal, and individual levels. Participants highlighted the relationship between sex work as a means for survival, experiences of sexual violence, and HIV risk. Participants discussed the high-risk situations they are forced to engage in to survive. Risk is seen as an ongoing part of survival for transgender and non-binary women and PrEP is a form of harm reduction that minimizes the risk associated with survival. Across both groups, HIV risk was seen as an occupational hazard associated with engagement in sex work due to the pervasive economic disenfranchisement experienced by TGNBW. PrEP is viewed as a life-saving precaution that mitigates HIV risk associated with survival, rather than individual sexual behavior or poor risk perception. Participants identified experiences of sexual violence and sexual assault as another high-risk context in which HIV risk is externally generated for transgender and non-binary women. PrEP
gives women agency over their sexual health and bodies. Finally, sexual experiences under the influence of drugs and/or alcohol also emerged as a high-risk context in which PrEP would be beneficial for transgender and non-binary women. Within this context, PrEP becomes a strategy for safety, reducing both risk for HIV and the psychological distress around potential HIV exposure due to having condomless sex when intoxicated. Highlighted throughout these examples is that TGNBW understand that HIV risk and survival are not mutually exclusive. Yet, public health and HIV prevention programs for TGNBW do not acknowledge the relationship between survival and HIV risk. Messaging and programs around HIV risk and PrEP do not talk about sex work, sexual violence, or drug and/or alcohol use, opting to solely focus on the sexual act itself instead of the larger context in which sexual activity is taking place.

**Conclusion**

These data illustrate the structural, interpersonal, and individual level factors associated with PrEP acceptability, uptake, and access. All study participants met multiple eligibility criteria for PrEP, thus are deemed most in need of and likely to benefit from PrEP. Demonstrated throughout each thematic area, is the missing component that context matters in HIV prevention and that missed opportunities to reduce HIV infection occur by solely focusing on sexual behavior. Labeling and targeting certain groups as high-risk with one size fits all HIV prevention messaging and programming renders invisible the social, psychological, and behavioral factors associated with stigma and discrimination at the intersection of racism, transphobia, and sexism. The next chapter will discuss the study’s findings and implications for HIV prevention policy and social work practice.
CHAPTER 9: DISCUSSION

Introduction

In the United States, transgender and non-binary women (TGNBW) are a highly vulnerable and marginalized community disproportionately affected by HIV (Baral et al., 2013; Herbst et al., 2008). HIV prevalence among TGNBW is estimated at 27.7%, higher than the 19% prevalence among cisgender men who have sex with men and STI prevalence among TGNBW is estimated at 21% (Herbst et al., 2008). The highest HIV prevalence is found among African American transgender women, averaging 56.3% (Herbst et al., 2008). Additionally, a recent analysis of data from the Center for Disease Control (CDC) found that between 2009-2014, of the transgender people with newly diagnosed HIV infection in the US, 84% were transgender women with 80% representing women of color (50.8% African American, 29.3% Latinx) (Clark et al., 2016).

A growing body of evidence demonstrates that TGNBW face numerous challenges which negatively influence their quality of life including, poverty, violence, incarceration and routine discrimination in housing, employment, educational, health care and social service settings (Grant, et al., 2011; James, et al., 2016; Khan, 2011; Lombardi, Wilchins, Priesing, & Malouf, 2001; Nemoto, Bödeker, & Iwamoto, 2011; Reisner, Bailey, & Sevelius, 2014; Testa et al., 2012). In addition to experiencing disparate rates of HIV infection, TGNBW are also at high risk for a host of adverse health outcomes, including substance misuse, depression, anxiety, and suicide (Baral et al., 2013; Benotsch et al., 2013; Clements-Nolle, Marx, Guzman, & Katz, 2001; Clements-Nolle, Marx, & Katz, 2006; Goldblum et al., 2012; Haas & Rodgers, 2014; Herbst et al., 2007; Neilands, & Sevelius, 2013; James, et al., 2016; Keuroghlian, Reisner, White, & Weiss, 2015; Reisner, Gamarel, Nemoto, & Operario, 2014; Reisner, Pardo, Gameral, Pardee,
Keo-Meier, 2015). For example, the 2015 United States Transgender Survey (USTS) (James, et al., 2016) found that transgender adults were more likely to use drugs (29%) and alcohol (63%) compared to the US general population (10% and 56% respectively) (Center for Behavioral Health and Statistics, 2015; 2016). Further, 82% of the USTS' respondents reported having serious thoughts about suicide, and 40% had attempted suicide at some point in their life compared to 4.6% of the US general population (James et al., 2016). Research has consistently documented how the many risks to the physical, emotional, and social health of TGNBW results from social stigma and negative societal response towards gender non-conformity at the structural, interpersonal, and individual level (Bradford, Reisner, Honnold, & Xavier, 2013; Clements-Nolle, Marx, Guzman, & Katz, 2001; Clements-Nolle, Marx, & Katz, 2006; Grant et al., 2011; Herbst et al., 2007; Lennon and Mistler, 2014; Lombardi, 2007; Nuttbrock et al., 2012; Testa et al., 2012; Wilson et al., 2009; Xavier, Bobbin, Singer, & Budd, 2008). The results of this dissertation support and add to the growing body of literature on the relationship between stigma, discrimination, decreased quality of life, and adverse health outcomes among the TGNBW community in three ways. First, the study findings provide evidence that supports the existing literature on the negative impact of stigma and discrimination at the structural, interpersonal, and individual level. Next, these results contribute much-needed data on how stigma and discrimination influence HIV risk. Finally, study findings present several resiliency factors at the structural, interpersonal, and individual level that mitigate HIV risk among this community.

Despite their disparate rates of HIV infection, the unique HIV risk and prevention needs of TGNBW have largely been ignored in HIV surveillance data and research because they are categorized as cisgender men who have sex with men (MSM). Most recently, the mis-categorization of TGNBW as cisgender MSM has contributed to a striking lack of research on
pre-exposure prophylaxis (PrEP) (the newest and most efficacious biomedical HIV prevention intervention) use among TGNBW. This lack of research is particularly striking in the field of PrEP for two reasons: 1) PrEP is a highly effective method of HIV prevention and 2) TGNBW are a priority population for which no efficacious HIV prevention intervention exists. In fact, when TGNBW are discussed or included in PrEP research or programs, often they are lumped together with cisgender MSM. By disregarding self-identified gender identity, PrEP research does not address the specific sociocultural and contextual factors that contribute to HIV risk among this community, thus creating barriers to PrEP uptake at the structural, interpersonal, and individual level. This dissertation was designed to identify the facilitators and barriers to PrEP access, uptake, and adherence among TGNBW at risk for HIV. In doing so, this study addressed four key research questions: 1) what are the individual, community, and structural level factors impacting transgender women’s willingness to utilize PrEP as an HIV prevention tool? 2) To what extent do these factors impede the integration of PrEP into the lives of transgender women? 3) What are best practices for integrating PrEP into health care for transgender women? And, 4) to what extent does need for and access to gender affirmation influence engagement in HIV risk behaviors among transgender women?

The results of this dissertation suggest that to increase PrEP access, uptake, and adherence there is a need for the development and design of strategies and programs that contextualize HIV risk among TGNBW as a social and psychological process rather than solely a byproduct of behavior. Situating HIV risk as a social and psychological process acknowledges that for TGNBW, risk factors are associated with multiple levels of social oppression (i.e., racism, transphobia, and sexism) (Sevelius, 2013; 2016). By recognizing that HIV risk is driven by social oppression, we begin to reframe the HIV prevention discussion to focus on the
intersection of the structural, interpersonal, and individual level factors contributing to HIV risk, rather than focusing solely on individual behaviors. To do otherwise may contribute to the alarming rates of HIV infection among this community by creating barriers to PrEP. This analysis views gender identity as an integral part of understanding the factors associated with HIV risk within the TGNBW community. It argues that categorizing TGNBW as cisgender MSM conveys and reinforces several beliefs including, a) TGNBW are in fact men, b) self-identified gender identity is not important to understanding sexual health and risk, and c) the sexual practices and experiences of TGNBW are inherently the same as cisgender men who have sex with men (Fiereck, 2013; Sevelius et al., 2016). Furthermore, it is possible that devaluing and ignoring self-identified gender identity within HIV research exacerbates the HIV disparities experienced by TGNBW.

The discussion and analysis of study results integrate theories of stigma and discrimination (Link and Phelan, 2001) as well as the Gender Affirmation Framework (Sevelius, 2013). First, theories of stigma and discrimination are applied to a socio-ecological model (Baral et al., 2013; Link and Phelan, 2001) conceptualizing structural, interpersonal, and individual level barriers to health care access and utilization for TGNBW as a consequence of transgender-related stigma and discrimination. Within this model, access to gender-affirming healthcare is necessary to facilitate PrEP access, uptake, and adherence. Further, to understand the contextual factors contributing to HIV risk among TGNBW, the Gender Affirmation Framework is utilized (Sevelius, 2013), which hypothesizes HIV risk among TGNBW as a negative outcome of social oppression. The Gender Affirmation Framework (Sevelius, 2013) proposes that TGNBW are forced into high-risk contexts where HIV risk increases due to the social and emotional impact of
stigma and discrimination. To understand TGNBW’s willingness to take PrEP it was imperative to identify the contextual factors that contribute to HIV risk for this community.

First, the structural, interpersonal, and individual level factors associated with PrEP uptake among the sample will be discussed. Next, how gender affirmation influences HIV risk for TGNBW will be considered. Then, implications for best practice in the field of PrEP will be explored. Finally, the last three sections will discuss implications for social work practice, study limitations, and directions for future research.

**Structural Factors**

Structural stigma is the manifestation of stigma (i.e., negative attitudes and beliefs attached to individuals or groups who differ from social or cultural norms) within the institutions of society (Link & Phelan, 2001). Structural stigma can occur in the absence of individual prejudice or discrimination (Link & Phelan, 2001). Examples of structural stigma against TGNB individuals include the lack federal anti-discrimination legislation protecting the civil rights of TGNB people against employment, educational, and housing discrimination (NCTE, 2016) as well as legislation mandating that TGNB individuals use the bathroom associated with their sex assigned at birth. For transgender and non-binary individuals, structural stigma manifests as cisgenderism (Ansara and Hegarty, 2012; Ansara and Hegarty, 2014; Lennon and Mistler, 2014), which is the institutional practice that refuses to acknowledge and support self-identified gender identity. Within the health care system, cisgenderism is enacted through a two-gender medical system that is based on the assumption that gender and biological sex are connected and unchangeable. For example, sex-specific eligibility criteria for procedures, screening tests, or treatments create structural barriers that make it challenging for providers to order or receive payment for a test or treatment for a patient who is considered ineligible based on sex-specific
eligibility criteria (GLBT Health Access, 2000; Khan, 2011; Sanchez et al., 2009; Snelgrove et al., 2012; White-Hughto, Reisner, & Pachankis, 2015). Results from this dissertation illustrate how institutional policies and practice shaped by cisgenderism influence TGNBW’s willingness to use PrEP.

At the structural level, a lack of consistent PrEP information specific to the HIV risk and sexual health needs of TGBW greatly affected the sample’s PrEP knowledge and willingness to use PrEP. Failing to create and disseminate PrEP information that is specific to and inclusive of TGNBW creates barriers to PrEP uptake by requiring providers and TGNBW to interpret and apply information that does not acknowledge why PrEP is important for this population. Among the TGNBW in this sample, access to PrEP information was both a facilitator and barrier to PrEP uptake. Differences in willingness to take PrEP were based on types of PrEP information, source(s) of information, and level of trust in the information source. Overall, there was a high-level of PrEP awareness (e.g., why PrEP is used and by whom and how effective it is) among the sample. However, awareness alone was not sufficient to result in a willingness to take PrEP. Most TGNBW not on PrEP attributed their PrEP awareness to a single source - a recent public health PrEP campaign that included ads on public transportation and health education literature. In contrast to awareness, PrEP knowledge was associated with access to greater PrEP information from a variety of sources, which in addition to a basic understanding of PrEP, included frequency of medication administration, potential side effects, and how PrEP works to protect against HIV. PrEP users also identified three factors which increased willingness to take PrEP: a) having a personal connection (i.e., close friend) to the source of PrEP information b) a willingness to seek out more information to decide whether PrEP was right for them, and c) active engagement from a provider around PrEP. These findings highlight the way structural
stigma (i.e., lack of consistent information) creates barriers to health care for TGNBW (GLBT Health Access, 2000; Khan, 2011; Sanchez et al., 2009; Snelgrove et al., 2012, White-Hughto, Reisner, & Pachankis, 2015). Simply put, because specific PrEP information for TGNBW does not exist potential PrEP uptake may not occur. Further, study results also underscore how cisgenderism results in TGNBW not being reached by the same information and social networks as MSM. Thus, demonstrating the need for structural interventions that create transgender inclusive and gender-affirming PrEP information and messaging to reach TGNBW through their social networks (Sevelius, 2016).

Two additional facilitators to PrEP uptake were active provider engagement around and payment assistance with PrEP. Active engagement entailed health care providers who had ongoing conversations with their patients about PrEP as opposed to a one-time discussion. For example, a participant on PrEP described how her provider both consistently and in a casual manner discussed PrEP each time she had an appointment. She attributed her provider's persistence with offering PrEP and non-judgmental attitude towards whether she took it as a significant facilitator to PrEP uptake. Further, providers who actively assisted participants with either getting on health insurance that covered PrEP or a PrEP payment assistance program were identified as critical facilitators to PrEP uptake. These findings illustrate how providers that actively helped with navigating insurance coverage and payment for PrEP increased both PrEP access and uptake. These results suggest that to affect PrEP access and uptake positively it is imperative for health centers to have PrEP navigation programs to reach TGNBW. These findings are consistent with existing literature that suggest if programs integrate HIV prevention into the broader health concerns of TGNBW (e.g., hormone therapy) they are more likely to
retain patients and have better health outcomes (Garofalo et al., 2012; Melendez & Pinto, 2009; Poteat, Reisner, & Radix, 2013; Sevelius et al., 2009; Sevelius, 2013).

Lastly, study findings suggest that willingness to take PrEP is negatively influenced by policies that categorize transgender women and MSM together, which fails to describe the HIV disparities among this population (Clements-Nolle et al., 2006; Goldblum et al., 2012; Haas & Rodgers, 2014; Keuroghlian, Reisner, White, & Weiss, 2015; Moody & Smith, 2013; Operario et al., 2014; Reisner, Gamarel, Nemoto, & Operario, 2014; Testa, Jimenez, & Rankin, 2014; Xavier et al., 2008). Among the sample, the conflation of TGNBW with cisgender MSM was identified as a significant barrier to PrEP uptake. Participants expressed frustration and anger at being compared to cisgender gay men because it both refuses to acknowledge and support who they are and accurately reflect the experiences that place them at risk for HIV. Relatedly, the sample stated that the categorization of TGNBW with cisgender MSM was another barrier to transgender-inclusive and gender-affirming PrEP programs. Participants echoed the need for PrEP and HIV prevention programming to mention and address the needs of TGNBW specifically. Further, participants felt that a lack of TGNBW specific programming explicitly tells the community that they do not matter or exist.

Several examples emerged demonstrating how structural stigma manifests within PrEP programming, including the absence of a) PrEP information specific to contextual factors (e.g., survival sex work) associated with HIV risk for TGNBW, b) diverse gender presentations in PrEP public health campaigns, and c) sexual health and risk assessment tools that accurately reflect the sexual health needs of TGNBW. These results suggest that because current HIV prevention programming is developed for cisgender MSM there is a lack of attention to and interest in the specific sociocultural and syndemic factors associated with HIV risk among
TGNBW (Bradford et al., 2013; Lombardi et al., 2001; Operario et al., 2014; Nemoto et al., 2011; Testa et al., 2012; Sevelius, et al., 2009; Sevelius, 2013). For example, participants stressed that pervasive economic disenfranchisement forced TGNBW into survival sex work (Nadal, Davidoff, & Fujii-Doe, 2014; Sevelius, et al., 2016), thus increasing HIV risk. However, despite research consistently documenting that TGNBW sex workers have higher rates of HIV than cisgender male sex workers (Operario, Soma, & Underhill, 2008) PrEP programming for TGNBW does not address sex work.

These findings illustrate how structural stigma (Link and Phelan, 2001) influences TGNBW’s willingness to use PrEP. Study results are consistent with existing literature that suggests TGNBW do not benefit from HIV prevention programming designed for cisgender MSM (Garofalo et al., 2012; Poteat, Reisner, & Radix, 2013; Reisner et al., 2016; Sevelius, et al., 2016). Within PrEP related healthcare structural stigma perpetuates a binary two-gender (i.e., male or female only according to sex assigned at birth) health care system (Lombardi, 2009; Poteat, 2013; Snelgrove, 2012; White, Reisner, & Pachankis, 2015) that assumes gender and biological sex are connected, binary, and immutable and that gender determination is based on external genitalia. This practice reinforces cultural and institutional beliefs, and practice that deny, pathologize, and delegitimize gender diversity by refusing to acknowledge or accept that natal sex can differ from social and psychological gender (Ansara and Hegarty, 2012; Ansara and Hegarty, 2014; Lennon and Mistler, 2014). Thus, resulting in the development and design of PrEP interventions and strategies that target cisgender MSM and ignore the specific HIV prevention needs of TGNBW.

Consistent with Link and Phelan’s (2001) theory of stigma and discrimination and the theory of cisgenderism (Ansara and Hegarty, 2012; Ansara and Hegarty, 2014; Lennon and
Mistler, 2014), these findings suggest that a two-gender health care system creates systemic barriers to transgender-inclusive and gender-affirming PrEP related health care. Study findings also support the extensive literature on healthcare access among the TGNB community, which demonstrates how structural stigma impacts healthcare access in three ways: 1) a lack of consistent information on the social, emotional and physical health needs of TGNBW, 2) difficulty locating a knowledgeable provider, and 3) institutional policies and procedures that do not accommodate and acknowledge transgender identities and bodies (GLBT Health Access, 2000; Khan, 2011; Sanchez et al., 2009; Snelgrove et al., 2012, White-Hughto, Reisner, & Pachankis, 2015). In the sample, a lack of consistent PrEP information and the absence of programs that are specific to and inclusive of TGNBW influenced willingness to take PrEP and access to PrEP related health care. Despite disproportionate rates of HIV infection within this community, evidence-based PrEP information for TGNBW still does not exist. A lack of PrEP information impacts uptake and access in two ways. The lack transgender inclusive PrEP information effects provider’s ability to receive training and education to provide PrEP related care that is gender affirming. Which in turn impacts TGNBW’s ability to find a knowledgeable PrEP provider. Furthermore, the absence of transgender-inclusive and gender-affirming PrEP programs perpetuates the policies and procedures (i.e., categorization of TGNBW with MSM) that do not acknowledge or care for transgender identities and bodies. A lack of transgender-specific and inclusive PrEP programming ignores the specific HIV risk and sexual health needs of this population and forces TGNBW to seek out PrEP within a system, which by design is not affirming of self-identified gender identity.
**Interpersonal Factors**

At the interpersonal level, stigma manifests as both enacted and felt stigma (Herek, 2007; Scambler & Hopkins, 1986). Enacted stigma refers to overt acts of discrimination (i.e., racism, transphobia, sexism) through slurs, rejection, ostracism or explicit forms of discrimination and violence (Scambler & Hopkins, 1986). Felt stigma is the fear of enacted stigma, in addition to feelings of shame associated with being a member of a marginalized group (Scambler & Hopkins, 1986). Within the health care system, interpersonal stigma reflects the attitudes, beliefs, and behaviors of both providers and patients (IOM, 2010). Direct and indirect forms of interpersonal stigma against transgender and non-binary individuals creates significant barriers to accessing health care. Examples of enacted interpersonal stigma in healthcare settings include, outright denial of services, to refusing to use a person's name or gender pronoun, to providers appearing shocked or in disbelief when a person discloses being transgender or non-binary (GLBT, 2000; Grant, et al., 2011; James, et al., 2016). Furthermore, there is also an increased likelihood for transgender and non-binary individuals to experience enacted stigma due to the multiple people patients interact with healthcare settings. Previous negative experiences and fear of stigmatization affect health seeking behaviors leading transgender and non-binary individuals to postpone or forgo preventative and emergency health care (Grant et al., 2011; James et al., 2016).

The results from this dissertation highlight two factors at the interpersonal level influencing TGNBW’s willingness to take PrEP. First, study findings illustrate how societal stigma towards the transgender and non-binary community and the fear of being stigmatized as HIV positive were potential barriers to PrEP uptake. The fear of being judged for using PrEP due to lack of awareness among potential sexual partners and the general public was identified as a
deterrent to PrEP uptake. For example, participants not on PrEP expressed apprehension towards openly disclosing their PrEP use because it implied sexual promiscuity and perpetuated societal stereotypes that portray TGNBW as hypersexualized (Garofalo et al. 2006; Sevelius, 2013). Another concern surrounded having their PrEP use discovered (e.g., someone else seeing their medication bottle) rather than personally disclosed. Participants worried that sexual partners would think they were HIV positive because PrEP is also a commonly used medication for HIV treatment. In contrast, for participants on PrEP, the disclosure of PrEP use was an opportunity to combat the negative stereotypes about TGNBW and HIV risk. To understand these results, it is vital to situate them within the existing literature on stigma and discrimination among TGNBW, which has found that at the interpersonal level TGNBW experience rejection from family and friends (Koken, et al., 2009; Mallon and De Crescenzo, 2006) and high rates of sexual violence and physical assault (Lombardi et al., 2001; Nemoto et al., 2011; Testa et al., 2012) and both have been associated with HIV risk (Clements-Nolle, Marx, & Katz, 2006; Kenagy & Bostwick, 2005; Lombardi, 1999; Lombardi & van Servellen, 2000; Lombardi et al., 2001; Nemoto, et al., 1999; Nemoto, et al., 2004; Xavier, Bobbin, Singer, & Budd, 2005). Within this context, it is possible that previous experiences of enacted interpersonal stigma shape some participants response towards PrEP. For example, participants may believe that the consequences (i.e., rejection, violence) associated with disclosure or being found out far outweigh the benefits of using PrEP. Fears around disclosure and the extreme violence associated with it are also rooted in historical and contemporary perspectives of TGNB identities that criminalize gender non-conformity (Capers, 2007; Meyerwitz, 2002; Mogul, Ritchie, & Whitlock, 2011; NCTE, 2016; Stryker, 2007), whereby the disclosure or presumption that an individual is transgender or non-binary is punishable by imprisonment.
A second factor emerged that may mitigate the negative consequences of interpersonal stigma and positively impact willingness to use PrEP among TGNBW. Study findings suggest that having personal relationships and a sense of community connectedness were facilitators to PrEP and uptake. Having friends, (especially other TGNBW) openly talk about their PrEP use and actively encourage their friends to go on PrEP increased awareness and also reduced PrEP related stigma. The ability to talk to other TGNBW about their motivations for taking and experiences on PrEP provided an invaluable resource. A personal connection to someone on PrEP offered first-hand information about side effects, efficacy, and adherence. Seeing other TGNBW on PrEP, gave participants the chance to envision that PrEP might be something right for them.

These findings also speak to participant’s overwhelming sense of community responsibility to change the social and cultural norms around HIV risk and PrEP use among TGNBW. PrEP was viewed as a game-changing, life-saving HIV prevention tool. To use PrEP was the chance to be a part of a historical moment in the fight against HIV. Participants saw their use of PrEP as an opportunity to affect the lives of future generations of TGNBW by actively participating in reducing the disproportionate rates of HIV among this community. These results are not surprising given the long history of community activism among the TGNB community and in particular TGNBW (Meyerwitz, 2002; Stryker, 2007; Wilchins, 1997). In the absence of social, legal, and medical recognition and support, the TGNB community has been forced to develop and disseminate their own information and strategies to provide support and get services. As the results of this dissertation indicate this practice has continued with regards to PrEP and is an essential component to PrEP uptake.
The findings from this dissertation illustrate specific examples of interpersonal stigma (i.e., enacted and felt stigma) that influence willingness to take PrEP and the potential resiliency factors that increase PrEP uptake. Enacted stigma refers to instances of discrimination against individuals due to their perceived unacceptability or inferiority (Scambler & Hopkins, 1986). Persistent messaging and actions that dehumanize TGNBW as sexually promiscuous and sexual objects encourage HIV related stigma and transphobia at the interpersonal level to occur. For example, open hostility and judgment towards TGNBW on PrEP from potential sexual partners and other community members may impact willingness to take PrEP due to the desire to protect against experiences of stigma and discrimination.

Study findings demonstrate that willingness to take PrEP may be influenced in part by the fear of stigmatization and the shame associated with being seen as an HIV-positive TGNBW. To avoid being targets of enacted stigma, felt stigma often affects behavior. TGNBW modify or adapt their behavior in a variety of ways to avoid stigma in various aspects of their lives. For example, TGNBW may choose not to disclose their TGNB identity to their medical provider or may change their appearance to match their biological sex. It is possible that participants view not taking PrEP as a form of protection against HIV related stigma and transphobia and prioritize preventing further experiences of stigma over HIV prevention.

The present study extends the literature on interpersonal stigma and HIV risk among TGNBW individuals (Operario et al., 2014; Sevelius, Reznick, Hart, & Schwarcz, 2009; Sevelius, 2013) by identifying strategies that increase PrEP uptake as well as mitigate the adverse health outcomes associated with transphobia and HIV related stigma. Current literature on stigma and HIV risk among TGNBW consistently documents the role stigma and discrimination play in HIV risk (Bradford et al., 2013; Lombardi et al., 2001; Nemoto et al.,
However, few studies have examined the protective factors and strategies employed by the TGNBW community that decrease HIV incidence and increase positive health outcomes. The findings from this dissertation illustrate the importance of social support and community connectedness in combating the negative health impact (i.e., HIV risk) associated with interpersonal stigma. If TGNBW see themselves/ know someone on PrEP, they may be more willing to use PrEP. Having a connection to people in the TGNBW community on PrEP not only destigmatizes the use of PrEP but increases a sense of belonging and shared commitment to promoting positive health and well-being among TGNBW. Within this context, social support and community connectedness may act as a buffer to PrEP (HIV) related stigma and transphobia.

**Individual Factors**

At the individual level stigma manifests as the acceptance of society's negative regard for the stigmatized group (Scrambler & Hopkins, 1986). Individual stigma towards TGNB individuals is referred to as transphobia or the acceptance that those who transgress societal gender norms need to be feared and shunned (Herek, 2007). Internalized transphobia or self-stigma may cause TGNB individuals to feel that they do not deserve respect from family, friends, coworkers, sexual partners, and non-close others. In medical settings, TGNB individuals may think that they do not deserve respect from their health care provider or access to health care that is affirming and supportive (Grant et al., 2011; James et al., 2016; IOM, 2010). For example, participants not on PrEP expressed uncertainty around whether PrEP was right for them often citing the lack of PrEP information specific to transgender women. It is possible that participants belief that they are not appropriate (or deserving) of PrEP is a form of internalized transphobia. If the information and services do not exist, then I must not need them. Also, because of
internalized transphobia, TGNBW may not disclose key information to their health care provider; avoid seeking treatment, or refrain from challenging discrimination and other forms of enacted stigma (Dewey, 2008; Grant et al., 2011; James, et al., 2016). For example, TGNBW may be unwilling to disclose engagement in survival sex work to health care providers due to the pervasive stigma associated with participation in sex work as well as not wanting to further perpetuate the stereotype that all TGNBW are sex workers.

This study illustrates several factors at the individual level impacting willingness to take PrEP. Perception of HIV risk was both a facilitator and barrier to PrEP uptake. Participants who perceived themselves to be at risk wanted PrEP. Engagement in transactional sex and previous experiences where potential HIV exposure occurred were motivating factors, which positively influenced willingness to use PrEP. For participants whose HIV risk was low or for whom PrEP did not address the type of risk most important to them, risk perception was a barrier to PrEP uptake. For example, participants who reported low sexual activity or having a monogamous sexual partner felt their current sexual activity did not warrant the use of PrEP. However, for these participants, current low-risk behavior and perception did not impact their willingness to consider PrEP in the future. Participants discussed how if their risk level for HIV changed (e.g., engaging in sex work, having multiple sex partners), they would reconsider taking PrEP. Thus, demonstrating an understanding that risk can change over time and that the behaviors and contexts a person engages in exist on a continuum, a person is not just high-risk or low-risk. In contrast to previous research, which found that TGNBW underestimate their risk for HIV (Herbst et al., 2008), these findings demonstrate a nuanced understanding of HIV risk and the contexts in which risk occurs.
Another key finding demonstrates that increased psychological well-being and sexual satisfaction due to reduced HIV worry were benefits to PrEP uptake. Taking PrEP increased self-esteem by reducing the sense of fatalism around HIV that is common among TGNBW. PrEP was seen as a protective factor against the ongoing stigma and discrimination TGNBW face in their daily lives. Because of PrEP, becoming HIV-positive was no longer inevitable. This finding provides a striking counterpoint to existing studies, which have found that low self-esteem, depression, anxiety, substance use, victimization related to gender identity and expression, and intimate partner violence have been associated with HIV infection and sexual risk behavior among TGNBW (Brennan et al., 2012; Jefferson et al., 2013; Nuttbrock et al., 2009; Operario et al., 2014; Sevelius, et al., 2009; Sevelius, 2013). PrEP use gave participants the belief that they were worth living, a tool to fight for their lives and control over their bodies. Sex became more enjoyable because of PrEP. Participants expressed a sense of relief knowing that with PrEP they no longer always worried about getting HIV during each sexual encounter. If accidental exposure to HIV occurred, participants felt confident that PrEP provided an extra layer of protection that condoms did not.

A potential barrier to PrEP uptake was the fear that PrEP would negatively interact with participants’ feminizing hormone regimen, thereby limiting its effectiveness. Not surprising, for the majority of participants, the number one health care priority was their gender transition. These findings are consistent with existing literature on the importance of hormone therapy among TGNBW (Melendez and Pinto, 2007; Nuttbrock et al., 2009). Participants expressed hesitation about taking a medication that could slow down or stop their gender transition. Findings indicate that both groups expressed similar concerns about potential drug-to-drug interactions between PrEP and feminizing hormones. However, PrEP users were able to
overcome this barrier once they received information about what is currently known about drug-to-drug interactions, indicating that with targeted, evidence-based information this barrier may be easily overcome.

Study results also indicate that taking multiple medications was a barrier to PrEP use among participants not on PrEP. A common theme that emerged was not wanting to add another medication to an existing medication regimen. Participants felt that they were already on too many medications. In addition to feminizing hormones, participants mentioned taking psychiatric medications for depression, anxiety, and sleep. It is possible that PrEP is not prioritized because unlike taking feminizing hormones (e.g., feminization of secondary sex characteristics) or psychiatric medications (e.g., relief from depression, anxiety, and insomnia symptoms) it is used to prevent potential exposure as opposed to treating symptoms (i.e., prevention vs. treatment/intervention). Finally, participants expressed a willingness to take PrEP if available in a long-acting injectable form. For several participants not on PrEP getting an injection was more favorable than taking a daily oral pill and was equated with the potential for better PrEP adherence. Indicating that the availability of long-acting injectable PrEP may be a potential facilitator to future PrEP use among TGNBW who might otherwise not be on oral PrEP.

These findings provide preliminary support for the Gender Affirmation Framework (Sevelius, 2013) by demonstrating how PrEP use can mitigate the negative health consequences of stigma, social oppression, and psychological distress. The Gender Affirmation Framework (Sevelius, 2013) contextualizes HIV risk among transgender and non-binary women as a social and psychological process rather than solely a result of individual sexual behavior. Study findings suggest that PrEP use both reduces the psychological distress (e.g., HIV worry, anxiety, low self-esteem, internalized transphobia) linked to stigma and social oppression and the
increased risk for HIV associated with the high-risk contexts (e.g., sex work) TGNBW are forced into because of social oppression and psychological distress. For example, the use of PrEP promoted a sense of agency over participant's health and body. By taking PrEP, participants were actively taking control of their physical, emotional, and sexual health.

Finally, these results illustrate how individual-level barriers to PrEP uptake (e.g., prioritization of gender transition) are influenced by structural level factors. As highlighted throughout this discussion, study findings suggest that a lack of transgender-inclusive and gender-affirming PrEP information and programs (i.e., structural) contributes negatively to PrEP uptake (i.e., individual). A discussed above, the lack of information on drug-to-drug interactions between PrEP and feminizing hormones was identified as an individual-level barrier to PrEP uptake. At the structural level, HIV prevention and public health programs create unnecessary barriers to PrEP uptake by failing to acknowledge and support the prioritization of hormone use for gender transition. Important opportunities to reduce HIV infection rates among TGNBW are missed by the structural practice of viewing HIV prevention as a separate process from gender transition. These findings are similar to existing research on increasing access to HIV treatment for HIV positive TGNBW, which calls for the integration of HIV treatment into over gender-affirming healthcare (Melendez and Pinto, 2007; Nuttbrock et al., 2009). The results of this dissertation speak to the current state of HIV prevention for TGNBW, providing preliminary evidence to support a systemic change to PrEP implementation and dissemination for this high-priority community. To continue to ignore how factors at the structural, interpersonal, and individual levels work together to influence willingness to take PrEP, PrEP uptake, and access further contribute to and exacerbate the HIV disparities among TGNBW.
Gender Affirmation and HIV Risk

As discussed throughout this dissertation, gender affirmation is the social process that recognizes and supports TGNB individual’s gender identity and expression (Bockting et al., 2006; Melendez and Pinto, 2007; Nuttbrock et al., 2009; Sevelius, 2013). While the need for gender affirmation is not unique to the TGNB community, it often takes on a more prominent role given TGNB individuals gender minority status. For TGNB individuals, gender affirmation is a vital component of their sense of self and a validation of their gender identity and expression (Melendez and Pinto, 2007; Nuttbrock et al., 2009). Gender affirmation can include the use of TGNB individuals correct name and pronouns, to the development of gender-affirming health care programs, to the payment (from insurance) of gender transition health care, to the active acceptance of the range of gender expressions these communities claim. Despite the importance of gender affirmation among TGNB individuals, the relationship between the need for gender affirmation and HIV risk has not been thoroughly investigated (Reisner, et al., 2015; Sevelius, 2013).

Results from this dissertation illustrate how extreme marginalization (due to multiple and intersecting forms of oppression) and a high need for and decreased access to gender affirmation contributes to HIV risk among TGNBW (Sevelius, 2013). Study findings illustrate how a lack of access to gender affirmation (i.e., explicit and implicit rejection of self-identified gender identity and expression) at the structural (society and institutions) (Grant, et al., 2011; James, et al., 2017) and interpersonal (family, friends, community) level (Lombardi et al., 2001; Klein & Golub, 2013; Nemoto et al., 2011; Nuttbrock, et al., 2013; Testa et al., 2012; Wilson, et al., 2012) contributes to adverse social, psychological, and behavioral health outcomes among TGNBW. For example, rejection from family members (for being TGNB) was associated with
homelessness, while broader societal rejection of TGNBW made it challenging to find housing, employment, or obtain an education (Cochran et al., 2002; Koken, et al., 2009; Mallon and De Crescenzo, 2006; Reisner et al., 2015; Wilson, et al., 2009). Results also inferred that employment, housing, and education were only accessible to TGNBW who “passed” (i.e., looked/viewed as cisgender women). Participants expressed anger at being discriminated against when trying to get a job because they were either perceived to be transgender or did not have legal documents that matched their gender identity. These findings are consistent with previous research on stigma and discrimination and quality of life for TGBNW (Bradford et al., 2013; Grant et al., 2011; James, et al., 2017; Khan, 2011; Nemoto et al., 2011; Sevelius et al., 2009; Sevelius, 2013; Strousma, 2014).

Overall, participants expressed the belief that systemic factors such as racism, transphobia, and sexism were more strongly linked to HIV risk, than their individual sexual behavior. The majority of participants rejected the belief that TGNBW chose to put themselves in risky situations and agreed that this frame places blame on the individual rather than acknowledging the structural factors contributing to HIV risk. In an attempt to reduce the consequences of stigma and social oppression participants reported that they are forced into high-risk contexts. It is within these high-risk contexts that HIV risk behaviors (e.g., condomless sex) occur (Herbst, et al., 2008; Kenagy, 2002; Kenagy, 2005; Nemoto et al., 2006; Reback & Simon, 2004; Simon, Reback, & Bemis, 2000).

Participants highlighted the relationship between HIV risk and survival. For example, participants talked about being forced to engage in survival sex work due to social and economic disenfranchisement (Baral et al., 2013; Poteat, Reisner, & Radix, 2013; Sevelius, et al., 2009; Sevelius, 2013). Participants shared experiences of having condomless anal sex in exchange for
greater financial incentives from clients, thus having to decide between survival and HIV risk. HIV risk is something that is forced upon TGNBW, rather than a result of behavioral choice or agency. Within this context, PrEP is a form of harm reduction that can minimize the negative effects of behaviors that are necessary for survival.

Experiences of sexual violence and sexual assault were also identified as high-risk situations where HIV risk is externally generated for TGNBW (Clements-Nolle et al., 2001; Herbst et al., 2008; Lombardi et al., 2001; Nemoto et al., 2011; Testa et al., 2012). The vast majority of participants reported multiple occurrences of sexual assault. Participants stated that TGNBW were forced into situations (e.g., survival sex, sex to obtain gender affirmation, sexual relationships with unequal power) where they were exposed to sexual violence due to rejection from family, friends, and society (Nuttbrock, et al., 2013; Wilson, 2012). Participants saw PrEP as a necessity given the disparate rates of sexual violence among TGNBW.

Sexual experiences under the influence of drugs and alcohol (Nemoto et al., 2011; Nemoto, et al., 2004; Operario, et al., 2014; Risser, et al., 2005) emerged as another high-risk context where PrEP is beneficial for TGNBW. For example, participants identified instances where they either engaged knowingly in condomless sex while intoxicated or were forced to use drugs during sex work. In both contexts (i.e., experiences of sexual violence and sex under the influence of drugs and alcohol) PrEP is a strategy for safety, reducing both risks for HIV and the psychological distress around potential exposure to HIV.

Research has extensively documented that HIV risk for TGNBW is associated with individual sexual risk behaviors (Bockting et al., 1998; Herbst, et al., 2008; Kenagy, 2002; Melendez and Pinto, 2007; Nemoto et al., 2004; Operario et al., 2011; Reisner et al., 2009; Rodriguez-Madera and Toro-Alfonso, 2005; Sausa et al., 2007; Sugano et al., 2006). In contrast,
the results from this dissertation suggest that HIV risk among this community is intrinsically linked to survival. Study findings consistently provide evidence to support the Gender Affirmation Framework (Sevelius, 2013) by demonstrating the relationship between multiple levels of stigma, discrimination, oppression, and HIV risk. Further, without recognition or support for gender identity and expression TGNBW must navigate within a world that on a fundamental level does not value them as people. Within this context TGNBW must fight for survival while simultaneously being exposed to HIV risk. The data presented in this dissertation ask that public health and HIV prevention policies and programs no longer view the structural, interpersonal, and individual level factors associated with stigma and oppression as separate from HIV risk. The next section presents concrete examples for best practice to increase PrEP knowledge, access, and uptake to TGNBW.

Best Practices

The findings from this study provide several suggestions for best practice to increase TGNBW’s willingness to use PrEP. First, to increase PrEP awareness and uptake, HIV prevention and sexual health information, messaging, and programs must be transgender inclusive and gender-affirming. Study findings indicate that the first step to making HIV prevention policies and programs more inclusive is eliminating the practice of categorizing TGNBW with cisgender MSM (Fiereck, 2015; Sevelius, 2013, 2016). Another important aspect to creating inclusive and affirming HIV prevention information and messaging is to include transgender and non-binary women with diverse gender presentations in PrEP advertising and health information campaigns, rather than prioritizing TGNBW who “pass.” Participants stated that to increase willingness to take PrEP, TGNBW should be able to see themselves reflected in current messaging campaigns. Without diverse representation, TGNBW may not know that PrEP
is right for them. Furthermore, findings suggest that inclusive and affirming HIV prevention programs must include sexual health assessment tools and health education literature that accurately reflects: a) the sexual and gender identities of TGNBW and their sexual partners, b) the sexual activity TGNBW are engaging in, c) the high-risk contexts where HIV risk increases, d) information on whether there are drug-to-drug interactions between feminizing hormones and PrEP and e) information on new forms of PrEP that are being developed.

These findings also illustrate how active provider engagement around PrEP and active payment assistance for PrEP are integral to increasing PrEP uptake among TGNBW. Active provider engagement included not only the act of telling patients about PrEP but giving health education information (e.g., efficacy, dosage/frequency, side effects, drug-to-drug interactions) to help make informed decisions about whether to take PrEP. For patients who were hesitant about taking PrEP, active provider engagement included having ongoing conversations with them about PrEP availability and benefits. An important factor to active provider engagement is that conversations about PrEP were built into participant’s ongoing gender affirming health care rather than requiring TGNBW to separately seek out PrEP related care. Another aspect of active engagement is the creation of PrEP-related outreach services to reach TGNBW who would most benefit from PrEP (e.g., street-based sex workers, homeless youth, and young adults). This low-threshold service is a way to leverage PrEP to increase access to and utilization of health care and other support services to TGNBW that must prioritize survival over attending regular medical appointments. Study findings highlight that active payment assistance includes helping patients understand whether current health insurance covers PrEP, assistance with signing up for health insurance that will cover PrEP or apply for a medication payment assistance program associated with a pharmaceutical company.
Finally, the study findings indicate that community mobilization/activism strategies are important facilitators to increase PrEP knowledge and uptake among transgender and non-binary women. Having community members openly talk about their PrEP use and knowing friends on PrEP were critical factors to a willingness to take PrEP. Once on PrEP participants expressed a sense of responsibility to help reduce HIV infection rates among TGNBW by sharing their PrEP knowledge with friends and other community members to increase PrEP uptake. To support these strategies, providers must acknowledge and support the role of friends and community in the dissemination of PrEP information.

The findings from the present study have several implications for biomedical HIV prevention. PrEP is the newest and most promising biomedical HIV prevention intervention to date, yet those who would most benefit continue to have differential uptake and access compared to White cisgender MSM (CDC, 2018). In the United States, transgender and non-binary women have been identified as the group with the highest rates of new HIV diagnoses compared to cisgender men and women (CDC, 2011, Baral, et al., 2013; Herbst, et al., 2008). However, despite disparate rates of HIV infection, there are currently no guidelines providing specific recommendations for PrEP dissemination to this population (Escudero, et al., 2014; Sevelius, et al., 2016). The lack of TGNBW specific PrEP guidelines is largely a result of the historical practice of including TGNBW under the behavioral risk group cisgender MSM in HIV surveillance data and research. Aggregating TGNBW with cisgender MSM ignores this population’s specific HIV risk and prevention needs and allows funding for HIV prevention to be funneled solely to the development and design of programs and prevention strategies for those who are assigned male at birth.
Study findings suggest that TGNBW have distinct sexual health and HIV prevention needs that are not addressed by current PrEP policies and programs. These results also suggest that initiatives to increase PrEP uptake among TGNBW will be hindered without specific guidelines for PrEP dissemination to this high-priority population. Furthermore, these findings indicate that to increase PrEP knowledge, uptake, and access, HIV prevention funding must be allocated to the development and design of programs and prevention strategies specific to and inclusive of TGNBW.

**Implications for Social Work Practice**

Over 35 years into the HIV epidemic, PrEP is currently the most promising biomedical HIV prevention intervention to emerge with the greatest potential for eradicating new HIV infections. Despite an increase in PrEP uptake across the United States, those most at risk for HIV continue to be left behind. The history of HIV in the United States epitomizes social inequality and social injustice and demonstrates how large segments of the population have been and continue to be left behind, while others benefit from biomedical HIV prevention and treatment. For marginalized populations, the factors that contribute to these disparities may pose a greater risk for HIV than individual behavior. At a time when scientific advances are rapidly changing the field of HIV prevention and treatment, social workers must develop the skills to integrate and translate this information, while simultaneously addressing the structural factors that allow for disparities in access to and uptake of PrEP. To do otherwise goes against the professions code of ethics, which charges social workers with the primary goal of addressing social problems by challenging social injustice at the structural, interpersonal, and individual levels (NASW, 2017).
From the outset of the HIV epidemic, the field of social work has played an integral role in providing material, social, and emotional support services to persons living with and at risk for HIV (Wheeler, 2007; 2011). The findings from this dissertation suggest several areas where social workers can help increase access, uptake, and adherence to PrEP. First, study findings highlight the structural factors that create contexts in which HIV risk increases and allow for disparities in access to and uptake of PrEP. As such it is imperative for the social work profession to address these structural factors through advocating, creating, and implementing policies (e.g., reevaluating policies, funding, and programs for HIV prevention to provide housing and other public benefits and services to those who are HIV negative) that affect systemic change rather than solely focusing on interventions that seek to change individual behavior.

Second, these findings suggest that PrEP is a critical component to mitigating the negative health outcomes associated with these structural factors. One goal of social welfare is to help ameliorate the negative consequences associated with stigma and discrimination. Social workers interact with TGNBW within various social service contexts and are uniquely positioned to increase PrEP knowledge, access, and uptake through active engagement and assistance. Active support entails communicating the relationship between structural factors and HIV risk to TGNBW through providing transgender-inclusive and gender-affirming health education information on PrEP and navigating the process of obtaining and paying for the medication. Additionally, social workers play an important role in reaching TGNBW who are most at-risk for HIV given the multiple high-risk contexts they are forced into for survival. As such, social workers can both design and implement low-threshold services to increase PrEP uptake and adherence.
Third, study findings demonstrate the importance of community mobilization/activism around PrEP. The social work profession has a long history of community organizing within marginalized communities. These findings suggest that social workers can play a crucial role in teaching community building and advocacy skills to both increase PrEP uptake and address the structural factors that increase HIV risk for this community. For example, this can include advocating at the federal, state, and local level to increase access to gender affirming health care for TGNBW, supporting community-led models and programs that increase employment and educational opportunities for TGNBW, and organizing with the community around the needs and issues they deem most important.

**Limitations**

There are several notable limitations to the present study. First, this study utilized an exploratory qualitative research design, which relied on a small convenience sample recruited in New York City where there have been considerable efforts to increase awareness and uptake of PrEP on both the state and city level, thus limiting the generalizability of these findings. While the recruitment strategy targeted TGNBW through multiple avenues (social media, in person flyers at CBO’s for TGNBW, and word of mouth) it is possible that TGNBW who did not know or had not heard of PrEP self-selected out of participation. Thus, skewing the sample towards TGNBW engaged in health care. Second, because all participants were insured (public or private health insurance) and the vast majority received gender-affirming healthcare study findings may not apply to TGNBW outside of a large urban area where there is access to expanded Medicaid and transgender-related health care. Given the disparities in access to health care and insurance among transgender and non-binary individuals across the United States, these findings may be different among a national sample of TGNBW (James, et al., 2017).
Third, participants not on PrEP reported a high-level of PrEP awareness. However, 75% stated that they did not want or would not take PrEP. Previous research on PrEP knowledge among transgender and non-binary women found low levels of PrEP awareness and knowledge and high-levels of willingness to take PrEP once provided PrEP information (Sevelius, 2016). Because of the lack of transgender-specific PrEP research and health education information, these findings must be interpreted with caution. It is possible that the sources of information (public health campaign vs. trained research assistant) and the context (real world vs. research environment) in which this information was provided influenced these results.

Fourth, the eligibility criteria for study participation were based on the CDC's PrEP guidelines for MSM. As discussed throughout this dissertation, the lack of PrEP guidelines specific to the factors associated with HIV risk for transgender and non-binary women is a significant barrier to PrEP uptake and access. It is possible that by using the CDC's PrEP eligibility criteria for MSM, the study findings do not adequately represent the diversity of sexual experience and HIV risk behaviors among this community.

Fifth, it is possible that the findings from this dissertation are limited by the research team's subjectivity. All members of the research team identify as TGNB and have extensive experience working with social service and healthcare organizations serving the TGNB community in New York City. While the research team's connections to the TGNB communities and organizations serving the community contributed to the success of this project, it is possible that these connections hindered the ability to recruit individuals who were not connected to one of these organizations or who do not openly identify as a member of the TGNB community. Conversely, some TGNBW may not have felt comfortable participating in a study with a research team connected to the community due to concerns about confidentiality. Also, the
increased visibility of the TGNB community has led to a burgeoning field of research with TGNB people. It is also possible that an oversaturation of research studies within the New York City area contributed to a lack of willingness to participate. With many studies simultaneously going on, potential participants may have felt "othered" or tired of being targeted to participate in research studies.

Lastly, participating in an in-person qualitative interview with another transgender person may have influenced participants responses due to social desirability. Participants may have tailored their answers towards what they believed the research team would find more favorable. Conversely, participants may have withheld certain information about their experiences due to fear of being judged or stigmatized for their behavior from the research team.

It is important to acknowledge that these limitations do not detract from the important findings generated by this dissertation. The results presented throughout provide a nuanced interpretation of HIV risk and PrEP use among TGNBW. Moreover, these results have the potential to significantly reshape the design, development, and implementation of HIV prevention programs and strategies, at a time when such data are needed.

**Future Directions for Research**

To date, there have been few studies on PrEP use among transgender and non-binary women. The findings from this dissertation suggest several directions for future research. First, little to no research exists on the sexual *health* (distinct from risk) of transgender and non-binary women. As demonstrated throughout this study, transgender and non-binary women engage in a variety of sexual experiences within different contexts and with people of different gender identities and expressions. Future research is needed to develop quantitative survey measures to test these findings with a national sample of transgender and non-binary women. Second, these
findings suggest that a lack of transgender-inclusive and gender-affirming sexual health assessment tools and health education information create barriers to PrEP knowledge, uptake, and access. Research must develop and test valid and reliable sexual health and risk assessment tools that accurately reflect the experiences that increase HIV risk for TGNBW, to assist in the development of PrEP guidelines and the design of PrEP programs that are specific to TGNBW.

Third, these findings demonstrate a need for reliable information on whether PrEP negatively interacts with commonly used feminizing hormones. For the majority of participants, their gender transition process was identified as the number one health priority. As such, longitudinal studies that test drug levels (PrEP and hormones) in TGNBW on PrEP are needed as well as studies that investigate the pharmokentics of the medications in real-world settings.

Fourth, new and promising forms of PrEP (e.g., long-acting injectable) are currently being tested in clinical trials. Participants not on PrEP indicated that they would be more willing to use PrEP if it was administered as an injection rather than a daily oral pill. Future studies must include TGNBW to ensure that implementation guidelines specific to and inclusive of transgender and non-binary women are developed.

Fifth, study results highlight the need for transgender-inclusive and gender-affirming PrEP programs to increase access and uptake. Research studies must partner with community-based health centers and organizations that have existing PrEP programs and protocols for TGNBW to identify and examine the factors associated with PrEP access, uptake, and adherence in a real-world setting. Further, studies should also work with organizations providing low threshold services (such as outreach to homeless transgender youth and young adults) to developing strategies that leverage engagement in PrEP towards improving the overall health of transgender and non-binary women. Finally, future research must stop categorizing transgender and non-
binary women with MSM. There is a need for longitudinal studies examining HIV risk, prevention and treatment that are inclusive of (i.e., cisgender women and transgender women) and specific to transgender and non-binary women. A research agenda that addresses HIV risk among this community at the structural, interpersonal, and individual level has the greatest potential to change HIV policy and direct funding towards the development and design of strategies and programs that reduce the disparate rates of HIV within this community.

Table 1. Demographics of Sample by Group (N=30)

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Total N=30</th>
<th>No PrEP n=15</th>
<th>PrEP n=15</th>
</tr>
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<tr>
<td><strong>Age</strong></td>
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</tr>
<tr>
<td>Under 30</td>
<td>18 (60.0)</td>
<td>7 (46.7)</td>
<td>11 (73.3)</td>
</tr>
<tr>
<td>30 and older</td>
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<td>8 (53.3)</td>
<td>4 (26.7)</td>
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<tr>
<td><strong>Gender Identity</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Binary</td>
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<td>14 (93.3)</td>
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<td>1 (6.7)</td>
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<td>6 (40.0)</td>
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<td>3 (20.0)</td>
<td>3 (20.0)</td>
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<tr>
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<td>2 (13.3)</td>
<td>6 (40.0)</td>
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<tr>
<td>Asian/Pacific Islander</td>
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<td>2 (13.3)</td>
<td>2 (13.3)</td>
</tr>
<tr>
<td>Multiracial</td>
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<td><strong>Sexual Orientation</strong></td>
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<td>Heterosexual/Straight</td>
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<td>10 (66.7)</td>
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<tr>
<td>Gay</td>
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<td>2 (13.3)</td>
<td>0</td>
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<tr>
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<td>3 (20.0)</td>
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<td>5 (33.3)</td>
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<tr>
<td>Pansexual</td>
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<td>2 (13.3)</td>
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<td><strong>Income</strong></td>
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<td></td>
</tr>
<tr>
<td>Less than $12,000</td>
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<td>15 (100.0)</td>
<td>11 (73.3)</td>
</tr>
<tr>
<td>$12,000 +</td>
<td>4 (13.3)</td>
<td>0</td>
<td>4 (13.3)</td>
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<td><strong>Employment</strong></td>
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<td>In the workforce</td>
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<td>3 (20.0)</td>
</tr>
<tr>
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<td>15 (100.0)</td>
<td>12 (80.0)</td>
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<tr>
<td>Public</td>
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<td>15 (100.0)</td>
<td>11 (73.3)</td>
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<tr>
<td>Private</td>
<td>4 (13.3)</td>
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<tr>
<td></td>
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<td>No PrEP n=15</td>
<td>PrEP n=15</td>
</tr>
<tr>
<td>-------------------------</td>
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<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
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<td><strong>CDC Eligibility</strong></td>
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</tr>
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<td>Condomless anal sex in the past 6 months</td>
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<td>12 (80.0)</td>
<td>15 (100.0)</td>
</tr>
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<td>STI Diagnosis in the past 6 months</td>
<td>1 (3.3)</td>
<td>0</td>
<td>1 (6.6)</td>
</tr>
<tr>
<td>HIV-positive sex partner</td>
<td>6 (20.0)</td>
<td>2 (13.3)</td>
<td>4 (26.6)</td>
</tr>
<tr>
<td>Any CDC PrEP eligibility criteria (3 criteria above)</td>
<td>30 (100.0)</td>
<td>15 (100.0)</td>
<td>15 (100.0)</td>
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<td><strong>PrEP Indications</strong></td>
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<td></td>
<td></td>
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<tr>
<td>Multiple Sex Partners</td>
<td>10 (33.3)</td>
<td>4 (26.6)</td>
<td>6 (40.0)</td>
</tr>
<tr>
<td>A partner with multiple sex partners</td>
<td>9 (30.0)</td>
<td>3 (20.0)</td>
<td>6 (40.0)</td>
</tr>
<tr>
<td>A partner who HIV status is unknown</td>
<td>16 (53.3)</td>
<td>7 (46.6)</td>
<td>9 (60.0)</td>
</tr>
</tbody>
</table>
Appendix A: IRB Approval Letter

Approval Notice
Continuing Review

09/21/2017

Gus Klein,
Hunter College

RE: IRB File #2015-1189
   Knowledge, Acceptability, and Access to Pre-Exposure Prophylaxis (PrEP) among the Transgender Community

Dear Gus Klein,

Your Continuing Review was reviewed and approved on 09/20/2017. You may continue the research.

Please note the following information about your approved research protocol:

Protocol Approval Period: 09/20/2017 - 09/19/2020
Protocol Risk Determination: Minimal
Expedited Category(s): (6) Collection of data from voice, video, digital, or image recordings made for research purposes;
   (7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b) (2) and (b)(3). This listing refers only to research that is not exempt.);

Documents / Materials:

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<th>Type</th>
<th>Description</th>
<th>Version #</th>
<th>Date</th>
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<tr>
<td>Informed Consent/Permission</td>
<td>Consent Form - One to One</td>
<td>1</td>
<td>09/08/2017</td>
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<td>Document</td>
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Appendix B: Recruitment Flyer
Trans PrEP?

Are you a woman of trans experience or a member of the transfeminine community?

Are you currently taking PrEP (Truvada) as a form of HIV Prevention?

The Hunter HIV/AIDS Research Team (HART) at Hunter College is conducting a research study to better understand attitudes, beliefs, and experiences regarding a strategy for HIV prevention called Pre-exposure Prophylaxis (PrEP). This study is designed to gather information about factors that might influence the use of and access to PrEP for transgender and non-binary individuals.

We are conducting interviews with transfeminine individuals who are currently on PrEP. Interviews last between 1 – 1 ½ hours.

Participants will receive $40 in appreciation for their time.

Interviews will take place at Hunter College at 68th Street and Lexington.

INTERESTED? Click here to see if you are eligible:

https://cunyhunter.co1.qualtrics.com/SE/?SID=SV_0rGdtCavFp124iX

CUNY
University Integrated IRB
Protocol: 2015-1189
Approved: 09/29/2016
Expires: 09/28/2017
Appendix C: Eligibility Screening Script and Questions

Screening Script and Questions

Hi thanks for calling. First I'm going to tell you a bit about ourselves and the study, then, if you're still interested, I'll ask you some questions to determine whether or not you're eligible to participate. We’re a group of researchers from HART, Hunter HIV/AIDS Research Team. We're affiliated with Hunter College, of the City University of New York. We are conducting a study on PrEP knowledge, use, and access among the transgender community. As the first step to understanding the potential of PrEP as an HIV prevention strategy for the trans* community we are conducting a series of one to one and a half hour interviews with transgender individuals who are either currently on PrEP or might be interested in and/or eligible for PrEP. We are particularly interested in opinions about what might make PrEP more or less acceptable to transgender individuals in NYC and about what things community-based health centers and social service organizations might be able to do to reduce disparities in access to gender affirming prevention and care services that may directly impact PrEP adoption and access.

If you are interested in participating in an interview, I will ask you a series of questions to see whether you are eligible. The questions will be about yourself, including some demographic information and some information about your sexual behavior and substance use.

If it seems like you’re eligible after answering these questions, you’ll have the opportunity to schedule an interview as soon as possible. The interview would last between an hour to an hour and a half and would include questions about: a) your attitudes and opinions about PrEP; b) what you think might make trans* individuals more or less likely to use PrEP; and c) your opinions about the best way to create a program that would provide PrEP to trans* folks who need it most. The interview will take place at our research offices at Hunter College @ 68th and Lexington Ave. In appreciation for your time, you would be paid $40 in cash upon completion of the interview.

In the event that you are not eligible for the study, we will ask you if you would like to be contacted for future studies for which you may be eligible. If you are interested, we will ask for your contact information. We will use your answers to these screening questions to determine whether you are eligible for future studies so that we can contact you. If you do not want your contact information linked to your answers you do not have to provide your contact information. Regardless of your decision, all of your answers will be kept confidential.

Do you have any questions about the study so far?

If you are eligible and choose to participate, any information about you will be kept confidential to the extent permitted by law.

VERBAL CONSENT: Do you feel comfortable answering a few personal questions right now so that I can determine if you’re eligible to participate? Yes / No
1. How did you hear about the study?

2. What is your age? ____

3. What is your zip code? _____

4. What is your race or ethnicity?
   a. Black/African American
   b. Latino/Hispanic
   c. White/Caucasian
   d. Asian/Pacific Islander
   e. Native American
   f. Multiracial
   g. Other (Specify:_____________)

5. What is your sex assigned at birth?
   a. Male
   b. Female
   c. Intersex

6. What is your current gender identity
   a. Male
   b. Female
   c. Transwoman (male to female)
   d. Transman (man to female)
   e. Gender Non-Conforming
   f. Genderqueer
   g. Other____________________

7. What do you consider sexual identity?
   a. Straight
   b. Gay
   c. Lesbian
   d. Bisexual
   e. Queer
   f. MSM
   g. Other (Specify:___________)

8. What is your current employment status? (Check all that apply)
   a. Full-Time
   b. Part-Time
   c. More Than One Job
   d. Self-Employed, own your business
   e. Self-Employed, contract worker
   f. Unemployed But Looking
g. Unemployed and Stopped Looking  
h. On Disability  
i. Student  
j. Retired  
k. Homemaker or Full-time Parent  
l. Other (please specify) ____________________  

9. What is your current gross annual household income (before taxes)?  
a. Less than $12,000  
b. $12,000-$24,999  
c. $25,000-$34,999  
d. $35,000-$49,999  
e. $50,000-$74,999  
f. $75,000-$150,000  
g. Over $150,000  

10. What type of health insurance do you have?  
a. I have NO health insurance coverage  
b. Insurance through a current or former employer (employee health plan, COBRA, retiree benefits)  
c. Insurance through someone else’s employer (spouse, partner, parents, etc.)  
d. Insurance you or someone in your family purchased  
e. Medicare  
f. Medicaid  
g. ADAP  
h. Military health care/Champus/Veterans Administration/Tri-Care  
i. Student Insurance through College or University  
j. Other (please specify) ____________________  

11. Do you drink alcohol?  

12. Approximately how many alcoholic drinks have you had in the past 30 days?  

13. Do you have sex with: (Yes / No)  
a. Cisgender men  
b. Cisgender women  
c. Trans/GNC women  
d. Trans/GNC men  
e. Other ____________________  

14. In the past six months have you had receptive anal/vaginal/or front hole sex with a:  
a. Cisgender man  
b. Transgender woman  

15. In the past six months how often have you had condomless sex? (always, sometimes, never)
16. In the past month have you had:
   a. An HIV positive partner
   b. Multiple sex partners
   c. A partner with multiple sex partners
   d. A partner whose HIV status is unknown

17. Have you recently tested positive for a sexually transmitted infection? (e.g. syphilis, chlamydia)? Yes/No

18. If yes, which one?

19. Are you currently taking PrEP? (Yes/No)

20. If yes, what’s the name of the medication you are prescribed? (Truvada)

21. How do you pay for PrEP?

22. How much is your co-pay?

23. What is your HIV Status?
   a. Positive
   b. Negative
   c. I don’t know

Eligible = Q2 ≥18, Q5 and Q6= current gender identity is different from sex assigned at birth, Q13= cisgender men and/or transgender women, Q23=b or c, and Q13=yes, and/or Q14=yes, and/or Q16≥1 and/or Q17=yes, and Q19=Yes (to be eligible for the PrEP group).

- It looks like you are eligible. Are you still interested in participating? Yes / No

If Yes: Great! We would also like to send you a text or email with directions to our office and a reminder the day before your appointment. Do you have a working, personal telephone number or email that we can use? Give me a minute to pull up our calendar and we can schedule an appointment for you to come to our office for an interview.

Text for Contact Information:
Name:
Cell Number: okay to text: Yes/No  okay to leave message: Yes/No
Email:
Best Contact Method: email_____  call_____  text_____

If No: Thank you for your time! Would you like us to contact you for any future studies?

If ineligible: - Thank you for your time! Based off your answers to the screening questions, you are not eligible for participation in this study. We often are recruiting for new studies, would you like use to contact you for any future studies?
**IF Yes:** Would you prefer to be contacted via email or phone?

Text for Contact Information:
Name:
Cell Number:          okay to text: Yes/No  okay to leave message: Yes/No
Email:
Best Contact Method: email_____ call_____ text_____

**IF No:** Thank you again for your time!
Appendix D: Semi-Structured Interview Guide

Increasing Access to PrEP among Transgender Women and Trans Feminine Individuals

Semi-Structured Interview Guide

I. Introduction (ALL PARTICIPANTS)
   • The goal of this study is to gather information about the primary care, sexual health care experiences and needs of the transfeminine community. This interview will deal with 4 main areas, the general health care you currently receive, your sexual health, pre-exposure prophylaxis (PrEP) and provider communication (or how you want your doctor to talk to you).

II. QUESTIONS FOR PARTICIPANTS

Interviewer: The first set of questions focus on the types of health care you currently have access to and use, which may include primary care, sexual health, transition-related, non-western medicine/healing, mental health, and any other specialty care.

A. Health Care
   1. What types of health care do you currently use? (Probe different types of health care)
   2. Of the types of health care, you just mentioned, which do you use on a regular basis?
   3. In general, how would you describe the health care you receive? (Note: distinguish between regular care and any other care)
      a. What are the aspects that you consider positive?
      b. What are the aspects that you consider negative?
   4. In general, when looking for a provider, what are the 3 most important things you look for?
      a. In thinking of these three things, have you had to compromise on any of them regarding the care you get now?
   5. Tell me about the best experience you’ve had with a provider about your health.
      a. What made it good or affirming?
      b. What did the provider say?
   6. Tell me about the worst experience you’ve had with a provider about your health.
      a. What made it a negative experience?
      b. What did the provider say or do?
      c. What should the provider have said or done differently?
7. What was it like trying to find your current primary care provider?
   a. What were some the positives about this process?
   b. What were some of the negatives about this process
8. Can you describe the primary care that you currently receive, what does it include?
   a. How often do you see your primary care provider?
   b. How does your provider talk to you about your health, your body, your transition?
9. Is there health care you currently need or want, but can’t get? What is it and why?

**Interviewer:** The next set of questions deals more specifically with your sexual health. Much of the focus on HIV and trans* people is about risk behavior and disease prevention. Little if any information is available on sexuality, including sexual relationships and sexual experiences that are pleasurable, fulfilling, and safe (and by safe we mean free from pressure, discrimination, or violence). Instead of starting with a question about HIV risk, we’d first like you to describe your ideal sex life.

B. Sexual Health
1. Can you describe your ideal sex life?
2. Can you talk a little bit about your current sex life and the ways in which it is or isn’t like your ideal.
3. What role does HIV and other STI’s play in your sex life?
4. When was the last time you discussed your sexual health with a provider?
   a. Who brought it up? (If the participant brought it up) Was there a specific reason/issue that you wanted to address with your provider? (If provider brought it up) What did they say?
   b. How did that conversation go?
5. When was the last time a provider took a sexual history? What did they say?
6. What role do drugs and/or alcohol play in your sex life?
7. When was the last time you discussed your drug and/or alcohol use with a provider?
   a. Who brought it up? (If the participant brought it up) Was there a specific reason/issue that you wanted to address with your provider? (If provider brought it up) What did they say?
   b. How did that conversation go?
C. PrEP (if person is on PrEP skip to section D)

Interviewer: The next set of questions are about pre-exposure prophylaxis, which is often called PrEP or Truvada?

1. What have you heard about PrEP (pre-exposure prophylaxis or Truvada)?
2. What have you heard about PrEP? or about how it works?
3. Has a health care provider every talked to you about PrEP? If yes, what did they say?
4. If you were to consider taking PrEP, what would you want to know to help you decide whether or not to take it?

**Potential probes:**
- a. What types of things would you most want to know about PrEP?
- b. What things would be the biggest barriers to your considering PrEP?
- c. What do you think would be the ideal method or program for reaching trans* individuals who might want to take PrEP?

5. In general, how would you describe your thoughts and attitudes toward PrEP?

**Potential probes:**
- a. What are the aspects of PrEP that you consider positive?
- b. What are the aspects of PrEP that you consider negative?
- c. How do you think that your answers are similar or different from other trans* people you know?

6. Let’s say you decided to use PrEP. What do you think it would be like?

**Potential probes:**
- a. What do you think the best things about being on PrEP would be?
- b. What would be the worst things about being on PrEP?

7. One thing that will be really important for people who decide to take PrEP is that they remember to take the medication every day.

**Potential probes:**
- a. What do you think would be easy or difficult about remembering to take PrEP pills daily?
- b. What do you think would be most helpful in helping trans* people take PrEP daily?
- c. How could health care providers help with this process?
d. What do you think would be the biggest barrier to trans* people accessing this type of support?

8. If PrEP was available in an injectable/gel form would you be willing to get an injection every month, every 3 months or use a gel? [If yes]Can you say why? [If no] Are there any circumstances under which you would be willing?

D. Participants on PrEP only ask these questions if person is currently on PrEP (skip and go to Section E)

1. How long have you been taking PrEP?

2. How did you first hear about PrEP?

3. What do you know about PrEP or about how it works?

4. In general, how would you describe your thoughts and attitudes toward PrEP?

**Potential probes:**

a. What are the aspects of PrEP that you consider positive?

b. What are the aspects of PrEP that you consider negative?

c. How do you think that your answers are similar or different from other trans* folks you know?

5. When did you start taking PrEP? Why did you start?

6. When you were considering taking PrEP, what factors entered into that decision?

**Potential probes:**

a. What types of things did you most want to know about PrEP?

b. What things were the biggest barriers for you taking PrEP?

c. Who do you think would be the ideal candidate for PrEP?

d. What do you think is the ideal method or program for reaching trans* individuals who might want to take PrEP?

7. Since you’ve started taking PrEP, what has it been like?

**Potential probes:**

a. What are the best things about being on PrEP?

b. What are the worst things about being on PrEP?

8. One thing that will be really important for trans* people who decide to take PrEP is that they remember to take the medication every day.

   a. What has been easy or difficult about remembering to take PrEP pills daily?
b. What do you think would be most helpful in helping trans* people take PrEP daily?
c. How could health care providers help with this process?
d. What do you think would be the biggest barrier to trans* people accessing this type of support?

9. Do you openly talk about being on PrEP with friends, sexual partners? Why?

10. If PrEP was available in an injectable/gel form would you be willing to get an injection every month, every 3 months or use a gel? [If yes] Can you say why? [If no] Are there any circumstances under which you would be willing?

E. Provider Communication

**Interviewer:** One of the goals of this study is to get specific suggestions from transfeminine/trans women about how you would like providers to talk to you about your sexual health and the information you would like them to provide and the types of services you’d like that pertain to your sexual health.

1. How would you like your provider to talk to you about your body?
   a. What words do you want them to use?
   b. What questions would you want them to ask you?

2. How would you like your provider to talk to you about your sex life?
   a. What words do you want them to use?
   b. What questions would you want them to ask you?

3. What questions do you have about the process of transitioning that you would
   a. Ask a doctor
   b. Ask a friend
   c. Where do you currently go if you have a question? (website, support group…)
   d. Whose answers do you trust and why?

4. What sexual health services would you want providers to offer?

**Interviewer:** We’re almost at the end of the interview, just a couple more questions. We would like your input on where future research on transfeminine health care needs.

1. Thinking about your health care and sexual health needs right now, what are the 3 most important health care issues for you?
2. Thinking about trans fem community in general. What do you think are the 3 most important health care issues facing your community?

3. What are 3 ways you think trans women are strong given the struggles you go through.

4. Is there anything else you think we should’ve asked that we didn’t?

**Note**: This interview guide is designed to provide a basic structure and outline to the interview process. As qualitative interviews are designed to collect in-depth insights into participants’ particular attitudes and experiences, interviewers may need to ask clarification, follow-up, or other additional questions related to these topics in any particular interview.**
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