

GENDERED POWER AND HEALTHCARE ACCESS: A PARTICIPATORY STUDY WITH
TRANSGENDER AND GENDER DIVERSE YOUTH

By

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ABSTRACT

GENDERED POWER AND HEALTHCARE ACCESS: A PARTICIPATORY STUDY WITH TRANSGENDER AND GENDER DIVERSE YOUTH

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Systemic oppression of transgender and gender diverse (TGD) individuals is fueled by societal stigmas derived from normative perspectives on sex and gender (Sevelius, 2013; Testa et al., 2012). Prior research indicates that the marginalized status of TGD youth may negatively impact their health and healthcare access (Hendricks & Testa, 2012). Overcoming barriers to equitable healthcare access for TGD youth requires an awareness of the oppressive power structures that impede their well-being and ability to flourish. Researchers have inadequately studied the manner in which gender shapes TGD youth's ability to seek out needed healthcare services safely and on how gender-based oppression impacts TGD youth's health and well-being told from youth's perspectives.

Using Walker and Pratto's (2004) theory of gendered power and a sequential mixed-methods participatory design, I collaborated with a TGD youth research and advisory team to explore gendered power and healthcare access in two unique samples of TGD youth. I intentionally used a participatory approach because researchers have historically excluded youth's perspectives on their social and structural marginalization and its impact on access to healthcare. Findings revealed a framework of gendered power composed of three distinct mechanisms that limited youth's power over their gender expression and identity. The framework's restrictive mechanisms—gatekeeping, violent control, and reification of heteropatriarchy—mirror extant theory on gender and power. These mechanisms of control were enacted differently than in the

case of cisgender women on whom prior theories were developed. Restrictive mechanisms of power also impacted youth's willingness to engage with and have confidence in healthcare providers. Further, among the sample of TGD youth living with HIV (n=28), I found the restrictive mechanisms of gendered power undermined TGD youth's steady engagement in HIV care, despite also finding that HIV care was the sole source of affirmation within medical environments. Mechanisms operated differently as a function of youth's age, race, gender identity, gender presentation, and socio-economic status. Finally, we identified restorative mechanisms for reclaiming control of and enacting autonomy over identity (e.g., educating and advocating for rights, lifting up the self and the TGD community, disrupting power imbalances, enacting physical expression).

The findings from this research provide an empirically based theoretical framework of gendered power that is developmentally appropriate for TGD youth. This study also underscores the importance of theories of gendered power in understanding healthcare access and general well-being among TGD youth. The results suggest the need to support youth reclamation of gendered power at individual interpersonal, and community levels. Findings also point to policy and practice interventions that would promote TGD youth's engagement in care, including revised medical training curriculum for practitioners of family medicine, pediatrics, and reproductive health on gender diversity and affirming TGD care. Finally, results highlight the need for gender affirming policies within youth-serving institutions that promote the validation, inclusion, and safety of TGD youth.

Keywords: transgender, gender diverse, gender-nonconforming, youth, power, gendered power

This dissertation is dedicated to transgender and gender diverse youth.
To those who were silenced.
To those who were taken from us.
And to those whose voices made this all possible.

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Finally, thank you to transgender and gender diverse youth. Every single one of you. Your voice, your courage, and your power have changed my life. I am in awe of your strength. Thank you.

PREFACE

Positioning the self: Author's letter to the Reader

Dear reader,

Welcome! I am choosing to begin this dissertation with a reflexivity letter wherein I critically examine my positionality in this project. I feel it is important that I discuss how I came to this research and my struggle with taking on this project prior to you engaging with the content.

Although I understand that this is not the norm for an academic document in Psychology, I am intentionally breaking that norm. I hope you will still welcome it.

A couple of years ago, I was put in contact with a colleague to discuss the potential of using their data for my dissertation. Their team had conducted a fantastic transformative mixed methods project with transgender and gender diverse youth (TGD) and they were interested in getting more of the data analyzed and disseminated. I was immediately interested. I felt incredibly humbled that they entrusted me with this project, but also terrified because I felt I was the wrong person to take it on given my lack of personal and professional experience with TGD youth.

Aware of the current state of TGD youth research, I knew this work was needed and important, but I recognized that a non-cisgender individual may be better suited to do this work. However, upon much reflection and after multiple conversations with colleagues, I realized that expecting all TGD youth research to come from TGD researchers is unreasonable and not a valid excuse to avoid taking on this project. Failing to take on this project because of my own personal fear, discomfort, and ignorance would contribute to the ongoing epistemic exclusion of TGD youth in psychology, and specifically community psychology research. Further, it could continue to deny

TGD youth their right to research that is representative of their experiences. In the end, I said 'yes' and hoped my discomfort would drive my desire to make sure the project was done right.

As a queer, White, cisgender, settler, woman, I believe equitable, intentional, and reflexive collaboration and communication with community members as co-researchers and advisors is an essential step to conduct research in an ethical and valid way. Therefore, I spent many of the first months of this dissertation reviewing what research was available, readings memoirs and novels about/written by TGD individuals, attending local functions and talks, and seeking out any knowledge I could on the topic from the community. Although I still have so much to learn, engaging with members of the community for so long before beginning the project was an important step for me to be able to write this proposal. These steps are not in my methods, nor are many of these readings cited in academic literature. Consequently, throughout the literature review I intentionally chose to interweave quotes, comments, and theorizing from writers, scholars and thinkers who are representative of this population and their experiences.

Furthermore, as a community psychologist, I believe research should be collaborative and community engaged. I often find myself working on large research teams made up of many different people who all bring different skills and knowledge to the table. Because this was a dissertation, I quickly found myself uncomfortably isolated in my work. I was working in a new content area, and I was delving into a very important, understudied and often unethically studied topic. In response, I recruited a Research and Advisory team made up of local TGD youth before I even wrote a word of this dissertation. Although I understand that dissertations are generally meant to be a relatively solo-researcher activity, it seemed unethical for me to wait until after my proposal to seek insight, advice, and critique from folks much more connected to these topics.

The members of the Research and Advisory Team have been instrumental to many of the ideas behind this project and I want to personally thank Ash Boss, Erika Promislow, Ethan Dawson, and Reid Ellefson-Frank for all their advice, insight, laughter, and support during this dissertation's design.

*Finally, although I engaged in a participatory approach to designing this project, I still wrestled with whether this was the safest approach for a community that has been historically mistreated by researchers. Even with participatory research, sometimes the benefits to the researcher do not equal the benefits to the participants or community advisers. Given this, I'd like to **again** thank the Research and Advisory Team for: 1) engaging in critical discussions about these issues with me, 2) understanding that my need for their collaboration was sometimes selfish, and 3) being willing to work to make the space a place where they too felt they were benefiting from their involvement.*

Keeping in mind all that I disclosed, I hope you will take this dissertation in with a critical and curious eye.

*Sincerely,
Dani*

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INTRODUCTION

“The history of transgender and gender nonconforming people in the United States is one of struggle, but also of self-determination and community building”

-Genny Beemyn, Trans Bodies, Trans Selves, p. 359

Throughout recent history, the transgender and gender diverse (TGD) community has made incredible effort to increase visibility about the lives and experiences of TGD people. Many of these efforts have been led by courageous TGD youth striving for rights, representation, and equality. Nevertheless, discrimination, violence, and stigma persist, wreaking havoc on the health, safety and wellbeing of the TGD community, especially youth (Grant, Mottet, Tanis, Harrison, Herman & Keisling, 2011; World Health Organization [WHO], 2015). TGD youth remain one of the most marginalized groups in the United States. From lack of policies and protections to little or no access to information and resources, our country has undeniably hindered progressive efforts for TGD people. Today, hate and bigotry contribute to the horrific rates of discrimination and violence committed against TGD people and the exclusion and erasure of TGD people from research, theory, policies, and programming (Bauer, Hammond, Travers, Kaay, Hohenadel & Boyce, 2009; Grant et al., 2011). The continual mistreatment of TGD youth signals the ongoing need for positive social change efforts in every social setting and broader society (Grant et al., 2011; WHO, 2015).

A key component of any social change effort involves addressing oppressive power structures that fuel inequality. Although there are several different conceptions of power, in community psychology, power is most often defined as an individual's sense of personal influence and their ability and opportunities to influence a course of events (Prilletensky, 2008; Speer & Hughey, 1995; Serrano-Garcia, 1994). In this way, power lies at the root of the hierarchies within society that perpetuate discrimination, engender stigma, and encourage

exclusion. To dismantle powerful systems, we must understand how power operates and how power is exercised to limit, control, or liberate TGD youth.

With these studies, I sought to move scholarly research a small step closer to the trailblazing work of TGD activists by exploring the gendered nature of power among TGD youth. Gendered power refers to the way in which gender impacts an individuals' sense of personal influence to access resources and make decisions (Prillettensky, 2008; Walker & Pratto, 2004).

Some of the most pressing needs facing TGD youth center on health, wellbeing, and access to quality care and services, particularly among TGD youth living with HIV. The healthcare system, thus, serves as a necessary and salient arena in which to explore these issues. A secondary, yet equally important aim of this dissertation was to increase visibility of TGD youth and TGD issues in scholarly research, highlighting the ways in which TGD individuals have been epistemically excluded from academic health research. Accordingly, with this dissertation, I supported the participation, voice, and engagement of TGD youth at every stage of the research process by convening a team of TGD students to serve as co-researchers and advisers throughout the entirety of the project (hereafter referred to as the Research and Advisory Team).

Given the exploratory nature and complexity of the topic, this dissertation is divided into two studies (Study A and Study B). Both studies were guided by Walker and Pratto's (2004) theory of gendered power. Each study investigated different aspects of gendered power and healthcare access among TGD youth. The purpose of Study A was to gain youth's opinion and interpretation of gendered power using participatory focus group data collection and analysis. More specifically, with Study A, I aimed to understand how youth define and discuss gendered

power in the context of their experiences and how, if at all, gendered power influences healthcare access. The purpose of Study B was to explore how gendered power is manifested in discussions about accessing HIV prevention and care services using a secondary dataset.

CHAPTER 1: LITERATURE REVIEW

To set the stage for this dissertation, I begin with a broad overview of TGD terminology and the current state of the research on TGD youth. Subsequently, I review what we know about TGD from current literature and why basic knowledge on TGD youth is lacking. Next, I review relevant literature pertaining to health, wellbeing, and healthcare access for TGD youth. I then introduce Walker & Pratto's (2004) theory of gendered power as a preliminary framework for understanding TGD youth's health and healthcare access. Finally, I outline the specific research aims and objectives.

“Gender is over – if you want it.” (If You Want It, LTD, 2019)

Terminology

Gender terminology is constantly evolving and is therefore important to discuss before beginning this literature review. The term cis or cisgender refers to individuals whose current identity aligns with the sex they were assigned at birth (National LGBT Health Education Center [National LGBT], 2017). The term “TGD” will be used to encompass all individuals whose gender identity or expression does not align with the sex they were assigned at birth (Adams, 2015; National LGBT, 2017). This umbrella term includes transgender women, transgender men, trans* people, as well as gender nonbinary, gender nonconforming, genderfluid, agender, polygender, two-spirit, bigender, and genderqueer individuals (National LGBT, 2017).

How we identify and express our genders has moved beyond the traditional binary and heteropatriarchal system (Harris, 2010; Valdes, 1995; West & Zimmerman, 1987). Some TGD people may operate within the binary gender paradigm (e.g., boy/man, girl/woman, transgender man, transgender woman). Others may describe their gender as fluid or not ascribe to the system

of gender at all (e.g., genderqueer, gender fluid, agender, non-binary, poly gender, bigender, gender nonconforming) (Clark, Veale, Townsend, Frohard-Dourlent, & Saewyc, 2018; Frohard-Dourlent, Dobson, Doull, Saewyc, & Clark, 2017). Furthermore, some conceptions of gender are rooted in individual history or spirituality rather than the heteropatriarchal binary imposed during colonization (e.g., two-spirit) (Deschamps & 2-Spirited People of the 1st Nations, 1998; Driskill, 2004; Morgensen, 2010; Thomas & Jacobs 1999). For more information on TGD terminology please see the linked [guide](#) (National LGBT, 2017).

“Masculine and feminine roles are not biologically fixed, but socially constructed”

-Judith Butler, 2011, pg. NA.

TGD youth in a Heteropatriarchal Society

Our sex assigned at birth does not always determine our individual gender identity and expression, and therefore our gender should not be assumed. Gender is complicated, not static, and most importantly, gender is diverse (Beauvoir, 1972; Ellis, McNeil & Bailey 2014). More and more rapidly, society is accepting that normative binary conceptions of gender (e.g., boy/man; girl/woman) no longer reflect the experience of all people. These societal changes can be observed in efforts to change programming and policies to reflect a more pluralistic understanding of gender (e.g., all-gender bathrooms; gender discrimination protections; research with non-binary individuals). However, pluralistic conceptions of gender are by no means how a majority of people in the United States view gender. Despite progress some communities have made in accepting policies that reflect a non-binary understanding of gender, cultural norms in this country are governed by colonial systems of heteropatriarchy. Heteropatriarchy is a sociopolitical system that defines gender as binary based on sex and asserts men’s dominance over women (Harris, 2011; Valdes & Queers, 1995). With the emergence of queer and feminist

theory, heteropatriarchy continues to reinforce and reassert heterosexual, cisgender and masculine dominance (Harris, 2011).

Heteropatriarchy serves as a system of gender-based oppression that is woven into our society and its basic organization. Most families, schools, and institutions across the nation still impose binary and heteropatriarchal expectations on youth. Developmentally, youth and adolescence are critical periods of identity formation, intellectual transitions, and development wherein young people are expected to question and explore their identities (Erikson, 1968). Imposing binary expectations about gender sends a message that gender is not an identity to be explored. The assumption that a young person unquestionably identifies with the sex they were assigned at birth forces TGD people to fit into a predetermined set of customs, norms, and expectations that may be discordant with their self-conception and self-expression. Consequently, TGD youth often report confusion, fear, rejection, and shame as a result of trying to conform to the dominant societal gender standards (Grossman & D'Augelli, 2006; McCann, Keogh, Doyle & Coyne, 2017; Reisner, Greytak, Parsons & Ybarra, 2015). Additionally, these beliefs may influence the assumptions of people who interact with TGD youth, policies that govern TGD youth's rights, and research about TGD youth, sometimes in harmful ways. This next section discusses how heteropatriarchal assumptions have influenced TGD youth's power and decision making through the control of academic research and developing knowledge of TGD youth's needs and experiences.

TGD youth in Academic Research

Research about or specifically inclusive of TGD youth and their experiences is limited (Reisner et al., 2016). To illustrate, a recent systematic review of articles focused on TGD youth health published between 2006 and 2016 yielded only 20 papers (McCann, Keogh, Doyle &

Coyne, 2017). This is critically important to the interpretation of current research about TGD individuals. When researchers make TGD gender identities invisible, either through exclusion or lack of authentic participation, we take away TGD youth's power. Historically, TGD people have been systematically erased or excluded from research (Adams et al., 2017; Bauer et al., 2009). Researchers maintain exclusionary practices through failing to collect and use gender identity information, privileging binary gender conceptions, conflating gender identity and sexual orientation, recruiting and sampling inappropriately, and failing to employ participatory approaches to TGD research. Failure to include TGD individuals in academic research in an authentic and ethical way thwarts many TGD people from participating in research studies and restricts the knowledge, resources, opportunities, and decision-making power available to TGD youth (Baril & Trevenen, 2014; Mustanski, 2015).

‘Nothing about us without us’

An alarming majority of researchers, particularly health researchers, still operate within binary and heteropatriarchal assumptions of gender, where sex assigned at birth and current gender identity unequivocally match. As a result, research surveys mirror this assumption by only permitting participants to select “male” or “female” as their gender (Arbeit, Fisher, Macapagal & Mustanski, 2016; Coleman et al., 2011; Krieger, 2003). This act invalidates TGD individual's gender identity and may also discourage them from participating in research. As a result, the current number of TGD youth living in the United States is nearly impossible to estimate (Bauer, 2009; Frohard-Dourlent et al., 2017; Shultz, 2015). These exclusions limit our understanding of the strengths, needs, and experiences of TGD people and bleed into current societal norms (Frohard-Dourlent et al., 2017; Halberstam, 1998;). In the United States, a two-question approach to collecting sex and gender identity information is now recommended in research. (Sausa, Sevelius, Keatley, Iñiguez, & Reyes, 2009; Tate, Ledbetter & Youssef, 2013;

The Williams Institute, 2014;). The two-question approach first asks the respondent to disclose the sex they were assigned at birth and then follows up with a question about their current gender identity. This approach captures the differences between sex and gender. However, simply because a survey collects the correct gender information from a participant does not ensure that that information will be handled with the care and concern it deserves. Researchers tend to privilege binary experiences of gender and in doing so may force specific options to be selected for gender identity that may not align with the participants' self-conception (e.g., not offering options for nonbinary gender identity selection) (Ansara & Hegarty, 2014; Beemyn, 2015; Nicolazzo, 2014; Rankin & Beemyn, 2012). Broad categorizations of "transgender" do not always acknowledge subgroup identities or identities that align with more than one category. To illustrate, one study reported that approximately 25-35% of individuals who marked "transgender" as an option actually identified as gender diverse or more than one category and about 1-2% of individuals who marked "male" or "female" actually identified as gender diverse (Barr, Budge, & Andelson, 2016; James et al., 2016; Mikalson, Pardo, & Green, 2012). As a result, privileging binary conceptions of gender has contributed to a lack of complex understanding of the lives and experiences of TGD people.

After data collection, researchers may choose to aggregate TGD people into larger, oftentimes binary, categories of gender. The basis for how they chose to aggregate is rarely reported (e.g., based on birth sex, based on current gender identity, based on current gender expression) (Arbeit et al., 2016). Other researchers may choose to exclude TGD participants from recruitment, sampling or analyses all together. Finally, many studies inappropriately conflate sexual orientation and gender identity (Bauer et al., 2009; Koegh et al., 2006). Researchers commonly report conducting research with "LGBT youth," yet what they really

have is a population of non-heterosexual participants about whom they have limited information on gender identity. For example, in a review LGBT-related articles, only 2.6% were specifically focused on TGD people (Snyder, 2011).

Taken together, the epistemic exclusion of TGD youth perpetuates incomplete and inaccurate narratives about the lives of TGD youth. Exclusionary research communicates that TGD individuals' unique experiences do not matter enough to be explored. Academic research has the power to influence policy, programming, and even social norms. Research that excludes the unique experiences of TGD youth can disempower by misinforming policy and programming that perpetuates exclusionary practices (Bauer, 2009; Frohard-Dourlent et al., 2017; Shultz, 2015). Given that this dissertation centers around the ways in which people and systems wield power in harmful ways, it is crucial that readers of a review of TGD research be informed of the ways exclusionary research practices affect our understanding of TGD youth experiences, particularly within health settings.

"I believe that telling our stories, first to ourselves and then to one another and the world, is a revolutionary act. It is an act that can be met with hostility, exclusion, and violence. It can also lead to love, understanding, transcendence, and community."

-Janet Mock, *Redefining Realness*

Health Disparities among TGD Youth

TGD people remain one of the most marginalized groups in the United States. Emerging research increasingly suggests that the marginalization of TGD people is largely fueled by societal stigmas derived from normative perspectives on sex and gender (Hendricks & Testa, 2012; Sevelius, 2013; Testa et al., 2012). TGD individuals are perceived as transgressing the socially expected gender binary. As such, TGD people are ridiculed, rejected, and oppressed. (Adams, 2015; Bockting, 1999; Johns et al., 2019). The National Center for Transgender Equality and the National Gay and Lesbian Taskforce conducted the first national study of

discrimination among 6,450 TGD adolescents, youth, and adults [National Discrimination Report] (Grant et al., 2011). In this report, 78% of TGD respondents reported experiences of verbal harassment and 35% of respondents disclosed physical assault prompted by their gender identity. Oftentimes, discrimination and harassment of TGD youth occurs across settings specifically designed to keep youth safe (e.g., schools, hospitals, homes) (Winter et al., 2016).

As is the case for other social minorities, refusal of the majority to understand, acknowledge, and accept TGD persons breeds widespread hate and oppression across several ecological levels (Freire, 1996; Young, 2004). Oppression, in turn, contributes to compounding social and structural stressors which may negatively impact an individual's health (Bockting, Miner, Romine, Hamilton & Coleman, 2013; Clements-Nolle et al., 2006; Grant, 2011; Hendricks & Testa, 2012; Meyer, 2003; Nemoto et al., 2011; Reisner et al., 2014; Sevelius, 2013; Testa et al., 2012). As a result of persistent social stressors, TGD youth bear a disproportionate risk for a wide range of negative mental physical, and sexual health outcomes (Poteat, German & Kerrigan, 2013; Reisner et al., 2016; Winter et al., 2016). In a recent systematic review, Reisner and colleagues (2016) synthesized research studies pertinent to TGD youth health from 2008 to 2014. This review identified inequality among TGD youth in the areas of mental health, substance use, homelessness, and sexual and reproductive health.

Mental health. TGD people are significantly more likely to present with mental health difficulties than their cisgender counterparts (Reisner et al., 2016). Rates of completed or attempted suicide among TGD people compared to cisgender people demonstrate this stark contrast (Pritchard, 2013). Approximately 41% of TGD respondents reported attempted suicide compared to only 1.6% of the general population (Grant et al., 2011; Reardon, 2016; Poteat, German & Kerrigan, 2013; Winter et al., 2016). Furthermore, TGD youth are at a very high risk

for serious mental distress, with many studies reporting alarmingly high rates of depression, anxiety, and self-harming thoughts and behaviors (McCann & Sharek, 2016; McDermott, Hughes & Rawlins, 2016; Reisner et al., 2015; Veale et al., 2016). TGD youth face substantial barriers to accessing adequate and gender affirming mental healthcare, which further exacerbates health concerns (McCann, Keogh, Doyle & Coyne, 2017; Puckett et al., 2018).

Substance use and housing instability. Substance use is incredibly prevalent among TGD youth (Flentje, Heck, & Sorensen, 2014). Again, although we lack surveillance data on TGD youth, community-based convenience samples demonstrate higher rates of alcohol use, marijuana use, and other illicit drugs among this population when compared to cisgender youth of the same age (Garofalo, Deleon, Osmer, Doll & Harper, 2006; Reisner, Greytak, Parsons & Ybarra, 2015). Research suggests high rates of substance use may be in response to serious life stressors often present in the lives of TGD youth (Hotton, Farofalo, Kuhns & Johnson, 2013; Singh, 2013). Stressors such as family rejection, discrimination, and violence lead many TGD youth to live on the streets or in unstable living environments, often highly correlated with substance use (Clements-Nolle et al., 2001; Shelton, 2016; Wilson et al., 2009). Similarly, recent studies suggest that substance use often serves as a coping mechanism for stigma and gender minority stressors (Hotton, et al., 2013; Reisner, Pardo, Gamarel, Hughto, Pardee & Keo-Meier, 2015).

Housing instability is especially prevalent among TGD youth, particularly among transgender women (Garofalo et al., 2006; McCann & Brown, 2019; Shelton, 2016). Although no exact prevalence statistics exist for homelessness among TGD youth, 19% of TGD adults report at least one instance of homelessness in their lifetime (National Coalition for the Homelessness, 2017). A recent survey suggests TGD youth make up the majority of homeless youth in the

United States (Whitbeck et al., 2016). As a result of limited access to housing and stable employment, TGD youth may turn to survival sex as to sustain basic needs (Grant et al., 2011).

Sexual and reproductive health. In Reisner and colleagues' (2016) review of health inequalities among TGD youth, sexual and reproductive health emerged as major concern. Among transgender men and other gender diverse youth, there are very few studies examining reproductive health needs (Wanta & Unger, 2017). Two recent studies suggest transmasculine individuals access gynecological care at a significantly lower rate than cisgender women (Peitzmeier, Khullar, Reisner & Potter, 2014; Tabacac, Sutter, Wall & Baker, 2018). Also, TGD youth who wish to pursue gender affirming healthcare procedures—medical procedures that aim to align an individual's body with their gender identity— may have additional medical concerns related to their transition that require specific and compassionate care (James et al., 2016; Puckett, Cleary, Rossman, Mustanski & Newcomb, 2018).

HIV/AIDS. HIV and AIDS remain one of the most pressing health risks for TGD youth in this country, particularly for young transgender women of color (Baral et al., 2013; CDC, 2019; WHO, 2015). Due to a lack of systemic collection on sex and gender identity in health records, the exact prevalence of HIV among TGD populations remains difficult to estimate. In a national surveillance system study, Clark and colleagues (2017) found that one in three transgender women diagnosed with HIV were between the ages of 13 and 24, indicating the serious impact of HIV on transgender youth. Even less information is available on young transgender men, although recent research documents high-risk sexual behaviors among this population are common (Scheim, Bauer & Travers, 2017; Stephens, Bernstein, & Philip, 2011). Virtually no research exists that specifically looks at HIV rates among other gender diverse youth (e.g., genderqueer, gender non-conforming, agender, nonbinary) (Sausa, Sevelius, Keatley,

Iniguez & Reyes, 2018). As a result, there is a significant gap in our understanding of the social and structural HIV risk factors for TGD youth.

HIV requires consistent engagement with healthcare providers and healthcare systems to maintain health and reduce the likelihood of further transmission of the virus (Gardner et al., 2011). After receiving a reactive HIV test, timely linkage to HIV healthcare is crucial, and directly impacts long-term health and engagement outcomes (Hall, Tang, Westfall & Mugavero, 2013; Torian et al., 2008). Following linkage to care, individuals should gain access to and receive regular HIV-related healthcare, including receipt of and adherence to antiretroviral therapy. At this point, patients should be regularly monitored by HIV-specific physicians and receive treatment regimens. If an individual is adherent to treatment regimens, the patient achieves viral suppression. Achievement of viral suppression renders the virus untransmittable to others and reduces individual's risk of mortality and disease progression¹ (Cheever, 2007; Stephenson, 2005). Active engagement in HIV care has many important individual and community health outcomes (Mugavero, Amico, Horn & Thompson, 2013). Yet, despite positive outcomes associated with consistent engagement in HIV prevention and care, youth are less likely to engage in HIV care consistently when compared to any other subgroup due to many insurmountable challenges (Hall et al., 2012; Philbin et al., 2014; Zandoni & Mayer, 2014). For TGD youth these barriers may be exacerbated by social and structural stressors stemming from gender-based stigma and oppression.

Overall, TGD youth often have significant health needs that require consistent interactions with healthcare systems, services, and providers. These needs signal the importance

¹ For more in-depth definitions of HIV/AIDS related terms beyond the scope of this dissertation please see the linked [glossary](#) (AVERT, 2019; UNAIDS, 2015; US Department of Health and Human Services, 2018).

of studying the accessibility and utilization of healthcare resources for TGD youth (Rahman, Li & Moskowitz, 2018; Rider et al., 2018).

Healthcare Access Challenges

Previous literature has established that predisposing factors (e.g., age, race/ethnicity, mental health) and individual-level factors (e.g., fear, stigma, knowledge) make healthcare access more challenging (Denno et al., 2012; Kurth et al., 2015; Macapagal, Bhatia & Greene, 2016; Mugavero et al., 2013). Recently, more work has explored how extra-individual factors may also impact access to care in unique or compounding ways. Findings from these bodies of work suggest that youth face several extra-individual challenges to accessing and utilizing various healthcare services successfully. Broadly, these challenges can be categorized into accessibility issues (e.g., cost, transportation, service hours), service delivery issues (e.g., youth unfriendly services, stigma, fear), interpersonal issues (e.g., patient-provider relationships, lack of social support, rejection or fear of rejection), healthcare navigation (e.g., health insurance and benefits, health system navigation), and basic survival needs (e.g., housing, food, employment) (Chiaramonte et al., 2018; Doshi et al., 2011; Philbin et al., 2014; Rahman, Li & Moskowitz, 2019; Remien et al., 2015; Rider et al., 2018; Tanner et al., 2014).

Fewer studies, however, have focused specifically on TGD youth. The limited literature examining TGD individuals more broadly finds that in addition to the aforementioned barriers, TGD populations face compounding challenges as a result of gender-based discrimination. For example, although money for transportation may be a prominent barrier for the general youth population, among TGD individuals that barrier is compounded by the fear of gender-based harassment or violence in public transportation (Cicero et al., 2019; Goldberg et al., 2019; Hendricks & Testa, 2012; Reisner et al., 2015). In healthcare settings, binary notions of gender are overwhelmingly normalized, forcing TGD youth to interact with people and systems that do

not understand, acknowledge, or accept TGD individuals. As a result, TGD individuals report extreme amounts of shame, fear, rejection, and avoidance (Bockting, Miner, Swinburne Romine, Hamilton, & Coleman, 2013; Grossman & D'Augelli, 2006; Lykens, LeBlanc, & Bockting, 2018; Reisner et al., 2015). Successfully navigating the systems necessary to get the resources and care needed to be healthy is particularly challenging for youth (Kaufman, Pinzon, Canadian Pediatric Society, & Adolescent Health Committee, 2007). This is often a result of young people attempting to navigate complicated systems meant for adults. For TGD youth, navigating healthcare systems may be further complicated by cis-normativity or the belief that gender is binary and unquestionably tied to birth sex (Bauer et al., 2009). Cis-normativity within systems creates spaces where TGD youth feel invisible, invalidated and unsafe. Further, cis-normative systems often require TGD individuals to self-advocate for their rights and educate others working within the system (Clark et al., 2014; Veale et al., 2015; Frohard-Dourlent, 2018). Finally, access to basic survival needs is commonly reported to take precedence over healthcare access for youth living with HIV (Chiaramonte et al., 2018; Philbin et al., 2014). For TGD youth of color living with HIV, unemployment, dropping out of school, survival sex, and homelessness are tremendously prevalent suggesting that this barrier to care may be uniquely intensified for TGD youth.

Overall, evidence suggests TGD youth face numerous challenges navigating complex cis-normative and adult-centric health and social systems, oftentimes with very little support (Gridely et al., 2016; Rider, McMorris, Gower, Coleman, & Eisenberg, 2018; Singh, Meng & Hansen, 2013; Wilson Chen, Arayasirikul, Wenzel, & Raymond, 2015). To improve healthcare access for TGD youth, we must understand how gender shapes TGD youth's ability to seek out needed healthcare services safely. A gendered power perspective allows for a nuanced view of

healthcare access among TGD youth wherein the steady influence of gender-based stigma and heteropatriarchal systems of oppression are elucidated. Given the nascency of this research area, we have only gathered a basic understanding of the different barriers facing TGD youth healthcare access. We have yet to explore underlying mechanisms such as gendered power that may exacerbate or compound existing healthcare access challenges for TGD youth.

Gendered Power

Among cisgender female populations, health inequities are increasingly framed through the lens of gendered power and powerlessness. Among cisgender women, theories of gendered power have been used to explain underlying mechanisms of STI and HIV risk, exposure to violence, and general health outcomes (Amaro & Anita, 2000; Chiaramonte et al., 2020; Connell, 2013; Gutierrez, 1990; McCauley et al., 2019; Rosenthal & Levy, 2010; Pulerwitz, Amaro, DeJong, Gortmaker & Rudd, 2002; Wingood & DiClemente, 2000). Evidence from such studies suggest that gender norms, cultural practices, policies, economic factors, and institutional practices collectively contribute to and perpetuate unequal power relations between women and men. These unequal power relations coerce women into risky behaviors and put cisgender women at a higher risk for negative health outcomes such as HIV and STIs. For example, in Rosenthal and Levy's application of gendered power to study HIV risk, they discuss how violence or threat of violence during sexual encounters renders cis-women powerless to negotiate condom use or safer sex (Rosenthal & Levy, 2002).

Current theories of gendered power are based on normative and binary perceptions of gender, assuming alignment of birth sex and gender behavior and identification. These theories are oriented toward cisgender (often White and heterosexual) women, grounded in the notion that women hold unequal status relative to men in a patriarchal world. No research to date has applied a gendered power framing to issues of healthcare access among TGD youth. Interactions

between TGD youth and their healthcare providers and social systems more broadly occur within a social structure where non-minority groups have less power. TGD people disrupt the normative societal expectations and hegemonic narratives we expect for gender, and, as a result, disrupt our current views of gendered power (Bockting, 1999; de Vries, 2015).

Walker and Pratto's (2004) theory of gendered power offers a helpful framework to organize the different factors that may affect gendered power among TGD youth. Their conception of gendered power is rooted within social dominance theory, which posits that societies are organized into hierarchies based on group memberships and social categories (Sidanius & Pratto, 2003). Groups at the top of the hierarchy enjoy a disproportionate share of resources and opportunity, while groups at the bottom of the hierarchy face marginalization, discrimination, and less access to resources and opportunity (Sidanius & Pratto, 2003). Specifically, Walker and Pratto theorized that there are four mechanisms of gendered power that work to maintain inequality: 1) shared cultural beliefs about gender; 2) allocation and control of resources; 3) violence and force; and 4) obligations to social systems.

This dissertation uses Walker and Pratto's (2004) theory to conceptualize gendered power as the way in which gender impacts an individual's sense of personal influence to access resources or make decisions in their life. As such gendered power is maintained through relationships, institutions, policies, and societal norms (Connell, 2013; Walker & Pratto, 2004). In the context of healthcare access, gendered power is the degree to which the ability or opportunity to seek out or engage with healthcare services are enabled or inhibited because of an individual's gender. To illustrate, in healthcare settings, failure to provide healthcare that is medically accurate and accessible services to TGD youth *specifically* because of their gender identity, drastically reduces the power TGD youth have over decisions regarding their health.

Alternatively, providing care that is inclusive, affirming, and educational creates opportunities for TGD youth to make informed decisions about their health and body (Sevelius, 2013). In this way, a gendered power framing in studies of healthcare access may be beneficial in understanding challenges TGD youth face to staying safe and healthy.

Walker and Pratto's (2004) initial conceptualization is not without its limitations. Namely, although this is a novel interpretation of gendered power, it still fails to conceptualize gender in a contemporary way. As such, I expect gendered power among TGD youth may differ from Walker & Pratto's (2004) conceptualization. Therefore, in this dissertation, the Walker & Pratto's theory serves as a preliminary foundation for the application of a framework to healthcare access that future work with TGD youth can build upon. Finally, another key limitation of this framework is the failure to explore critically the intersection of other social identities with gender. As such, in addition to exploring how gendered power functions to oppress TGD youth, this dissertation will also take note of how minority racial or ethnic identities intersect with minority gender identities to impact gendered power. The next section briefly defines each of the four mechanisms of gendered power, describes how these concepts may or may not apply to TGD youth broadly, and then discusses how mechanisms may be related to TGD healthcare access.

"It's easy to fictionalize an issue when you're not aware of the many ways in which you are privileged by it."

— Kate Bornstein, 2019, pg. 86

Consensual ideologies. The first mechanism of gendered power centers around shared cultural beliefs about gender roles, norms, and stereotypes (Walker & Pratto, 2004). Consensual ideologies dictate how people should behave, what they should desire, how violators of such ideologies should be sanctioned, and how resources should be allocated (Sidanius & Pratto,

2003). Judith Butler famously argued that gender is performative (1990). Butler explains that we take on the role that is expected of us (e.g., through acting, speaking, dressing) and this performance produces a series of effects in several aspects of our lives (Butler, 1996, 1990, 2002; West & Fenstermaker, 1995). As such, gender performances only create individual-level expectations and behaviors and may impact social and institutional level opportunities. Traditional gendered expectations and their corresponding social obligations constrain the ability for individuals to make decisions about their body, their work, their relationships, and self-expression. Many argue that these policed gender norms allow for the maintenance of power hierarchies (Connell, 1987; Pratto & Walker, 2004).

In their original conception of the theory, Walker and Pratto (2004) discussed how gender stereotypes about cisgender women (e.g., warm, loving, and passive caretakers) and cisgender men (e.g., strong, intelligent, and confident leaders) legitimize gendered power imbalances in the home, workplace, and over women's bodies (Cejka & Eagly, 1999; Eagly, Wood, & Johannesen-Schmidt, 2004). Beliefs and stereotypes about TGD individuals may similarly work to oppress, and in some cases, liberate TGD youth. TGD people are often stereotyped as highly sexual or pathologized as disordered (Ansara & Hegarty, 2012; Betcher 2013). These stereotypes may legitimize those behaviors for TGD individuals, and as a result, expose them to undue risk or harm. Moreover, members of society may reject the very notion of a TGD individual, unable to conceive of TGD people's existence in the world. These ideologies may be used to prohibit a trans woman from using a women's locker room or restroom, staying in a women's shelter, and affect how they are treated within our government-run systems (e.g., criminal justice, foster care) (Mountz, Sarah, Capous-Desyllas, Pourciau, 2019). Conversely, some TGD people may use normative gender ideologies as a guide for how to (or how not to) express themselves in their

current gender identity, particularly if they identify within the binary. For example, in her book, *Gender Outlaw: On men women and the rest of us*, Kate Bornstein, discusses how she used gender norms to “pass” as a woman during the early stages of her transition. She says: “*As a part of learning to pass as a woman, I was taught to avoid eye contact with walking down the street; that looking someone in the eye was a male cue.*” (1994 p. 33). In this way, binary transgender women may experience similar power imbalances as cisgender women.

Within the context of healthcare access, medical providers may maintain beliefs about TGD people that can impact healthcare access of TGD youth. Healthcare providers are viewed as experts on an individual’s health and therefore are in a position of power over their patients. As such, providers have a unique role in affirming or invalidating an individual’s gender.

Acceptance, respect, and affirmation of TGD individuals is related to better engagement in healthcare services (Harper et al., 2019; Sevelius, 2013). Gender affirmation is the process of affirming an individual’s gender identity, particularly regarding healthcare-seeking behaviors (Sevelius, 2013). For a TGD youth, receipt of gender-affirming healthcare could take the form of proper pronoun use when interacting with and talking about a TGD patient, asking gender-appropriate questions about a patient’s health, and creating a space within a healthcare setting that is welcoming to different gender identities. If gender affirmation is the process of acknowledging and affirming an individual’s gender identity and is associated with increased access and willingness to engage in healthcare, gender affirmation therefore may be viewed as a form of gendered empowerment.

Due to heteropatriarchal and cis-normative social norms, many providers possess beliefs about TGD youth that are inconsistent with gender affirming healthcare. These beliefs may render providers unprepared, unwilling, or unwelcoming to TGD people (Anand et al., 2017;

Harper et al., 2019; Poteat et al., 2013; Puckett et al., 2018; Sevelius, 2013). TGD youth consistently report non-affirming, uncomfortable, and discriminatory interactions with providers and with other adults in the spaces in which TGD youth seek out care (Bradford, Reisner, Honnold & Xavier, 2013; Grant et al., 2011; Harper et al., 2019). In the National Discrimination Report, one-third of respondents reported postponing necessary care due to fear of discrimination based on their gender identity (Grant et al., 2011). For the youth who have sought out care, many describe receipt of unsatisfactory services, interwoven with microaggressions and disregard for their unique needs (Grant et al., 2011; Kitts, 2010). In a study of 182 transgender adults, Kenagy and Hsieh (2005) found that one in four respondents were denied medical care outright due to their gender identity. Additionally, TGD youth of color may experience unique difficulty accessing healthcare as a result of consensual ideologies that lie at the intersections between minority racial or ethnic identity and their gender identity (Crenshaw, 1991; Jefferson, Neilands, & Sevelius, 2014). For example, distrust of the medical and social systems as a result of systematic discrimination and racism historically experienced by Black communities may distinctively impact healthcare access for TGD youth of color (Cooper & David, 1986; Feagin & Bennefield 2014; Harris, Crenshaw, Gotanda, Peller & Thomas, 2012; Snorton, 2017).

Consensual ideologies about gender do not lie solely in the individual's or the provider's beliefs. Family members, teachers, peers, and policy makers may maintain beliefs about TGD youth, and particularly TGD youth of color, that also impact healthcare access. Consensual ideologies about TGD people can infiltrate the institutions, systems, laws, and policies which govern TGD health and healthcare access. For example, in Unger's (2015) study of health provider training they found that over 80% of obstetricians and gynecologists did not receive any training specific to TGD people during their residency, clearly illustrating institutional

discrimination within medical schools. Similarly, in a study of primary care providers, Poteat, German and Kerrigan (2013) found that *all* respondents reported feelings of ill preparedness during their first encounter with a transgender patient. Moreover, one transgender patient from the same study stated that healthcare providers were unequipped to meet their healthcare needs and unprepared for the very existence of a non-cisgender individual.

Overall, current research paints a dark portrait of the proliferation of mistreatment, rejection or discrimination perpetrated toward TGD youth because of their minority gender identity. Within many settings, research clearly evinces how traditional beliefs about gender may be affecting TGD youth. Consistent encounters with people who possess negative beliefs about TGD people can result in increased exposure to several individual, social, and structural stressors (Hendricks & Testa, 2012). Together, these studies illustrate how the impact of consensual ideologies about TGD people must be examined beyond an individual and relational level to explore how institutional and policy-level beliefs about TGD youth may impact healthcare access. However, no research to date has explored how consensual ideologies, in combination with other forms of gendered power may impact TGD youth's confidence, willingness, and agency to safely seek out healthcare services and resources. Furthermore, knowledge of how consensual ideologies differ by gender identity within the TGD population is noticeably lacking. Finally, we do not yet understand how consensual ideologies about gender intersect with beliefs about other minority identities in the context of healthcare access.

Resource control. The second mechanism outlined in Walker and Pratto's (2004) theory of gendered power is allocation and control of resources. Individuals, organizations, and institutions at the top of the hierarchy generally govern resources and, as a result, exercise power through their constraint and disbursement. In almost all capitalist societies and economic

systems, people who assume masculine (primarily White) identities enjoy more power (Pratto & Walker, 2004). For cisgender women, Walker and Pratto (2004) discuss how local customs and laws, gender segregation in the workforce, pay gaps, and women's financial dependence on men contribute to women's lack of access to and control over resources. For TGD individuals, similar mechanisms may be in effect. Again, it is important to consider these mechanisms as a function of cis-normativity *and* racism in the United States for TGD youth of color.

TGD youth report difficulties accessing housing, education, basic goods, healthcare, and public services due to gender-based discrimination (Grant et al., 2011; Harper et al., 2019; McCann, Keogh, Doyle & Coyle, 2017). Within the workplace, for example, TGD youth and adults face systemic injustices because of their gender, contributing to unemployment, underemployment, or self-employment (Grant et al., 2011; Mitchell, 2009; Morton, 2008; Nemoto & Operario, 2006; Winter et al., 2016). In a study of workplace discrimination in the United Kingdom, Winter and colleagues (2007) found that 42% of transgender individuals did not live in their preferred gender roles for fear of losing their job, damaging their social standing, or being perceived as less competent (Davis, 2009). Similarly, school-based research suggests negative experiences at school are associated with increased absences and dropout rates (Greytak et al., 2013; Herman, 2013; McGuire et al., 2010). This can dramatically affect future educational attainment, income, or employment opportunities. Within higher education, youth reported difficulties finding on-campus housing that met their needs and experiencing discrimination or difficulty obtaining housing in the community due to mismatch of legal identification documents and gender identity or presentation (Singh et al., 2013). For younger TGD youth, resources may also be controlled by parents or guardians (e.g., housing, finances, transportation). TGD youth who face family rejection due to their gender identity or expression

may lose access to safe and stable housing, transportation, and financial support typically provided in the home. Conflicts at home or in foster care may force TGD youth to seek out alternative ways to meet basic survival needs (Morton, Dworsky, & Samuels, 2017; National Center for Transgender Equality, 2018). For many TGD youth, this puts youth at risk for homelessness, truancy, drug use, or survival sex as a means for survival (McCann & Brown, 2019; Robinson, 2018; Shelton, 2016; Singh, 2013). This trajectory from unsupportive homes to the streets is particularly acute for transgender woman of color, suggesting that racism also plays a critical role in securing basic needs (Coronel-Villalobos & Saewyc, 2019). An inability to meet basic needs is a critical risk factor for disengaging or failing to engage in healthcare.

Finally, resource control can also encompass laws, policies, and societal norms that deny TGD youth access to information, resources, and legal or societal recognition of their gender and reinforce heteropatriarchal systems and cisgender privilege (Harris, 2011; Hatzenbuehler et al., 2010; Link & Phelan, 2014; Schilt & Westbrook, 2009; Valdes, 1995). TGD individuals are denied important information, resources, and education about their bodies, health, and sexuality from very young ages (Riggs & Bartholomaeus, 2018). Sexuality education in schools and communities has continually omitted transgender sexuality and health from most curriculums (Greytak et al., 2013; Owen, 2017; Riggs & Bartholomaeus, 2018). Therefore, TGD youth are regularly provided heteronormative and cis-normative information, restricting their access to knowledge. Without access to critical knowledge about their own bodies, TGD youth are exposed to increased sexual health risks and difficulties accessing services and resources.

In summary, a majority of people, organizations, and institutions that govern resources for TGD youth function within a heteropatriarchal system of oppression in which governance of resources favor cisgender men, particularly white men. As a result, resource allocation is deeply

rooted in gendered power. Recent research among TGD youth and adults find that TGD youth are consistently robbed of jobs, educational opportunities, information, and quality healthcare specifically because of their gender identity. Furthermore, providers, and the healthcare system more broadly, are restricting access to critical health resources for youth due to misinformation about TGD bodies, lack of skills, or prejudice. Despite this evidence, research on TGD individuals has yet to explore how resource control in combination with other facets of multisystemic gendered power may work together to impact healthcare access for TGD youth. Relatedly, we also have yet to explore how resource control may differ by different gender identities or racial/ethnic identities among TGD youth.

“there is a possibility that I will be murdered because I am trans, yes, there is that possibility. But at the end of the day, those that were murdered before me, I want to make sure they have a voice still”

-Dee Dee Watters, transgender rights advocate

Force. The third mechanism of gendered power is force. Violence and force are significant contributors to the maintenance of power hierarchies. An abundance of research over the past 3 decades has uncovered the many ways violence is used as a means to control another person, their children, and limit their access to financial, employment, educational or housing resources, and opportunities (Adams, Sullivan, Bybee & Greeson, 2008; Anderson, 1997; Connell, 2013; Gage & Hutchinson, 2006; Heath, 2014; Miller et al., 2010). Studies among cisgender women have argued that such exercise of power put women at higher risk for certain health and social hardships, such as homelessness, substance use, financial instability, STIs, HIV, and unplanned or unwanted pregnancies (Amaro & Raj, 2000; Campbell, 2002; CDC, 2005; Dunkle, et al., 2004; Pulerwitz, Amaro, DeJong, Gortmaker, & Rudd, 2002).

Among TGD youth, particularly TGD youth of color, these same power hierarchies affect the violence perpetrated against minorities and the way we talk and report on these injustices. We are only beginning to understand how violence functions as a form of gendered power for TGD youth and whether it operates similarly for subgroups of TGD youth. TGD youth, particularly trans women of color, are one of the most targeted minority groups regarding physical and psychological violence, with rates of violence and murder reaching epidemic numbers (Balzer et al., 2012; National Coalition of Anti-violence Programs, 2013; Witten, 2007). TGD homicides account for approximately 25 deaths of TGD people each year, the vast majority of which are young black transgender women (Human Rights Campaign, 2018). Although intimate partner violence (IPV) among TGD youth is understudied, available evidence suggests approximately 31 to 51% of TGD youth report lifetime experiences of IPV (Brown & Herman, 2015; Goldberg, Jadwin-Cakmak & Harper, 2018). In one of the few studies specifically focused on intimate partner violence among TGD youth, Goldberg, Jadwin-Cakmak and Harper find that gender-based stigma was a persistent theme in the majority of TGD youth's discussions of violence in their lives (2018). Similarly, in their 2015 piece, Cook-Daniels applied a power and control lens to understand domestic violence in transgender relationships. The authors discuss six ways in which abusers use gendered norms and beliefs as an instrument of power and control over their transgender partners (Cook-Daniels, 2015; Witten, 2007). These studies highlight how current research must attend to the ways in which violence is gendered and deeply entrenched as a means of gendered power.

Despite the incredible prevalence of violence in the lives of TGD youth, no study to date has explored the ways in which gendered-based violence and trauma may impact healthcare seeking for TGD youth (Reisner et al., 2015). Critical gaps exist in our understanding of how the

trauma experienced by TGD youth impacts their long-term health and healthcare seeking behaviors (Reisner et al., 2015). Again, among cisgender women, there is an abundance of literature supporting the notion that survivors of trauma experience unique barriers to help seeking, particularly if the survivor has previously had negative experiences with a provider (Angelone, Mitchell & Pilafova, 2007; Elhai, North & Frueh, 2005; Fehler-Cabral & Campbell, 2013; Fisher, Cullen & Turner, 2000). Like cisgender women, the desire to seek out healthcare in trauma-informed spaces and with trauma-informed providers may provide an additional healthcare access barrier. Violence, fear of violence, and trauma are critical components to theories of gendered power. Therefore, to fully understand the impact of gendered power, we must critically examine the ways in which violence may serve as a barrier to healthcare access for TGD youth.

Asymmetric social obligations. The final mechanism of Walker and Pratto's (2004) model of gendered power centers around our individual social systems and the obligations we have to those systems. For example, parents are responsible for their children, healthcare providers have obligations to their patients, and friends have obligations to their friends. Walker and Pratto's (2004) fourth mechanism of gendered power argues that these obligations and the benefits they may produce are not always equal; the party with fewer obligations has greater power. For example, women tend to have more obligations to their partners, children, families, and friends (Ford, 2006; Pratto & Walker, 2004). The root of this mechanism stems from women's obligation to their relationships and their children and how those obligations can oftentimes set women back professionally. For example, although more women are now encouraged to work outside the home, as compared to 20 years ago, the degree of obligation they have to their home and families remains constant (Prato & Walker, 2004). For TGD youth, we

do not yet understand how, if at all, social obligations function as a form of gendered power in the process of accessing healthcare.

Summary. Taken together, Walker & Pratto's (2004) theory of gendered power provides a fungible framework to identify the many ways in which TGD youth are oppressed due to the gender status quo. Despite knowledge that many extra-individual factors impacting healthcare access for TGD youth, no research to date has applied a gendered power framing to understanding these issues. As a result, we lack an understanding of the ways in which normative perceptions of gender within multiple systems and settings impact TGD youth health. We have also failed to critically explore how gendered power and race/ethnicity may intersect to impact healthcare access. Furthermore, while previous literature has drawn attention to different aspects of gendered power, no research exists that has explored what different facets of gendered power may exist specifically for TGD youth and how, if at all, they converge to impact healthcare access.

Research Aims and Objectives

The primary aim of this dissertation was to explore experiences of gendered power in TGD youth with a specific focus on how gendered power shapes experiences of healthcare access. Given the exploratory nature of research with TGD populations, it was important that I approach this exploration from multiple angles. Accordingly, this dissertation is divided into two separate studies that each explore a different aspect of gendered power and resource access among subpopulations of TGD youth. The Research and Advisory Team worked in partnership with me as co-researchers and advisors to both studies. Table 1 presents an overview of the Research Aims and Objectives, as well as a brief description of the Research and Advisory Team's role on both studies.

Table 1. Overview of Research Aims and Objectives

	Study A	Study B
Method	Youth Participatory Focus Groups	Qualitative Secondary Data Analysis
Purpose	Gain youths' opinion and interpretation of gendered power in general	Explore how gendered power is manifested in discussions about accessing HIV prevention and care services
Primary Research Questions	How do TGD youth describe power in relationship to their identities? How do TGD youth describe gendered power and health? In what circumstances and settings do youth feel powerful or powerless?	Does gendered power emerge as a theme in TGD youth experiences of navigating HIV healthcare?
Across both studies	How do discussions of power differ based on gender identity or race/ethnic minority status? How do emergent themes relate to Walker and Pratto's theory of gendered power?	
Data	5 Focus Groups with local TGD youth	Secondary qualitative interviews with 28 TGD youth living with HIV
Analysis	Youth GO: Participatory focus group data collection and analysis method	Structural coding and thematic analysis
Research & Advisory Team Role	Development of protocol and prompts, facilitation, between-group analysis	Defining, clarifying, and interpreting themes

In Study A, we explored TGD youths' perceptions of gendered power in general using a youth participatory focus group protocol. I chose to use a youth participatory method, which I believe is the most robust way to develop our knowledge around gendered power. TGD youth participants in this study generated data in the focus group session as well as participated in within group analysis. Few studies exist that intentionally include youth participants in the analysis process to add further context and insight to findings. In Study A, I asked youth participants to define and discuss what power meant to them and how power intersected with their gender and other social identities. We then discussed in what circumstances and settings youth felt powerful or powerless and how, if at all, those feelings intersected with their gender

identity. Finally, we discussed how, if at all, gendered power impacted their experiences navigating healthcare settings. In this study, the Research and Advisory Team collaborated on project design, focus group facilitation/data collection, and cross-group analysis.

In Study B, I examined the relationship between gendered power and healthcare access for TGD people living with HIV. Using secondary data, this study explored how, if at all, gendered power manifested in discussions about accessing HIV prevention and care services among TGD youth living with HIV. Given that this study was designed to explore HIV prevention and care engagement among TGD youth, not gendered power, coding was informed by the discussions generated in Study A of gendered power. In this study, the Research and Advisory Team collaborated during the thematic definition, interpretation, and explanation phases of the qualitative analysis. Across both studies, I was interested in whether emergent themes of gendered power differed based on gender identity or racial/ethnic minority status and how, if at all, emergent themes surrounding gendered power related to Walker and Pratto's (2004) conception.

CHAPTER 2: METHODOLOGY

This dissertation is rooted within a participatory research paradigm. Participatory research burgeoned as a reaction to positivism to close the distance between researchers and communities (Heron & Reason, 1997; Lincoln, Lynham & Guba, 2011). The general objective of participatory research is to produce knowledge collaboratively that can benefit community members while acknowledging and actively working to change the historical imbalance of power between the researchers, the participants, and the community the research affects (Heron & Reason, 1997; Groat & Want, 2001; Noel, 2016; Reason, 2008). True participatory research should arise directly from the needs of the community, with the specific aim of integrating researchers' theoretical and methodological knowledge with the community partners' real-world knowledge and experiences in order to solve pressing community problems, effect social change, or improve the quality of life of community members. (Israel et al., 2019; Strand, Cutforth, Stoecker, Marullo & Donohue, 2003; W. K. Kellogg Foundation's Community Health Scholars Program, 2001). Participatory research is often discussed on a spectrum along which co-production of knowledge and intentional collaboration varies (see Figure 1).

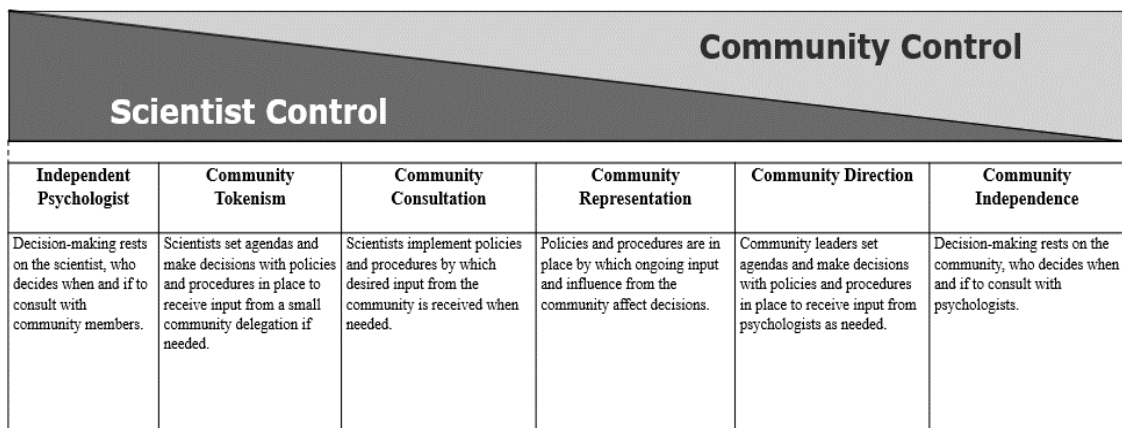


Figure 1. Community Research Continuum Adapted from Community-AID Lab CEnR Presentation, at ASU, 2017

Towards the far right end of the spectrum, the community members, community partners, and researchers share leadership and decision-making power about the research idea, design, and final product (Israel Schulz, Parker & Becker, 1998; Ferreira & Gendron, 2011; Wallerstein & Duran, 2011). The current study falls in the ‘Community Representation’ box along the continuum, wherein I have intentionally included of community members as equitable partners in the research process to foster co-learning and capacity building (Israel et al., 1998; Minkler & Wallerstein, 2011).

Participatory research is a natural fit for this dissertation. Equitable and intentional collaboration with TGD youth as co-researchers is crucial to begin to fill the many knowledge gaps about their unique experiences. Consequently, a local community research advisory team (separate from the research study participants) was created specifically for this project (The Research and Advisory Team). During the initial project conceptualization and development, I reached out to local and university-affiliated groups and activists interested in learning more about research and getting involved in this project. Although about nine individuals expressed interest, five were able to commit. All identify as either transgender women, transgender men, nonbinary, or agender. Advisers’ ages range from 18 and 22 years. During the initial phases of project conception, we met as a group every 2 weeks for 2 hours in person, and communicated regularly in between meetings through a chat app. Team members have been instrumental in the conceptualization and design of the research project and have served as advisors and collaborators throughout the research. In addition, the team has worked together to identify individual member’s goals and desires that our team can work on addressing in relation to TGD youth issues. A final goal of the Research and Advisory Team was to decide what to do with the findings, what type of products we would like to produce, how to disseminate findings, and

determine next steps in pursuit of social justice for TGD youth. As such, from initial conceptualization through final dissemination, the Research and Advisory Team had meaningful engagement, opportunity, and some degree of power over the research design, data collection, and dissemination decisions.

Given the topic of this research concerns power, it would be hypocritical if this research did not employ a research approach that addresses the many ways in which power imbalances are acknowledged, critically examined, and attended to throughout the research process. As such, it is important to note that despite the well-known benefits, participatory research comes with many risks and limitations (Dhillon, 2017). The degree to which community participation and engagement meaningfully occurs during the research process often varies. Moreover, the degree of power and participation researchers and community members desire is not always feasible (Etmaksi & Plant, 2007; Israel et al., 2019). Conducting true participatory research (on the far right end of the continuum in Figure 1) within an academic institution as a doctoral dissertation is incredibly difficult. The practices of the institution, institutional review boards requirements, and departmental bylaws create inflexible systems of power often discordant with participatory research values. For example, as a doctoral student, final decisions about this project must be approved by my dissertation chair and committee members in a meeting in which my Research and Advisory Team has no voice. This drastically alters power dynamics. As a result, I have taken measures to reduce power imbalances within this system. First, I have selected committee members who are familiar with my participatory approach. These committee members understand what might be necessary to retain participatory values throughout the project. Second, the institutional review board was made aware that amendments to the project might be necessary as discussions with Research and Advisory Team progress. Finally, and most

importantly, I committed to my Research and Advisory Team that after completing the university requirements for the dissertation, I will make sure to see through my commitments to the team, which are still in the process of being determined.

Research Design

To address the research objectives, this dissertation employed a sequential mixed method design in which two separate qualitative studies were conducted sequentially, each with unique qualitative methods. This project used mixed methods to establish a deeper and more concrete understanding of a phenomenon (Bartholomew & Brown, 2012; Greene, 2007; Tashakkori & Teddlie, 1998). Study A was conducted first. The findings from Study A then informed the analysis of Study B (Greene, 2007; Tashakkori & Teddlie, 1998). Finally, another cross-cutting piece of the project lay in the consistent engagement of TGD Research and Advisory Team throughout the execution of each study (see Table 1).

Separately, mixed-methods research and participatory research both serve as acceptable approaches to explore how power functions in the lives and experiences of TGD youth. Participatory approaches encourage the inclusion of youth voice, address power imbalances, and facilitate co-learning and capacity building. Mixed-methods research supports a deep and rigorous investigation into a phenomenon of interest to explore and develop a culturally appropriate theoretical framework (Hall, 2005; Park, Brydon-Miller, Hall & Jackson, 1993; Robinson, David & Hill, 2016; Tandon, 2002). Given the dearth of empirical and theoretical work in this area, a mixed-methods participatory approach served as a promising method to gain a more complete and rich understanding of diverse experiences of a highly concealed group, while taking into consideration the ethical and cultural concerns regarding research with this population (Robinson, David & Hill, 2016).

CHAPTER 3: STUDY A - YOUTH PARTICIPATORY FOCUS GROUPS

As presented in the literature review, TGD individuals have been epistemically excluded from scholarly research, which has significantly affected current research, theory, and general knowledge available about TGD youth. Although recent literature and theory suggests that gendered power likely impacts TGD youth's ability to access healthcare, no study to date has specifically elicited from TGD youth their perspectives on power. This study was designed in response to this exclusion, and directly engaged TGD youth in discussions and interpretations of power and health. As such, this study supported the participation, voice, and engagement of TGD youth at every stage of the research process.

Using youth participatory focus group techniques, this study engaged youth in a discussion on power, identity, and health. Specific aims were to: 1) uncover how TGD youth talked and thought about power in their lives; 2) explore how their gender identity and other social identities influenced perceptions of power; 3) identify circumstances and settings in which TGD youth felt powerful or powerless and how these experiences might relate to their gender identity; 4) explore how, if at all, gendered power impacted experiences with health or healthcare navigation; 5) introduce TGD youth to qualitative data analysis techniques in a developmentally appropriate and engaging manner. In sum, this study aimed to build a more complete picture of TGD youth's experiences with gendered power and how it impacts healthcare access.

Participants and Procedures

IRB. This study was approved as exempt by the Institutional Review Board at Michigan State University. Consistent with new IRB requirements because of Covid-19, one focus group

was conducted virtually, as in-person data collection was prohibited at that time. The exempt determination letter is available in Appendix A.

Participants. For this study, we recruited youth between the ages of 18 and 24 years who do not identify with or are questioning their identification with the sex they were assigned at birth (e.g., trans, transgender, trans woman, trans man, man, woman, gender nonconforming, gender queer, any other gender, or questioning their gender identity), and who consented to participate in a focus group with 2-5 other local TGD youth.

We recruited youth from three Michigan cities (e.g., Lansing, Ann Arbor, Detroit) in which the study coordinator or research team members had connections to TGD youth and/or TGD youth groups. We used our existing contacts with local LGBT groups and leaders to distribute flyers in community spaces that TGD youth frequent and on social media. The TGD youth Research and Advisory Team and I designed the recruitment materials, which instructed youth to contact me for more information. These materials were approved by the IRB (available in Appendix A).

Twenty-five participants expressed interest in the study. One individual was under age 18 and could not participate, two individuals did not complete their scheduled screening call, and three participants were unable to attend any of the scheduled focus groups. In total, we screened and consented 19 participants for participation in a total of five focus groups, which is generally acknowledged as enough to reach saturation (Fusch, & Ness, 2015; Hennink, Kaiser & Weber, 2019; Morgan, 1997). Two groups were conducted in Lansing, one group in Ann Arbor, and two groups in Detroit. One participant attended the first Detroit group, but ended up leaving soon after introductions were made. This participant decided to attend the second Detroit focus group instead. Her information is only included in the second Detroit group. Finally, although we

targeted youth between the ages of 18 and 24, we believe (based on in-group responses) that at least 2 participants were older than age 24 (approximately 26-29 years old).

Recruitment. We purposively recruited for diversity of youth participants. We hoped for each group to be diverse in terms of gender and race/ethnicity, such that each group would have at least two participants who identified within the binary (e.g., man, woman, transgender man, transgender woman) and at least one participant who identified outside the binary (e.g., non-binary, genderqueer, questioning, gender nonconforming). We also intended to recruit until each group has at least one youth of color. However, our final groups' demographic makeup varied significantly by location. Across groups, we were able to recruit a diverse sample, however, within groups, racial and gender diversity was minimal. With race, for example, the Lansing groups (Group 1 and 5) and Ann Arbor groups (Group 2) were primarily White, whereas the Detroit groups (Groups 3 and 4) were primarily Black. With gender, groups were also made up of participants who identified as of the same gender. The Ann Arbor group (Group 2) was primarily gender diverse. The Detroit groups (Groups 3 and 4) were primarily trans women. Finally, the Lansing groups (Groups 1 and 5) were a mix of transgender men, transgender women, and gender diverse individuals. The composition of the groups may reflect gender and racial segregation specifically within the TGD community or may be a byproduct of our recruitment methods.

Procedures. Everyone who was interested in participating in the focus groups reached out to me and was pre-screened over the telephone. The screening call inquired about the participant's age and current gender identity. On this call, I briefly explained the purpose of the focus groups and asked if they felt comfortable participating in the focus group with 2 to 4 other TGD youth living in the area. Potential participants were reminded that they would not

experience any adverse consequences from declining to participate in the focus groups. If the participant met all eligibility criteria, I went through the informed consent process immediately after the initial eligibility screening. Finally, I confirmed whether participants needed transportation assistance to access the focus group venue. The consent form is available in Appendix C.

Upon arrival at the focus group venue, youth were consented again. During this time, I reviewed the consent form, reiterating that confidentiality could not be completely ensured given the nature of focus groups. I also reminded the potential participants that it was possible they may know someone in the group. I let participants know that after introductions, there would be a break during which they could safely exit the focus group if they chose. I also reiterated that participants were free to not speak and could leave the focus group at any time during the session with no adverse consequences. After youth indicated that they understood the issues detailed in our consent discussion and expressed their willingness to participate, I asked the participants for their signed consent. Participants were compensated \$30 in Visa gift cards after agreeing to participate and provided \$20 to cover any transportation costs.

Youth Generate and Organize (Youth GO) Protocol

To collect the focus group data, I used a modified version of a participatory data collection and analysis approach called Youth GO (Stacy, Acevedo-Polakovich, & Rosewood, 2018; Stacy, Castro & Acevedo-Polakovich, 2020). Youth GO was developed as a process to engage youth meaningfully in the data collection, data analysis, and interpretation of the research (Stacy, Acevedo-Polakovich & Rosewood, 2018). Drawing from key components from existing youth participatory approaches (e.g., Youth ReACT, Group Level Assessment) (Foster-Fishman, Law, Lichty, & Aoun, 2010; Vaughn et al., 2011), Youth GO exposes participants to three

important aspects of qualitative data analysis: Data reduction, data organization, and conclusion drawing and verification (Chen, Weiss, Johnston Nicholson, & Girls Incorporated, 2010; London, Zimmerman, & Erbstein, 2003). Like these existing participatory approaches, Youth GO retains the values and principles necessary to engage youth in research in a developmentally appropriate way while also elevating youth's voices and experiences.

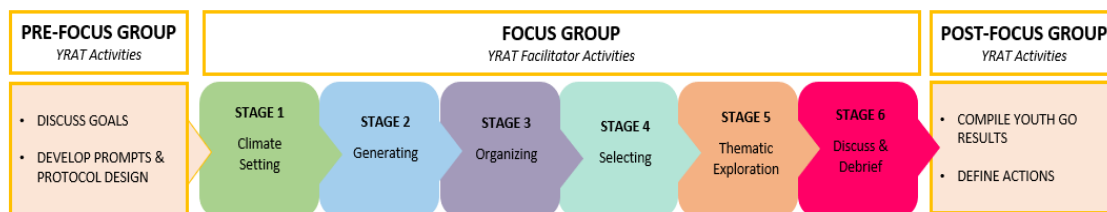


Figure 2. Modified Youth GO for complex and participatory research projects

The protocol is broken up into 5 steps in which youth generate data, learn qualitative analysis techniques, code and categorize the data, and discuss the findings. This study used a modified version of Youth GO (Figure 2) which includes three additional phases. First, I added a pre-focus group phase in which members of the community (the Research and Advisory Team) gathered to brainstorm, design, and test focus group prompts and protocols to be used in the Youth GO session. Second, I added a post-focus group phase after the completion of data collection, community members (the Research and Advisory Team) engaged in a thorough process of combining, comparing, and contrasting findings across focus groups and defined final group actions for dissemination of findings. Within the focus group session, I added 'Stage 5 Thematic Exploration' which focused on mapping relationships, commonalities, and differences among emergent themes (Miles & Huberman, 1994). Finally, I incorporated a cross-group analysis phase after completion of all the focus groups. The following section will go through each step of the modified Youth GO data collection and analysis protocol.

Pre-Focus group: Goal setting and design. Prior to beginning the Youth GO focus groups, the goals of the process and the protocol for the process needed to be determined. To do so, I met with the Research and Advisory Team to discuss following questions: 1) what are our goals for these focus group sessions? 2) what information are we hoping to learn? 3) what will we do with that information? 4) how can we best capture this information? 5) how should we word the prompts? 6) how should we organize the prompts? 7) what ethical concerns need to be considered? During this phase we developed and pilot-tested the protocol. The protocol was modified based on a series of discussions as well as several practice role-play sessions with each other and with graduate student volunteers. The full Youth GO protocol and script is available in the appendix D.

Facilitators and Training. Facilitators were members of the Research and Advisory Team. Facilitators received a 2-hour training from Sara T. Stacy, MA—the lead developer of the Youth GO protocol. The training included an overview of Youth GO, important skills and techniques for conducting focus groups with youth, and finally, a walk-through and discussion of the protocol. The facilitators also received a training from Jamie Erdheim, M Ed—a trained youth advocate and sex educator. In the training, Jamie covered specifics about working with and facilitating sessions with TGD youth.

Stage 1: Climate setting. The Youth GO session began with the climate setting phase in which the facilitators introduced themselves and the goals of Youth GO. During this stage, the participants created a set of group rules to guide discussion and manage group dynamics. We addressed the importance of confidentiality, privacy, and making space for others. During this stage, I introduced myself and explained that I would be taking notes and co-facilitating throughout the entirety of the session. Finally, the facilitators presented an icebreaker question to

build rapport and to get the participants comfortable engaging in discussion together. The ice breaker question was: *"What is something you love or something about yourself that you wish people asked you about more?"* The full description of the protocol is available in the Appendix E.

Stage 2: Generating. During stage 2, the first prompt was revealed on a flip chart and read out loud to the participants. At this point, participants were encouraged to reflect and then individually write down their responses on sticky notes and stick them onto the flip chart. As participants were generating ideas, they were encouraged to ask questions. Facilitators clarified and probed on responses. After all responses were collected, facilitators lead a discussion in which participants could reflect on all responses and clarify as needed. This process repeated for all prompts.

Prompts: The first prompt aimed to get at broad understanding of how participants defined power: *"What comes to mind when you think of the word power? What does power mean to you?"* After this prompt, we defined power, and then asked the participants if they would like to modify or add to their previous response. The second prompt focused specifically on gendered power: *"How do you feel people's perception of you and your identity affects the amount of power you have?"* The third and fourth prompts aimed to get participants talking about experiences in which they felt they had or did not have power: *"Has there been a time in your life where you felt powerful or in control over your life or decisions?"* and *"Has there been a time in your life where you felt your power or control over your life and decisions was restricted or diminished?"* Finally, we asked the participant to reflect on gender, power and their health: *"Now we'd like you to think about how your gender identity has impacted power over your health or ability to access to health-related resources?"*

Stage 3: Organizing. The organizing phase had two main goals: 1) teach youth how to organize and code data, and 2) support youth in the organization and categorization of the data they developed in phase 2. To achieve goal 1, youth participated in an item-sorting game that introduces data organization skills in a developmentally appropriate fashion (Preskill & Russ-Eft, 2005). Briefly, the game walks youth through the process of creating categories and organizing and re-organizing the items based on different instructions. After the game, the facilitators supported the youth in the process of collaboratively organizing and interpreting the data from Phase 2 (Generating). Participants placed organized responses onto colored paper and created a label to signify a theme.

Stage 4: Selecting. Building on what was learned in Phase 3, participants worked to identify central categories for the themes that emerged in Phase 3. In addition, participants and facilitators discussed and defined meaningful categories for each theme. These definitions were recorded, refined, and agreed on by the group.

Stage 5: Theoretical exploration. During this phase, the facilitators engaged the participants in a deeper discussion of the themes that were generated. This phase is essentially akin to a group analytic memoing process. In qualitative research, an analytic memo is a brief narrative tracking the analysts' thoughts, ideas, and reflections about the data and emergent themes (Saldaña, 2015). Analytic memos can serve many different purposes (e.g., noting personal feelings, ideas for future directions, definitions for emergent codes). The purpose of memos in this phase was to make connections and assertions across themes. Therefore, using the definitions of themes from the Phase 4 (Selecting), facilitators probed participants to consider similarities, differences, and overlap across themes. These responses were summarized onto the flip charts as the group refined its thinking.

Phase 5: Debrief and discussion. Finally, youth participants were encouraged to reflect on the entire Youth GO process through a group discussion guided by the facilitators. Finally, participants had the option to leave their email addresses if they wanted to receive updates about the study. We also provided index cards that participants could choose to fill out. The index cards had the following questions printed on them: *“What wishes do you have for other transgender and gender diverse young people in this country? What do you wish researchers and policy makers paid more attention to regarding TGD youth?”* Some groups did not have enough time for this step and were sent a follow up Qualtrics survey to respond. At this point in the process, as the study coordinator I was available in case any of the participants had individual questions, concerns, or needs. Following this phase, I debriefed with the co-facilitators. Kreuger (1998) suggests debriefing with the following questions: ‘What were the most important themes or ideas discussed?’ ‘How did these differ than what we expected?’ ‘How did this group differ from other focus groups?’ ‘What quotes should be remembered to include?’ ‘Were there any unexpected or unanticipated findings?’ (p. 50). We took notes on these discussions (Morgan, 1998).

Post-Focus group: Compile results and define actions. Throughout the entirety of the focus group session, we took notes to clarify discussions, add contextual detail, and note personal reflections. Upon completion of each focus group session, I asked the facilitators to write down any reflective or descriptive information they recalled from the focus group session. Finally, after completion of each group, we listened to the audio recording and added details or clarifications to our notes.

Next, all the data generated during the sessions was digitized, formatted, and combined into one packet per group (analytic packet). The analytic packet detailed each Youth GO phase

and the corresponding notes, pictures of flip chart responses, themes, and memos generated during the focus group session. To illustrate, in Phase 1 (Generating), focus group participants generated responses to each prompt on post-it notes and then stuck them on a flip chart. For the analytic packet, each post-it note response was typed up and listed under the corresponding prompt. Additionally, any notes or memorable quotes corresponding to this phase were added to this portion of the document. When necessary, we returned to the recordings for clarification. During phase 2 and 3 (Organizing; Selecting), focus group participants sorted responses into themes (on colored paper) with labels and definitions. All of this information was compiled into the analytic packet. Again, notes or memorable quotes corresponding to these phases were integrated and recordings were used for clarification or refinement of notes. During phase 4 (Theoretical Exploration) discussions of the similarities and differences across emergent themes were documented in simple analytic memos. These memos were added to the packet. Finally, we added any final comments that arose during the debrief and discussion phase (Phase 5) to the final analytic packet.

Analytic Plan

Within-group analysis. The analysis began during the first focus group. The Youth GO focus group session was designed to include within group analysis wherein data was generated and then participants in the focus group session engaged in analysis and thematic interpretation of their own discussion. The modified Youth GO protocol maps nicely onto Miles and Huberman's (1994) qualitative analysis process. To illustrate, Table 2 displays how the protocol inherently contains its own within-group analysis process.

Table 2. Youth GO as an analysis process

Miles & Huberman (1994)	Modified Youth GO
1. Get familiar with the diversity of verbatim data collected	Phase 1: Generating
2. Sort codes and pattern between the codes	Phase 2: Organizing
3. Elaborate a set of generalizations	Phase 3: Selecting
4. Isolate a pattern	
5. Cluster commonalities and differences	Phase 4: Theoretical Exploration
6. Recognize, contrast, and map categories and themes	
7. Finalize the materials, reexamining the data if necessary. Draw conclusions	Phase 5: Debrief and Discussion Post FG: Compile results and define actions

Cross-group analysis. After the completion of data collection and preparation of the analytic packets, the Research and Advisory Team and I analyzed data across groups. This step was crucial to enhance transferability and to deepen our understanding of gendered power across contexts (Denzin, 1993; Miles, Huberman & Saldaña, 2014; Morgan, 1998). We took a note-based analysis approach (Krueger, 1998) in which the primary analysis document was the analytic packet described earlier, comprised of field notes, flip chart responses, themes (labels, definitions, examples) and analytic memos. Following Morgan's (1998) suggestions for focus group analysis and report writing, we began by reviewing and annotating the analytic packets from each focus group, noting key findings and quotes. Using a variable-oriented strategy (Miles, Huberman & Saldaña, 2014), we often returned to the study's research aims to highlight and note patterns in both the responses generated from the prompts and the themes created by the focus group participants (Morgan, 1993).

Next, we explored the similarities and differences by looking for themes that were consistent and unique across groups. We also attempted to make sense of these differences by considering individual characteristics (e.g., gender identities; ethno-racial identities; age) and

group characteristics (e.g., location). Next, using the information from previous steps, we constructed an Overview Grid to summarize and describe all focus group discussions. Overview Grids are a useful approach to display and summarize focus group data when working with a team of analysts (Morgan, 1993). The Research and Advisory team and I worked together to fill out this grid until we agreed on the content displayed. The grid helped to focus our findings, develop assertions, and draw conclusions.

Finally, the Research and Advisory team and I tested cross-group assertions about gendered power. An assertion is ‘a declarative statement of summarized synthesis, supported by confirming evidence from the data and revised when disconfirming evidence or discrepant cases require modification of the assertion (Miles et al., 2014, p. 99). Developing and testing assertions is a commonly used technique in qualitative analytic induction (Erikson, 1986). In the current study, the Research and Advisory Team and I developed an assertion, then found disconfirming or confirming evidence from the analytic packets and the overview grid to support or contest the assertion. We repeated and revised until we agreed on the assertions and conclusions drawn from these data.

Trustworthiness

Lincoln and Guba (1985) outline four criteria to increase trustworthiness or confidence in the qualitative data analysis: credibility, transferability, dependability, and confirmability. To ensure trustworthiness of the current study, I used dependability and credibility techniques (Lincoln & Guba, 1985). Credibility is the degree to which researchers are confident that the findings and interpretation of findings represent the information generated from the participants (Lincoln & Guba, 1995). Member checking strategies were used to maintain credibility for the proposed study. Member checking is the process of feeding back findings and conclusions of

research study to the original participants for their interpretation and feedback. In this study, member checking was inherently part of the focus group session. Throughout each phase of the Youth GO protocol, there was space for reflection, debrief and review of interpretation and findings.

Reflexivity in qualitative research is the process of self-reflection about one's role as a researcher and one's relationship to the research participants (Lincoln & Guba, 1995). Reflexivity remained key throughout this study. In addition to my reflection of my own biases as a researcher at the beginning of this document, other processes for self-reflection were incorporated throughout the study. First, I filled out a journal entry after every meeting with the TGD Research and Advisory Team. The other team members were also encouraged to do the same. After each focus group facilitation session, the facilitators wrote a reflection about how they thought the session went. Although these journal entries and reflections were not data we chose to analyze, they informed our confidence in the data we were collecting and our thoughts about future directions for this type of research. In addition, before each analysis session, we disclosed our biases going into the analysis. For example, we discussed how our experiences might inform the weight we give a theme or response and how our memory of the frequency of a theme may not always be accurate. These conversations were particularly helpful during the assertion-testing portion of the analysis.

CHAPTER 4: RESULTS - STUDY A

Description of Groups

Five focus groups were conducted with a total of 19 TGD youth. Each group comprised 3 to 5 participants. Table 3 provides a detailed description of the demographics of each group. As shown, Focus Group 1 contained primarily White transgender men or masculine-identifying youth. Focus Group 2 comprised primarily gender diverse White youth. Focus Groups 3 and 4 comprised predominantly Black transgender women. Focus Group 5 was composed of primarily White transgender women. Groups 1, 2 and 5 were composed of people who were 1-2 years younger than those in groups 3 and 4, which included TGD youth who were college or graduate students. Groups 3 and 4 were predominantly older youth/young adults who were not in school/out of school and employed.

Table 3. Description of Focus Group Participants

#	Location	n	Race/ Ethnicity	Gender	Age
1	East Lansing	3	White	Gender queer masculine	Mean =21.3
			White	Transgender man	
			Asian/Mixed	Transgender man	Range =18-24
2	Ann Arbor	5	White	Trans masculine non-binary/genderqueer	Mean =22.6
			White	Transgender / Nonbinary / Agender	
			White	Non-Binary / Gender Fluid / Genderfuck	Range =20-24
			Asian	Genderfluid/transgender	
			White	Transsexual male	
3	Detroit	5	Black	Transgender woman	Mean = 23.6.
			Black	Transgender woman	
			Black	Transgender woman	Range = 21-26
			Black	Transgender woman	
			White	Transgender woman	

Table 3. (cont.)

4	Detroit	3	Black	Transgender woman	Mean = 23
			Black	Transgender woman	Range = 20-26
5	Virtual (Lansing)	3	Black	Androgynous man	
			White	Transgender woman	Mean = 21.3
			White	Transgender woman	Range = 20-22
			White	Transgender man	

Defining Power

Through research aim 1, the Research and Advisory Team and I sought to understand the factors that influence TGD youth's relationship with power—specifically, what power means to TGD youth and what circumstances or settings contribute to youth's feelings of power(lessness). At the beginning of each focus group session, we provided a definition of power ('the ability or opportunity to make a decision about your life or circumstances in your life and follow through on that decision'). At the end of each focus group session, participants were asked to categorize, theme, and summarize their group's collective thoughts on power. Although the definition we provided resonated with participants, most groups found the definition to be too simple. One group commented:

Participant 1: "I feel like this definition is kind of singular, like doesn't really talk about people or systems..."

Participant 2: "...or resources, because you can't make the changes if you don't have resources."

In general, focus group participants' definition of power was significantly more complex and multifaceted than our definition. For TGD youth, power was characterized by agency over decisions about their bodies, their identities, and their ability to lead healthy, successful lives. Furthermore, participants believed power was multisystemic and could be controlled or created on an individual level or a macro level. Power was described as an agent of prejudice; it clashed

and converged with other meaningful social identities that were entrenched in cultural and historical contexts. Power was impermanent; it could be lost and reclaimed.

Mechanisms of Power

Table 4 displays the mechanisms identified in the current study and the mechanisms of gendered power in Walker & Pratto's (2004) theory. Youth identified mechanisms that restrict their power (gatekeeping, violent control and reifying heteropatriarchy) and mechanisms that restore their power (educating and advocating for rights, lifting up self and the TGD community, disrupting power imbalances, enacting physical expression). The restrictive mechanisms were deeply rooted in systems of oppression—the discriminatory institutions, structures, laws, and social norms that underlie our society. Because TGD youth identified with a marginalized gender identity, members of privileged groups were able to exert their power over TGD youth and reinforce normative gendered power dynamics. These mechanisms were used to limit, threaten or control TGD youth's agency over their identity. However, youth also identified strategies for reclaiming power. Just as restrictive mechanisms for maintaining powerlessness among TGD youth were rooted in systems designed to remove or undermine individual agency, mechanisms for restoring power promoted agency by dismantling these gender-based oppressive systems at the systemic and community levels.

In the focus group sessions, participants noted that gender-based oppression occurs in the context of other forms of identity-based oppression. Therefore, analysis of participants' perspectives on power must employ an intersectional perspective to contextualize the mechanisms of power and powerlessness for focus group participants who hold multiple social identities. In this study, participants discussed oppression based on race, class, sex, and gender.

The following section describes each of three restrictive mechanisms of powerlessness. Next, I discuss the ways in which participant's multiple social identities impacted their experience of restrictive and restorative mechanisms of power. Finally, I will introduce each restrictive mechanism and highlight when youth felt powerful focusing on the creative ways in which they reclaimed their power from oppressors.

Table 4. Comparison of Walker & Pratto's (2004) theory of gendered power and results of the current study

Walker & Pratto's Mechanisms of Gendered Power	Description	Current Study's Mechanisms of Gendered Power	Description
Allocation and Control of Resources	Local customs, laws, or domestic arrangements that contribute to cisgender women's lack of access and control over resources	Gatekeeping	Prohibitory people and policies that restrict or control another individual or groups' access over resources, opportunities, or advancement
Force	"Unofficial terror", rape, sexual assault, or any violence perpetrated against cisgender women	Violent Control	Name calling, misgendering, misnaming, or harassing someone based on identification with a marginalized social group
Consensual Ideologies	Shared cultural beliefs about gender roles, norms, and stereotypes about cisgender women	Reifying Heteropatriarchy	Enforcing societal expectations and norms about gender
Asymmetric Social Obligations	Cisgender women's responsibilities to their social systems (e.g. families)	--	--
--	--	Restorative Mechanisms of Gendered Power	Strategies and tactics to reclaim to dignity, self-worth, and control over identity

Restrictive Mechanism 1: Gatekeeping

One of the major mechanisms to restrict power and maintain systems of oppression was gatekeeping. Specifically, participants discussed prohibitory people and prohibitory systems

(e.g., laws, procedures, policies) that control an individual's or group's access to necessary resources, opportunities, and advancement. One participant said: *"It has caused a sense of restriction of a whole scale in the sense of the resources we have access to due to our gender identity."* Through various types of gatekeeping, participants felt powerless to the external forces that governed personal decisions over their bodies, identities, and futures.

Parental gatekeeping. Parents were gatekeepers to vital resources necessary for survival (e.g., housing, money, transportation, food, health insurance) among younger participants. Access to these resources was contingent upon complying with parental rules and expectations. This often meant that TGD youth had to present as their birth sex to maintain access to resources. Parents also exercised control by taking away youth agency in decision making. One participant said: *"I won't be able to make decisions for myself until I graduate,"* referring to how their parents controlled all their decisions, particularly gender-related decisions, while the parents were paying for the participant's education. One youth described how they found themselves self-policing their behavior and expression in the same way their parents would. They said: *"I surveil myself now, which totally sucks, as a result of the power dynamics."* Youth also felt powerlessness when parents or other adults did not trust them to make decisions about their lives. One participant described this phenomenon as: *"infantilization of me/trans men."* This type of gatekeeping was especially upsetting to participants as regarded their medical decisions. One participant explicitly stated, *"My family has great control over my life, especially my medical life."* For youth who were still covered by their parents' insurance plans, parents had control over medical procedures, medications, and services youth desired. Parental control over youth's bodily autonomy was often leveraged through resources. One participant specifically noted that after coming out, their parents threatened to remove their medical insurance coverage. For these

youth, the inability to have a voice in decisions affecting their health, expression, and bodily autonomy contributed to considerable feelings of powerlessness.

Opportunity gatekeeping. Gatekeeping for these youth also occurred in contexts outside the home, such as in the workplace. In these contexts, gatekeeping was discussed as blocking opportunities, whether from advancement or employment. One gender-diverse participant felt that he lost a promotion opportunity because of his gender. He said: *“They’re not giving me the position I deserve so that I can be making the money I deserve because I am a gay androgynous male.”* This conversation continued, with participants discussing a place of employment that refused to hire trans or gay girls and instead would only place them as volunteers. One participant also disclosed that another company in the same community refused to hire them because of their gender identity: *“They said they wouldn’t hire me because of my experience. Because I wear makeup and stuff. That I wouldn’t be able to cross into the heterosexual community as well.”* Some participants discussed discomfort or fear associated with even applying for jobs because of learned rejection sensitivity (Downey & Feldman, 1996). One participant described how powerless they felt *“...when I had zero moneys and feel ‘too trans’ to get a good job”*.

Power was discussed very differently among Black participants when compared to White participants. More specifically, Black participants were more likely to discuss powerlessness stemming from the historical oppression of Black people *and* TGD people. As such, opportunity gatekeeping was primarily discussed within the Black focus groups, where participants felt that identifying as both Black and trans exponentially diminished their power over their future advancement and ability to obtain basic resources. One participant stated: *“Yes, my race and my sexual gender role has restricted me with getting jobs and also receiving assistance.”*

Being transgender also intersected with socioeconomic status, often due to the financial burden of medical transition. TGD youth considered the financial demands of medical transitions as yet another opportunity to be withheld from making important medical decisions about their bodies. One youth described transitioning as a privilege that: *“often requires you (or your family) to have enough money.”* Several high-SES participants recognized this privilege. One participant explicitly stated: *“Growing up high SES with wealthy parents, yes, gave me more power over transition-related decisions.”*

On the other hand, participants of lower SES or impacted by racial (and consequently financial) oppression, felt they were made powerless by their financial situations. One participant laid out all her medications from her purse during the focus group session to demonstrate the expense of a basic need. She said: *“For these little dumbass tablets, each pill was \$6. For these, it was each pill \$2...”* Finally, one participant discussed how the medical costs of transition limited the money available for other needed services, such as mental healthcare. They wrote: *“Being trans is also really expensive...Which doesn’t leave room for much other healthcare or mental health care (even though it causes a lot of health/mental health issues).”*

Youth in three focus groups discussed how the administration in their secondary schools restricted their power to be safely educated during the school day by enforcing transphobic policies. One youth said, *“When I went to school, the administration was the root of all my power lost.”* A participant in a different group noted ways in which religious schools (including theirs) enforced policies about clothing and hair length for boys and girls that created situations in which freedom of expression was sanctioned. Transphobia also extended beyond formal administrative policies into a toxic school climate. Youth described disrespectful daily interactions with school faculty and staff. One youth said: *“... [attending school was] definitely*

a point of contention for me since it was the place.....to hear these respected leaders spout so much hateful rhetoric.”

Systemic gatekeeping. All youth discussed ways in which the healthcare system restricted youth from having access to decision-making power over their own bodies and health. For many youth the healthcare needs related to their transitions were lengthy, expensive, and difficult to access. Participants described how each step to accessing transition-related healthcare was another opportunity to be shut out, invalidated, and left to feel powerless over their bodies:

“When they diagnose us and they see that you a trans woman—cause it show up in your file when it come to insurance—they play in your face. They switched my healthcare to somewhere I don’t even go. McLaren don’t even do anything for trans women. They didn’t pay for my medication, surgeries, doctors for trans things.”

Quality and continuity of care was particularly frustrating for TGD youth. One participant disclosed that throughout the 7 years of their medical transition, they had eight different doctors because they kept encountering providers who could not, or would not, provide quality care. One participant discussed switching doctors because of long wait times to get the ‘good’ doctors. For these youth, a ‘good’ doctor was someone who provided gender affirming care (e.g., competent about unique TGD health needs, respectful, validating). Finally, youth discussed complications with insurance coverage itself. A transgender man echoed this sentiment when describing being denied coverage for a hysterectomy. Similarly, several focus group participants discussed needing to overcome various obstacles to access hormone replacement therapy (HRT). One participant noted the difficulties merely renewing their prescription to HRT as a threat to their power over their own bodily autonomy. They wrote: *“I needed therapy letters to continue HRT after being 3+ years on HRT.”*

This type of gatekeeping was particularly acute for gender diverse participants, who were significantly more likely to encounter barriers trying to access gender-related healthcare. Gender

diverse participants often commented on the extreme lack of public awareness, specifically in the healthcare system, on the needs of gender diverse individuals. Within healthcare contexts, participants noted how they had to “*fight to have my pronouns used. Have my ID seen as legitimate and as worthy of [healthcare] care as binary trans people.*” A couple of participants experienced prejudice and restrictive institutional policies when trying to seek HRT. One participant expressed fear even in asking: “*I haven’t been able to go on T [Testosterone]. I’m afraid they won’t give it to me because I’m nonbinary.*”

Further, when discussing systemic gatekeeping as a mechanism to restrict power, Black participants often discussed being withheld from accessing basic needs (e.g., housing, food stamps, employment). In contrast, White participants often referred to gatekeeping solely within the healthcare system and in ways unrelated to their race. One participant discussed how being Black and trans impacted access to basic needs:

“I have to fight harder to get those certain things...like you’ve ‘gotta fight harder to get insurance. You’ve ‘gotta fight harder for housing. You’ve ‘gotta fight harder for jobs. Because I’m not just one thing. I’m two things the world don’t accept. I’m black and I’m trans.”

Restrictive Mechanism 2: Violent Control

Outside of systemic contexts, agency was also diminished through interpersonal interactions. Violence and harassment were discussed in every single group. Most often, participants reported being victim to verbal violence as a means of control them; to bully and intimidate them back into the gender status quo or make them feel othered. Acts of violence were informed by stereotypes, misrepresentations, and assumptions about TGD people. One participant pointedly stated: “*Intimidation is key to them, the heterosexuals.*” Throughout discussions of power and control, youth participants provided countless examples of verbal and emotional violence perpetrated by peers, family members, strangers, medical providers, teachers,

administrators, and policy makers. One participant said: *“Some of them [cis/het people] are scared of us [trans people] ...They try their best to tear us down and make us not feel comfortable.”*

Interpersonal harassment was particularly endemic in healthcare settings where several participants reported being: *“Misgendered/misnamed/treated strangely/with suspicion in medical spaces.”* One participant wrote about their experience in the emergency room: *“being misgendered. Being neglected. Being conscientiously objected to.”* During this same focus group, participants disclosed other interactions with providers that they deemed inappropriate, offensive, or even violent. One participant disclosed that their Gastroenterologist once asked him: *“how do they make your penis?”* Youth discussed how these experiences contributed to feelings of fear and distrust, particularly in medical settings. Gender-based violence was also evidenced in homes through select examples of physical and emotional abuse from parents and loved ones. A young White trans woman asked the recorders to be shut off while she disclosed her experience with homelessness, sexual assault, victimization, and human trafficking following her transition.

The predominately Black focus groups were more likely to discuss violence outside of interpersonal interactions and relationships. In these groups, Black TGD youth discussed institutional and community violence, lamenting the violent killings of Black trans women in Detroit. Black participants also discussed violence enacted in schools or in the workplace based on their gender identity. One participant felt that their trans gender identity was *‘tokenized and exploited’* at their place of work. The same group discussed *“outing”* as a form of violent control. They collectively commented on a local company that outed their sole trans employee. One participant explained to the group: *“They only hired one trans woman because they had a grant*

that they said to hire one trans woman. She thought she was going in with no one knowing she was trans. The whole building knew because of the grant.”

Discussions of gender-based violence were deeply entwined with the notion of ‘passing’ as it is commonly defined in the transgender community; being perceived by others in the gender they wish to present. This term originated in reference to racial identities. ‘Passing’ occurs when an individual in a racial group is classified as a member of another. Most often, the term is used to characterize minority individuals from a devalued racial group, typically “fair skinned” or “racially ambiguous,” who can be mistaken as White. Motivated by social privileges and/or survival, these individuals ‘pass’ as White and move within White society, avoiding discrimination and racism (Hobbs, 2014). Although the historical understanding of racial passing pertains to embodying a majority identity to navigate a racist world, the current understanding of gender passing pertains to attaining the successful and credible embodiment of the desired gender identity. As a result, many TGD youth, including participants in this study, desire a future where they can ‘pass’ as cisgender men or women, and avoid the discrimination that comes with TGD identification. One participant noted: *“when I get correctly gendered by strangers, it’s like this really nice feeling.”* In this way, the social rewards and advancement attained from ‘passing’ remain constant. In this study, participants who classified themselves as ‘not passing’ felt subjected to increased harassment and violence compared to their ‘passing’ peers: *“Being both trans and not passing often makes people feel like they can disrespect me. And often I don’t have the power to fight back because I’m afraid.”* Similarly, a trans woman who was not yet passing said: *“The more easily mockable I appear, the less power I have.”*

Across groups, participants noted the negative outcomes or consequences from being victims of violence. Youth felt powerless in these actual encounters, noting feelings of rejection,

shame, and invalidation. When asked if others' perceptions of youth influence the amount of power you have, one participant bluntly said: *"Yes. When my family repeatedly reject and misgender me."* Fear of violence also served to control youth's feelings and behaviors. One focus group engaged in a discussion about the hyperawareness of other's perceptions of them. One participant questioned: *"Am I in danger because of their perceptions?"*, another group member disclosed: *"Hiding the 'queer' parts of me to feel safer."* Another participant described internalizing negative comments: *"I'm a very powerful person, but because of people's perception of my identity, I feel a little insecure which causes me to diminish my power. I start to doubt myself and feel less powerful."*

Mechanism 3: Reifying Heteropatriarchy

Societal expectations and norms continue to be one of the strongest forces maintaining power imbalances among TGD people. Youth described how heteropatriarchal views about gender reinforced their feelings of otherness and powerlessness. This mechanism primarily functioned through the erasure of TGD youth and the enforcement of traditional gender norms. Youth described how when society privileges the cisgender identity, especially cis-masculine identity, it reduced agency about decisions over their lives and bodies.

Through the privileging of cisgender individuals, TGD youth felt their needs, experiences, or realities were erased. The ignorance and dismissal of TGD youth was especially impactful for nonbinary and gender diverse participants. Failure of the public to acknowledge the existence of gender diverse individuals left youth feeling invalidated. One participant said: *"if you're coming out as non-binary, there are a lot of people out there to just not accept that as a part of the gender spectrum and it's kind of sad really."* One gender diverse participant called out the greater LGBT community and smaller transgender community for maintaining injustice: *"I get more backlash from the gay community than the straight community, and most of it comes*

from trans women. How are you doing that? You can't want respect and then disrespect somebody else. It's a two-way street." Gender diverse participants often commented on the extreme lack of awareness in the public, and specifically the healthcare system, on the needs of their community. For these youth, systemic erasure of nonbinary individuals impacted the availability of gender-specific resources, information, policies, and protections. One participant explained that: *"A lot of cis people don't know that non-binary exists."* Two groups discussed that their doctors lacked awareness, and education of TGD healthcare which resulted in restricted access to medication, services, and resources. One participant said: *"Being nonbinary makes healthcare a nightmare."* Several youth called for more research on TGD specific health needs, particularly in relation to how hormones affect physical and mental health. One participant said: *"I want to see more research done on the effects of HRT on health because I feel like a lot of that is unknown."*

Participants lamented the overall lack of acceptance of TGD people through the enforcement of traditional gender norms: *"In education they don't tell you it's ok to be different. They always want you to conform as a society because they want you to succeed in society and that's what society wants you to do."* Feeling pressured to comply with gender norms was almost exclusively discussed among the nonbinary participants who felt compelled to comply with gender norms to avoid social sanctions. One participant wrote: *"Dressing within the binary earns me more respect."* Even participants who felt pride in their defiance of gender norms, discussed the negative outcomes that came with that defiance as a form of powerlessness. One participant wrote: *"Sometimes I feel like my pride in my ambiguity make people invalidate my perception of reality."*

Finally, across all groups, participants discussed the ways in which male privilege, perceived masculinity, and misogyny affects power. Given the diverse identities in focus groups, all participants were able to reflect on how it feels (or felt) to be perceived as masculine or male in any given space. These comments highlighted the pervasiveness of male privilege and power, even among individuals who reject societal gender norms. One participant discussed how once they started ‘passing’ as male, they felt like they had more control as compared to when they identified as female. They said: *“Right away what I noticed when I started passing more was less people who were a little bit more ready to take control for me.”* Similarly, participants identifying as gender diverse discussed receiving different treatment depending on how they were outwardly presenting on a given day. One participant said: *“In queer spaces, my whiteness and (incorrectly) perceived masculinity give me power and preference.”* Finally, some participants discussed how presenting as less masculine drastically reduced their agency in most settings. One participant said: *“My chest, if unbound, almost always demolishes my own power in non-queer spaces.”* Similarly, a young White trans woman discussed how her transition led to ‘violence’, ‘victimization’ and ‘exploitation’ that she never experienced when living as a man. Another participant described the noticeable difference in treatment from when they were perceived as masculine to now being perceived as feminine. They said: *“I’m very expressive, flamboyant at times. As a pre-t AFAB (assigned female sex at birth) person. I’m not taken seriously because association with femmeness and that’s hard. It’s different than when people thought I was cis.”* Two groups discussed inequities in cost and access for transition-related medication for transgender men versus transgender women. Furthermore, some comments indicated that inherent male privilege restricts power even within a marginalized gender identity. Black participants discussed how stereotypical views of Black women compounded feelings of

powerlessness, specifically when trying to attain employment. One participant said that society's view of women as “*emotional*” and trans Black women as “*traumatized*” led coworkers to invalidate her opinions:

“I’ve been in spaces professionally where people are ready to assume whatever I’m about to say, or whatever I’m about to suggest is going to be ‘too radical’ or its coming from a place of ‘pure emotion’. That what I’m saying is not logical. Like, ‘she’s a Black trans woman so she’s angry. She’s scared by all this trauma’. They assume what I have gone through, so they take everything you say with this skewed perspective. I can’t just be coming from a factual place. It can’t just be from me having knowledge about this subject. It has to be from...it has to come from a place of trauma. Or they pity you because they assume you had such a hard life. And it’s like, ‘well, no it wasn’t that bad actually’.”

Power and Intersectionality

A salient theme throughout all focus group discussions was my “*gender identity does not encompass all that I am.*” This quote captures two important ideas about how participants discussed power in light of their multiple social identities. Participants described others failing to honor their other identities and being reduced to the identity that the person in power finds most repugnant. Within these discussions, participants underscored that the privilege and oppression they experienced comes from their multiple identities, not solely from their gender identities. Further, each mechanism's execution or manifestation differed as a function of the unique combination of youths' identities, including gender identity. More simply, mechanisms through which power was restricted (e.g., gatekeeping, violent control, reifying heteropatriarchy) were moderated by other social identities.

Race. In this study, racial identities clearly moderated mechanisms of gendered power. People in Black and predominantly Black groups discussed the impact of racism on their lives broadly and specifically as TGD persons, underscoring how both racism and transphobia contributed to powerlessness. This intersection was most evident in discussions of ‘opportunity gatekeeping’, in which Black participants felt they had lost out on opportunities and resources

because of both racism and transphobia. The mechanism of violent control also manifested differently within predominately Black focus groups. Although all participants discussed the overwhelming prevalence of verbal violence and harassment in their lives, Black participants discussed being victim to or witnessing multiple forms of violence against TGD youth.

Ethno-racial identities were *only* discussed in groups that had at least one participant of color; racial identity was not discussed in the all-White group. Groups comprised of all (or predominantly) Black participants consistently identified both their race *and* gender when discussing power. For these participants, those identities were inseparable. For example, a trans woman who is Black discussed experiences as a “Black trans woman” rather than “a trans woman.” How Black participants discussed their gender identity interlocking with their racial identity highlights the importance of applying intersectional and critical race framing to gendered power work.

Socioeconomic statuses (SES). Youth’s SES also impacted perceptions of power and privilege. Many participants discussed the power that came from belonging to a higher socioeconomic class, and the ways in which access to money mitigated feelings of powerlessness. *“I feel like currently my power is restricted due to poverty and financial issues.”* Conversely, other participants disclosed how poverty only compounded their feelings of powerlessness. Again, as shown, SES moderated the gatekeeping mechanism by cushioning powerlessness for the rich and exacerbating it for the poor, who were also more likely to be Black.

Masculinity and femininity. Misogyny and male privilege considerably impacted TGD participants’ perceptions of power and powerlessness. Across all groups, participants discussed the ways in which their perceived masculinity or femininity affects power. Given the unique

gender experiences of the participants in these focus groups, all participants were able to discuss the ways in which the power they had over others or over themselves differed based on whether they were presenting as more feminine or masculine and the extent to which others attempted to exercise power over them. Conventionally masculine and feminine presentations and identities moderated the reifying heteropatriarchy mechanism such that masculine expressing TGD youth perceived themselves, or were perceived as, being more powerful.

Binary/nonbinary. Finally, binary and nonbinary gender identities emerged as important moderators of power. Individuals who identified within the binary, generally ascribed to the binary gender system, whereas nonbinary individuals rejected this system and identified outside of that system. These identities moderated gatekeeping and reifying heteropatriarchy mechanism. More specifically, nonbinary youth were considered less mainstream and therefore less well understood by adults in their lives, as well as broader society. As illustrated in this study, marginalization breeds misinformation, stigma, and oppression. Therefore, nonbinary youth struggled to gain access to transition-related healthcare, as well as information and validation of their identity.

Restorative Mechanisms

Although focus group participants identified numerous ways in which TGD youth's power over their identities was diminished, participants also identified mechanisms for restoring power. In these discussions, youth described creative strategies to take back control and feel powerful over their decisions, health, and identity. Four mechanisms for power reclamation are discussed: 1) enacting physical expression; 2) disrupting power imbalances; 3) educating and advocating for rights; and 4) lifting up the self and the TGD community.

Bodily autonomy and expression. The most common way participants discussed taking back power was through enacting bodily autonomy and physical expression. Specifically, participants felt powerful when they were able to present themselves to the world in the same way they see themselves. One participant explained: *“When I dress and present the way I want regardless of how people feel about me makes me feel like I took my power back.”* Several participants discussed how powerful they felt making decisions regarding their own bodies. Participants discussed getting tattoos, cutting hair, and getting piercings as acts of taking back the control of their body. One participant who described feelings of powerlessness when *“stupid cis men recognize my boobs,”* discussed the power they felt return to them when they bought their first binder. They said: *“Bought a binder the first time when I was 18. That was liberating.”* Other participants discussed how finally starting HRT and transition-related medical procedures contributed to feelings of power. Some participants found power in defying traditional gender expression norms: *“I feel powerful when I defy what others expect of me; when I make my own decisions.”* This was particularly common among gender diverse participants. One said: *“How I present. So being genderfluid is kind of a way for me to take back some of that power.”*

Finally, some participants noted that exercising or engaging in other physical activities helped them take power back. One participant said: *“Going dancing. It’s one of the few things that lets me feel in control of my body.”*

Disrupting imbalance. In contrast to the prohibitory people and policies restricting youth agency over their bodies, youth reclaimed power through changing the context that disempowered them. This occurred through youth actions of self-governance or systemic policy and practice changes that supported autonomy and agency over their lives, decisions, and identity.

On an individual level, youth took back power by making decisions for themselves, such as leaving home, getting a job, and controlling their own finances. Moving away to college was particularly empowering. One participant said:

“The power to be you...which is an odd concept already, but we don’t really have that kind of a privilege in your home. Going to college or somewhere you just have a bit more freedom with that it’s definitely a bit more uplifting and you feel more in control of things.”

Others commented on the sense of freedom they felt being away from home or working their first job: *“I feel like being at college and being away from your family that just gives you a freedom that a lot of people didn’t have before.”*

On a systemic level, participants discussed feeling more in control when systems and institutions implemented policies validating their gender and supporting their ability to access resources. Participants discussed the new Michigan policy that allows TGD individuals to change their gender marker on their license at the Department of Motor Vehicles, restoring their agency over their names and genders on legal documents (Michigan Secretary of State, 2019). Participants also appreciated gender-affirming university and workplace settings. One participant stated: *“[University Name] gave me the confidence to come out because they mandated that all professors had to do pronouns in their classes.”* Another participant described how they felt receiving a name tag with the correct name and pronouns for the first time:

“I got my first job last year and I got my first ever name tag with my preferred name on it and that was amazing. Having other people use that name and pronouns and everything that kind of empowered me a little bit but also helped me improve how I approach my own identity but made me feel like I had control in some aspect of my life.”

Within the health care system, one participant discussed a recent change to health insurance coverage for TGD people ordered by the Michigan governor (Michigan Department of Health and Human Services, 2020; Patient Protection and Affordable Care Act, Section 1557,

2010). She said: *“Molina [sic] is the insurance that covers the whole [transition] process, so nothing will get denied. Gretchen Whitmer just put it in place.”* These types of systemic changes created contexts in which youth felt a sense of agency again over their health. This extended to a system of doctors who were educated and gender affirming of TGD patients. A minority of participants discussed how being able to access and receive gender affirming healthcare felt like power was being restored. One participant said: *“I trust my doctor. I have [Doctors name] and he’s been sort of very transparent with it and has been up to date on the little research that has happened with hormone replacement therapy and I’ve had a good experience.”*

Finally, some participants did not wait for the system to change. Instead, these participants discussed reclaiming power by organizing and advocating for change. Youth within the Black and predominately Black focus groups reported taking back power by combating adversity through changing the people and settings that oppressed them. One participant said: *“Yes, when I feel someone feel like they can take my power away I take it back and show them how it supposed to be used.”* One participant discussed how they took the lead to instate a LGBTQ+ training at their workplace because of mistreatment they had experienced. Another discussed how she worked against her school’s teachers and administration to make her school a safer place for TGD youth:

“When I went to high school, I started transitioning in my 9/10 grade year. I had to fight for my respect. Now, if I go up there, there’s respect because of what I went through. Training happened because of me. Because I stepped up. I made it more powerful than it was... I had the whole district have the training. Not just the training. They had to do certain meetings because of the issues I brought up.”

Lifting up the self and TGD community. Although many participants felt defeated by experiences of violent control, gatekeeping and heteropatriarchy, participants were still able to harness hateful energy as positive and productive. One participant said: *“The love and hate I*

receive from people provide me with strength and confidence.” Another participant echoed a similar sentiment: *“I feel like my power comes when a ho feels like she can take my power.”*

Additionally, several participants discussed finding power through giving back to the community and helping other TGD youth. Supporting their peers contributed to feelings of validation and worth.

Support for the TGD community was evident across races. A Black trans woman discussed how she felt powerful supporting a White trans woman who was unable to attend trans support groups, because they were only for trans women of color. She said: *“I am here for your transition because I need somebody to be here for mine. I don’t care what color you is... Us younger girls, we have to tear down those walls and start building those bridges.”* Others discussed the power they felt in being a TGD *“role model.”* Youth enjoyed being able to support other TGD youth just by being visible to them. One participant elaborated: *“My visible queerness allows me to signal to other queer folks in spaces. I cherish that power.”* The idea of being visible for the sake of others and creating a safer space for the future TGD youth was noted across groups:

“...honestly, really the thing that keeps me going as far as expressing myself the ways that I want to when I feel safe enough to do so. I know it affects other people because other people expressing themselves differently affected me in a really positive way, and made it possible for me to do that. And, I feel that it’s important to pass that on... it is important to be seen, and to see others.”

Finally, participants also felt power from their own personal success and from collective success from the queer community: *“Hearing the success within our community makes me feel more powerful. I feel that due to the opportunities they have [our community], more opportunities are available to me.”* Youth who had overcome hardship felt especially powerful

for achieving their goals. This was particularly prominent in the Black groups when participants commented on the sense of power, they felt attaining jobs and graduating as Black TGD youth.

Educating and advocating. Finally, many participants discussed reclaiming power through education and advocacy. These participants discussed how they educated themselves about gender, transitioning, sexual health and other important topics. One group commented that, since they do not learn about transitioning or sexual health for TGD people in school, they learned through the informal conversations or the internet:

“I have gotten almost all of the information I know about T through, Hearsay. I have been in the community since 2014. I wanted to know everything so I would just go around to different people and ask things. For example, there is a Tumblr where you anonymously ask questions about how hormones work, and people answer and stuff like that. And just hearing people talk about their experiences for years, you learn.”

Staying informed and current on the health needs for TGD people provided youth with the necessary knowledge to advocate for themselves and their needs, particularly in healthcare settings. One youth said education helped them figure out how to “...take advantage over my needs/health.” Several youth also discussed feeling powerful when they pay that knowledge forward. One youth wrote: “Being able to be here (MSU) and help educate people, finding spaces where I’m wanted and change them for the better.”

Taken together, several mechanisms of gendered power emerged that either restricted or restored youth power. Gendered mechanisms were multilevel and intersectional in execution and experience. Through gatekeeping, violent control, and reification of heteropatriarchy, external forces attempted to control youth’s identity. In doing so, gendered mechanisms of power restricted youth’s agency over decisions, access to information, resources, and opportunities directly pertinent to youth’s health and general wellbeing. Furthermore, a central feature of youth’s discussions of gendered power focused on strategies to reclaim or restore power.

Restorative mechanisms addressed and dismantled existing gender power imbalances to promote behaviors, circumstances, and settings where TGD youth felt comfortable and in control of their bodies, their decisions, and more importantly, their identities. Finally, youth described direct and indirect impacts of gendered power on their ability to access healthcare resources and services safely, comfortably, and equitably.

CHAPTER 5: STUDY B - SECONDARY DATA ANALYSIS

Through secondary qualitative thematic analysis, Study B examined the relationship between gendered power and healthcare access for TGD youth living with HIV. Three specific research aims guided this analysis: 1) informed by the findings from Study A, I explored how gendered power is manifested in discussions with TGD youth living with HIV; 2) investigated how, if at all, gendered power influences engagement in HIV prevention and care (P&C) and, 3) looked for similarities and differences in experiences among people with different gender identities and racial/ethnic minority statuses.

Context

The current study involved a secondary data analysis of a subset of data from the Affirming Voices for Action Study (AVA), a mixed-methods study of the Adolescent Medicine Trials Network for HIV/AIDS interventions (ATN). AVA was a transformative multiphasic mixed-methods research study completed in 2017 in partnership with University of Michigan and the ATN. The ATN is a large research consortium focused on implementing and evaluating biomedical, psychosocial, and systemic interventions to curb the HIV epidemic among youth. The AVA study focused on exploring factors that influence the HIV prevention and care continuum for TGD youth who are living with HIV and those not living with HIV or who are unaware of their HIV status. During the primary data collection phase, the following types of data were collected: a) quantitative surveys from TGD youth living with HIV; b) quantitative surveys from TGD youth unaware of HIV status or not living with HIV; c) qualitative in-depth semi-structured interviews with TGD youth living with HIV; d) qualitative in-depth semi-structured interviews with TGD youth unaware of HIV status or not living with HIV; and e) qualitative semi-structured in-depth interviews with healthcare and social service providers.

Given the purpose and scope of this study, I used the data from phase c— qualitative interviews from TGD youth currently living with HIV (n=66).

Participants & Procedures

Recruitment. Potential participants were recruited from 14 local Adolescent Medicine Trial Units and local organizations serving TGD populations through purposive sampling (Ziff et al., 2006). Small incentives were provided to sites to aid in recruitment. Interested participants were given information about the study and subsequently screened for eligibility after obtaining verbal consent. Eligible participants were: 1) between the ages of 16 and 24 years old; 2) did not identify with their sex assigned at birth; 3) able to understand, read, and speak English; 4) able to provide informed consent; 5) willing to participate in the quantitative survey *and* an in-depth face-to-face interview, and, 6) reported to be living with HIV, not living with HIV or unaware of their HIV status.

Participants. Of the 181 youth in the full sample, 66 youth were currently living with HIV. Approximately 95% (n=63) of the participants living with HIV also completed the quantitative online survey. For these participants, we have detailed demographic data. Given the importance of knowing these participants' gender identity and racial/ethnic identity, I only used the interviews for which I can match demographic data from the quantitative survey. Furthermore, to further reduce the data corpus I used Miller and colleagues' (2018) measure of state-level sexual and gender minority stigma to select participants for my analytic sample. This measure comprises a composite score for each state based on the state's hate crime protections, adoption policies, employment and marriage discrimination laws, and laws on sexuality education. For this study, I decided to include youth living in only the middle third of states because they were neither the most nor least extreme settings. As a result, for the current study, I

examined the qualitative interviews from the participants who: 1) reported they were living with HIV, 2) completed both a qualitative and quantitative interview; and 3) who resided in states that were neither extremely conservative in their state sexual and gender minorities policies, nor extremely accepting.

The final analytic sample for the proposed study is 28 TGD youth living with HIV. In Table 5 I present the detailed demographic data for the full sample and the analytic sample side-by-side.

Table 5. Demographics of Total Sample and Analytic Sample

	Total Sample (n=181) 100.0%		Youth Living with HIV (n=63) 34.8%		Analytic Sample Middle third geo location – Living with HIV (n=28) 15.5%		Test Statistic +
DEMOGRAPHICS	M	SD	M	SD	M	SD	T
Mean Age in Years and Std. Dev.	20.69	2.23	21.30	1.91	21.57	1.73	-2.30 (179) *
	N	%	N	%	N	%	X²
Latino/ Hispanic Ethnicity							
No	129	71.3	102	73.4	24	85.7	3.38 (1)
Yes	52	28.7	15	23.8	4	14.3	
Race							
Black or African American Only	93	51.4	41	65.1	20	71.4	7.82 (5)
White Only	41	22.7	6	9.5	3	10.7	
American Indian Only	2	1.1	1	1.6	0	0.0	
American Pacific Islander Only	4	2.2	0	0.0	0	0.0	
Other Race Only	11	6.1	3	4.8	0	0.0	2.65 (1)
Multiracial	30	16.6	12	19.0	5	17.9	
Person of Color	125	69.1	52	82.5	25	89.3	
Gender Identity							
Female	38	21.0	15	23.8	7	25.0	17.22 (5) *
Male	14	7.7	5	7.9	2	10.7	
Trans female/trans woman	74	40.9	30	47.6	7	25.0	
Trans male/trans man	22	12.2	0	0.0	0	0.0	
Genderqueer/gender nonconforming	26	14.4	12	19.0	10	35.7	
A gender not listed here	7	3.9	1	1.6	1	3.6	

Table 5. (cont.)
Sexual Orientation

Straight/Heterosexual	49	27.1	16	25.4	3	10.7	
Gay/Lesbian/Same-Gender Attracted/Same-Gender Loving	62	34.3	27	42.9	15	53.6	
Bisexual	13	7.2	2	3.2	2	7.1	7.60 (6)
Queer	11	6.1	1	1.6	1	3.6	
Questioning/Not Sure	6	3.3	3	4.8	1	32.1	
Asexual	2	1.1	0	0.0	0	0.0	
Another Sexual Orientation	38	21.0	14	22.2	6	21.4	

Note. For binary or categorical variables, where frequencies are reported, the chi-square statistic and degrees of freedom (df) are shown or Fisher's exact where noted. For continuous variables, where mean and standard deviations (SD) are reported, the t-test statistic is reported. Significance was determined at $p < 0.05$.

*Significant at .05.

Participants were between the ages of 18 and 24 ($M=21.6$). Consistent with what we know about HIV rates among TGD youth, all participants living with HIV were TGD individuals who were assigned a male sex at birth (100%, $n=28$). Participants' current gender identities were: "female" (25%, $n=7$), "male" (10.7%, $n=2$), "trans female/trans woman" (25%, $n=7$), "genderqueer/gender fluid" (35.7%, $n=10$), and "a gender not listed here" (3.6%, $n=1$). Unlike the full sample, no participants living with HIV identified as transgender men. Approximately 14% of participants in the analytic sample identified as Latinx ($n=4$). Most participants were Black (71.4%) or multiracial (17.9%). The remaining participants were White (10.7%).

Measures. The AVA research team developed the semi-structured in-depth interview in collaboration with local advisory groups. The interview comprised approximately 50 questions about gender identity and barriers, facilitators, and recommendations for engagement in HIV care at every stage of the HIV care continuum. The interview was divided into 10 sections: 1) introductions, gender identity and transitioning; 2) general healthcare access; 3) HIV prevention; 4) HIV testing; 5) HIV linkage-to-care; 6) retention in HIV care; 7) prescription of antiretroviral medication; 8) adherence to antiretroviral medication; 9) viral suppression; and 10) recommendations to increase HIV healthcare access among TGD youth. Interviewers were

trained to probe for facilitators and barriers at different sociological levels (e.g., individual, interpersonal, organization, policy, and societal). Furthermore, the original study was grounded in phenomenology (Giorgi, 1997; Giorgi, & Giorgi, 2003). Therefore, interviewers were trained to encourage discussion of participants' experiences. A copy of the instrument and detailed guide (including interviewer probes) is available in Appendix E.

Procedures. Data collection for AVA occurred between July and December 2015. Participants completed an in-depth face-to-face qualitative interview with a trained interviewer. Interviews took approximately 30 min to 2.5 hours to complete. Participants were compensated for their time. All data collection procedures and protocols were approved by each local Institutional Review Board as well as the primary investigator's academic institution (University of Michigan). The secondary data analysis for the current study was deemed non-human subjects research by Michigan State University's Institutional Review Board (determination letter available in Appendix C).

Analytic Plan

To explore if and how youth talked about gendered power in their interactions with HIV prevention and care services, I used an inductive thematic analysis approach (Braun & Clarke, 2006; Guest, MacQueen & Namey, 2012). Thematic analysis is an analytic approach to qualitative analysis that is heavily influenced by grounded theory (Charmaz, 2008; Corbin &

³Grounded theory is a set of methods for data collection and analysis with the specific intention of developing a theory that is rooted in the specific data at hand (Charmaz, 2006). Grounded theory generally includes the following elements: 1) concurrent data collection and analysis; 2) purposeful theoretical sampling 3) identification of in-vivo codes; 4) systematic comparison and consideration of the dimensions and properties of codes; 5) organizing themes into categories that correspond with the conditions, actions, and consequences that are part of the process of interest; 6) building a single theory that explains the phenomenon of interest and 7) memo writing and member verification.

Strauss, 1997; Glaser & Strauss, 1967)³. At its core, thematic analysis is used to identify and analyze emergent themes and interpret relationships in qualitative data (Braun & Clark, 2006). The main goal for thematic analysis is to identify patterns inductively to understand how people feel, think, and talk about their experiences in relation to a specific topic. The output for thematic analysis can either be the development of a theory, solutions to real world problems, or simply better understanding of individual or group experiences (Guest, MacQueen & Namey, 2012). Finally, this approach is intended to be pragmatic and flexible, therefore does not ascribe to a specific theory or epistemology.

Thematic analysis is a well-suited approach for this dissertation for several reasons. First, thematic analysis is a rigorous method useful for generating exploratory knowledge on a given topic. Given the grounded theory influence, thematic analysis supports transparency in analytical decisions and methodical coding, organizing, and comparison processes. Second, thematic analysis is pragmatic. Unlike grounded theory, which necessitates concurrent data collection and analysis, thematic analysis is a pragmatic approach to qualitative research, often encouraging the use of multiple coding and analytical tools. Therefore, thematic analysis allows for more flexibility. This flexibility is particularly useful when working with larger sample sizes and lengthy interviews, as in the current study. Third, thematic analysis encourages theory development, but is flexible to other analysis outputs. This also fits with the current study given that this project was exploratory, but also informed by an existing theory. Although the goal of this study is not to apply Walker & Pratto's (2004) theory of gendered power directly, some of the coding was unquestionably informed by this theory and other previous literature. Furthermore, findings from Study A informed coding for the current study. Therefore, it is important to have an analysis method that allowed for both data-driven and theory-driven coding

approaches. Finally, thematic analysis is an easy method to implement and teach to others. This advantage is compatible with my participatory research paradigm, such that members of the TGD youth Research and Advisory Team had the option to get trained as analysts.

The analysis for the current study was broken up into two phases: 1) Structural coding for data reduction to segment, label, and index relevant excerpts from the larger data corpus; and 2) Thematic analysis to examine commonalities, differences, and relationships in participants' discussions of gendered power. Each phase is explained in detail below. Coding activities used both Nvivo and MAXQDA software. Quantitative demographic data were imported into MAXQDA as case characteristics linked to each individual participant.

Phase 1: Structural coding. The researchers who originally designed and collected the current study data expressed uncertainty about whether discussion of gendered power would emerge in the qualitative interviews. As a result, I began the analysis with a structural coding phase to confirm the quality and frequency of the discussions surrounding gendered power. Structural coding is a data reduction method that uses the topic of inquiry to segment data (Miles & Huberman, 1994; Namey, Guest, Thairu & Johnson, 2008). This method is well-suited for interview data, given that the interviews covered more content than was relevant for the current analysis. Therefore, I used structural coding to label and index excerpts from the larger interview that were relevant to gendered power (Namey et al., 2008). Using Walker and Pratto's (2004) theory of gendered power (see Table 6), a secondary coder and I double-coded one transcript at a time. After each coding session, we met to discuss the process, compare codes, and adjust the codebook, definitions and examples based on the data. This process continued until we reached 90% inter-coder agreement consistently on dual-coded transcripts. Subsequently, we each continued to code independently, following the predetermined codebook definition of gendered

power (See Table 6 for final Codebook). Upon completion, we were left with approximately 400 passages from the 28 interviews that pertained to gendered power.

Table 6. Phase 1: Final Structural Coding Codebook and Example (Walker & Pratto, 2004)

Structural Code	Definition	Coded Excerpt:
Gendered Power	Any behavior, thought, action, resource or opportunity that is affected by (positively or negatively) societal views of gender identity and expression	Interviewer: Can you tell me about any barriers that you've experienced while using healthcare services or while trying to use healthcare services (long pause). Maybe about an experience where you wanted to go to the doctor but weren't able to go? Respondent: Well, transportation is an issue, um, transportation is a very big issue because, um, well now I have a car, thank God, but back in the day, I didn't have a car and it was really hard because you don't want to be in the streets automatically - - you don't want to take public transportation because you don't know what anyone's going to say about your long hair - - you don't know what they're going to say about the way you walk. You don't know if they're going to like it too much, to the fact that they want to see you as a sexual object or if they hate you so much because they have something - - that have to deal with themselves. So, that's a really big barrier, is going out in public and trying to go to the doctor because you're scared of what public's going to say to you when they see you.
	Force: Use of violence or force to maintain power hierarchies. Use as an instrument to wield power over an instrument or group	
	Resource Control: Allocation of resources. Resources available, unavailable, given or removed based on gender identity	
	Consensual Ideologies: Shared cultural beliefs such as gender roles, norms and stereotypes that serve to constrain the ability for individuals to make decisions. Policing of gender norms.	
	Social Obligation: Obligations we have to our social systems. Argues that these obligations and the benefits they may produce are not always equal and the party with less obligation has higher power	

Phase 2: Thematic Analysis. Next, I themed the 'gendered power' excerpts identified during the structural coding phase. Following Braun and Clark's steps for thematic analysis in psychology, I used an inductive theming process to derive data-driven themes (Table 7) (Boyatzis, 1995; Braun & Clark, 2006; Rubin & Rubin, 2012). The next section goes through each of these steps.

Table 7. Phases of Thematic Analysis adapted from Braun and Clark (2008)

Phase		Description of the process
1	Familiarizing self with data	Reading and reviewing the data. Memoing initial ideas
2	Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3	Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme. Generate thematic map
4	Reviewing themes	Checking and cross-checking themes. Develop effects matrix
5	Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells. Generate clear definitions and names for each theme
6	Producing Report	Selection of vivid, compelling extract examples, final analysis of selected extracts, relating the analysis

Stage 1. Familiarizing self with data. Braun and Clark (2006) suggest beginning by reading and re-reading the data. During the pre-code and structural coding phases, I was deeply immersed in the data.

Stage 2. Generating initial codes. To generate initial gendered power sub-codes, I liberally coded excerpts identifying as many inductive codes as possible. I also tracked initial ideas about emerging themes and possible relationships in a process memo. Analytic process memos provided a space to reflect, expand, and hypothesize about what is emerging as regards patterns, themes, and assertions about the data (Saldaña, 2015).

Stage 3. Searching for themes. After generating the initial sub-codes, I reviewed each code and considered how codes may be organized to fit into broader themes. Throughout the process, I drew on data visualization tools and analytic memoing to identify and explain themes. Using concept mapping tools, I mapped out preliminary hypotheses about the emergent themes.

More specifically, I visualized theoretical connections, grouped different codes, and drew links between concepts. I also used the freeform shape tools to visualize the importance of each concept and theme by adjusting shapes, sizes, and colors. Additionally, I again drew on analytic memoing to develop hypotheses about relationships among themes. Specifically, I developed memos about: 1) how emergent themes related the findings from Study A; 2) reflections of commonalities, differences, and relationships based on the participants gender identity; 3) hypotheses about how themes are similar or different to other themes; 4) differences that were emerging among different subgroups of racial/ethnic minority status 5) reflection on how themes are related to Walker's and Pratto's (2004) conception of gendered power.

Stage 4. Reviewing themes. After initial themes were identified, I re-examined and refined themes for relevancy and fit. During this stage, I called upon the Research and Advisory Team for input. In our meeting, I presented the concept maps and analytic memos for their critical input. Together, we parsed out, combined, or organized themes into new or separate themes. We returned to the concept maps, analytic memos, and original gendered power excerpts to make sure the themes identified captured the entire data set, while also addressing the driving research aims.

Stage 5. Defining and naming themes. Using the information generated in the previous stages, I worked with the Research and Advisory Team to further refine and clarify each theme. During this stage, we created a name and definition for each theme (and subthemes). To assist with this process, we also created a thematic matrix to organizing themes, definitions, and underlying mechanisms. Thematic data matrices are especially helpful for describing and visualizing themes in larger, more complex datasets (Miles et al., 2014).

Stage 6. Producing the report. Finally, themes were summarized and reported in the results. Braun and Clark (2006) suggest including the underpinning assumptions, implications, and contextual conditions of each theme. They also encourage consideration of the way in which thematic elements are discussed or shared by participants. In this study, thematic descriptions helped to build an overall story about the topic.

Trustworthiness

I took several measures to ensure trustworthiness of the data (Lincoln & Guba, 1985; Seale, 1999). Dependability is the degree to which processes and procedures are conducted in a systematic manner (Lincoln & Guba, 1985). Transparency and consistency is critical to increasing confidence in qualitative research findings. As such, I kept an audit trail of all methodological and analytical decisions about these data. More specifically, all discussions, data decisions, codebook changes, coding memos, and coding annotations were recorded throughout the project.

Credibility involves demonstrating that readers can be confident that these data have been accurately represented. According to Lincoln and Guba (1985), prolonged engagement with the data is one way to demonstrate credibility. Although I did not specifically collect these data, I was intimately engaged through reading, coding, recoding, discussion, mapping, memo writing and reviewing of these data. As described earlier, with the support of the Blue Cross Blue Shield Student Researcher Award, I analyzed a subset of these data as a pilot coding process. Through this pilot, I developed familiarity with different interviewers as well as the content of the transcripts. Throughout the remaining analysis, I was continuously immersed in the data and returned to the transcripts for code development, memo writing and verifying assertions.

In the currently study, I established credibility through inter-coder agreement checking and peer debriefing. To increase the reliability of this analysis, a second coder and I completed intensive inter-coder agreement checks during the structural coding phase. We dual coded transcripts, annotating thoroughly, flagging confusing passages, and meeting regularly to discuss our coding. We continued this process until we reached over 90% agreement on dual-coded transcripts in the structural phase.

Finally, I demonstrated credibility through peer-debriefing with the Research and Advisory Team. The Research and Advisory Team members were engaged in the analytical and interpretation phases of the analysis and presented with code lists, analytic memos and concept maps in order to provide feedback about how I was representing the data. Furthermore, as TGD youth, the Research and Advisory Team members also helped to provide valuable context and clarification to the experiences of the TGD participants in this study.

CHAPTER 6: RESULTS - STUDY B

The purpose of this study was to understand gendered power and its influence on healthcare access among TGD youth living with HIV. Two specific research aims guided this study. First, I sought to confirm the presence of the mechanisms of gendered power identified in Study A. Secondly, I sought to determine how, if at all, mechanisms of gendered power influenced patterns of engagement in healthcare. In this section, I compare and contrast the mechanisms of gendered power for this sample of HIV-infected TGD youth with the youth in Study A. Then, I explore how mechanisms of gendered power affected HIV-infected TGD youth's successful engagement in HIV care.

Gendered Power Mechanisms

Youth in Study B described the same general mechanisms of gendered power as the youth in Study A. However, subtle differences emerged between the two samples in their descriptions of these mechanisms.

Restrictive Mechanisms

Gatekeeping. In Study A, one mechanism of restricting power was “gatekeeping,” or the act of controlling or limiting access to something because of one's gender identity. Gatekeepers were prohibitory people (e.g., parents, employers, teachers, providers) and systems (e.g., insurance policies, healthcare protocols) that possessed control over youth's access to necessary resources, opportunities, and advancement. In this study, gatekeeping also emerged as a prominent theme restricting youths' agency over their bodies and decisions. Three different types of gatekeeping were present in both Study A and study B: parental gatekeeping, opportunity gatekeeping, and systemic gatekeeping.

Parental gatekeeping. TGD youth in both studies identified parents as both gatekeepers and providers of basic needs (e.g., housing, education, financial support, transportation, medical insurance). Participants in Study A primarily discussed parents as controlling or managing medical decisions, educational attainment, and freedom of expression. In contrast, participants in this study were more likely to discuss parents actively removing housing and emotional support or forcing youth into situations where they would lose resources.

Like the youth in Study A, youth with accepting and supportive parents, youth enjoyed more access to support and resources. Conversely, participants with severed family relationships due to gender-based harassment or outright rejection lost access to several forms of emotional, material, and physical support. Under these circumstances, youth were forced to choose between being out on their own at a young age or presenting as their birth sex. The following quote illustrates how one youth was forced to choose between transitioning and staying in their mother's house:

“... with me being so close to my family and everything like that, my family, they're okay with me being gay, but when I told my mother I wanted to transition, she kinda like 'Well, you know, if you transition, you can get out. You can forget about all of this. Like, get that out of your mind real quick.' So, you know, as of now, I kinda deal with that, like I said, tryin' to make my mother happy and tryin' to keep our relationship with basically kind of living a lie. I mean, it's sad to say, but it is because if I was away from my mother or she accepted it, I would be livin' my full life the way that I want to.”

Opportunity gatekeeping. Youth in the current study described opportunity or discriminatory gatekeeping (i.e., blocking opportunities or advancement based on gender identity) similarly to the youth in Study A. In this study, TGD youth stated that employers and school administrations served as gatekeepers, restricting access to jobs and quality education. One student described their experience in school: “...the principal actually called me out of class one time and he told me either I come to school dressed as a boy or I don't come to school

at all because I'm distracting the learning environment because I didn't get, I didn't get it at all." Further, several participants struggled to attend school or dropped out because of their identity.

Systemic gatekeeping. Although youth in both studies believed that healthcare systems were keeping them from having agency over their medical transitions, youth in this study discussed transition-related healthcare needs with more depth and detail. One reason for this difference may be that many youth in the current study were still in the process of negotiating their transition. As a result, youth highlighted several barriers to starting or progressing their transition including service cost, length of treatment, health insurance access, lack of knowledgeable providers, age requirements, and service access knowledge. These challenges were particularly prominent in this sample because of the withdrawal of instrumental and emotional support as a function of gender identity.

In addition, participants in both studies discussed that some healthcare providers prevented progress in their transitions by exacerbating existing roadblocks or challenges such as denial of care, lack of TGD-specific services, or providing misinformation. Participants in the current study, however, extended this observation to their interactions with other types of service providers beyond traditional healthcare providers. (e.g., social workers, case workers, therapists).

One participant describes their experiences in therapy:

"As a gay male, cause that's what you show up as is you're a feminine male, they don't want to make you feel that you're transgender. They think that you're just someone that's confused. So, then, yes, you go through people that—I've gone through therapy and I've told them what I felt and they'll make it—tell me—they'll try to shut that door out, they try to tell me: 'no, you're just confused'."

Like Study A, lack of access to money and medical insurance, especially for those covering hormones and gender-affirmation procedures, prevented youth from having power over their medical transitions. One youth said:

“the last health insurance I did have, I had to go through so much, you know, just to keep that insurance...it never used to cover like the hormone treatment for my gender identity...if my insurance would have covered it than I would have been able to start hormone therapy a long time ago.”

Youth in this study described consequences of gatekeeping that were not discussed in Study A. For example, several participants talked about their own or their peers' experiences seeking out and using “black market” hormones and silicone injections because they could not access them in the “proper way.” One participant describes:

“...some of them [TGD youth] don't have insurance at all, so a lot of them have to literally go out and, you know, get stuff that's not safe....they start going online, you know, something I was thinking about doing when I didn't have insurance and, if I didn't have insurance, I probably would've went online (frankly), you know, because its something I really wanted and it seems to be times where I wanted to just take my life because it used to be so hard because its just, you know, its like you want something so bad and you been waiting for it and when it finally get here, it's like it's always an obstacle with it, you know, in the path and it's, it's hard, but I feel like, you know, the light is coming and getting better (optimistically).”

Violent control. In both studies, violence emerged as a mechanism used to control TGD youth's identity and decisions. In study A, violence was primarily verbal and perpetrated by family, strangers or service providers with certain subgroups also describing institutional and community violence. In this study, participants mentioned similar themes and expanded on those themes with richer contextual detail.

Youth discussed emotional, verbal and sexual violence as a means to control and intimidate them. Participants in this study reported pervasive, and disruptive experiences of violence. Participants were survivors of several different types of gender-based violence

including violent crimes (e.g., kidnapping, robbery), sexual assaults (e.g., molestations, rapes), verbal abuse (e.g., bullying, harassment), and emotional abuse (e.g., intimate partner violence).

“I mean because just, you know, I guess what I’ve been through and stuff in my life (thoughtfully). It kind of have a big toll on me, um (long pause) I think by me being, by me being molested so much, um, that could have something to do too with the affect, you know, because I been through so much with molestation, I been through abuse, I been a victim of bullying, I’ve been a victim of a lot of stuff (speaking softly).”

Violence and harassment were perpetrated by friends, family members, partners, strangers, medical providers, churches, schools, and even those within the LGB and TGD community. Participants were harassed in their homes, in public, schools, in medical settings, and even in places of worship. One participant illustrates experiences of verbal violence at their parish:

“We [participant and friends] go to the church together, all of us, and it was so weird because it’s just like the – everything was being directed toward us...you’re not supposed to make a person feel like that in your church home. I mean, you can give a person the truth without harming them verbally. Um, you know, without harming them verbally or making them feel very uncomfortable, um, and driving a person to a mental state.”

Unique to this study was the use of HIV as a weapon of violence. Several youth discussed how unsupportive family members used HIV as a threat to try to convince their children not to identify as TGD. One youth illustrates:

“Um, when I was younger like, fifth, sixth grade, and I was strugglin’ with my sexuality and she was very not accepting of my lifestyle [gender expression] and, um, she used to, uh, taunt me almost, to the point of like, like, um, ‘you’ll never be anything, you’ll never amount to anything, you’re, uh, gonna go to hell, uh, you’re gonna catch AIDS and die’.”

Reifying heteropatriarchy. In study A, power imbalances among TGD people were reinforced by normative perspectives on sex and gender, erasure of TGD youth, privileging the cisgender identity and enforcing of traditional gender norms. Compared to Study A, participants in this study discussed reifying heteropatriarchy less frequently. When it was mentioned, however, it was presented similarly to Study A as misrepresentation based on stereotypes,

discordance around complying with societal gender norms, and the erasure of TGD experience.

One participant illustrates:

“So that’s how I feel like we reality TV or when it comes to TV, when transgenders come on there, they’re going to look at us and be like, oh, um we’re mess starters, we try to break up happy homes and stuff like that. And all of us aren’t like that. And that’s what society going to see because they are based off that.”

Like Study A, participants discussed how the privileging of cisgender identities and widespread heteronormativity reduced youth’s agency by restricting access and safety in several settings. One participant said: *“I feel like we as transgender - - transsexual we have an unspoken voice, you know, it’s so many of us going through so much and I feel like we so misunderstood - - so many people - - so many people don’t understand us woman and then when they do try to put stuff out they, they, they bring a mockery out of it.”*

Summary. The gendered power passages in this study correspond to the existing structure of gendered power from Study A. All three of the restrictive mechanisms of gendered power that emerged in Study A were evidenced in Study B. Furthermore, no new restrictive mechanisms emerged. Although there are subtle differences across studies, this is to be expected given that Study B comprises a sample that is younger and predominately youth of Color.

Overview of HIV P&C Continuum in this Sample

Each of the mechanisms of gendered powerlessness emerged as impacting successful care engagement along the continuum. Among this sample of 28 TGD youth living with HIV, a majority of participants was engaged in HIV prevention and care (P&C). Over half of the study participants (16, 57%) had progressed through the entire HIV care continuum (prevention, testing, linkage to care, retention in Care, ART adherence and viral suppression). Several participants were on ART medications, but not virally suppressed (9, 32%). These individuals

reported either very low viral loads or unknown viral loads (due to not having had their next retention appointment yet). A minority of participants reported gaps in medical care appointments, medication adherence, and maintenance of viral suppression (3, 10%).

Gatekeeping and engagement in HIV P&C. Instrumental support from parents emerged as one of the most prominent influences of HIV P&C engagement. Youth whose family members affirmed their gender identity and were accepting of their HIV diagnosis reported fewer impediments to successful engagement in HIV care. Family members helped participants overcome logistical barriers such as transportation and remembering to take medication: *“I like that my mother knows [about my HIV] and I don’t have to hide it anymore and she tells me ‘Did you take your medicine?’ You know, it’s heart warmin’ that she cares.”* One participant described the importance of family support after HIV diagnosis:

“...I’ve seen some crazy things with different transgenders and everything because they didn’t have that support when they were younger. They didn’t have that support when they were, when they first got diagnosed and um, it should be there, it should really be there because people are dying more and more cases of HIV are happenin’ every day. People need that support. Transgenders need that support.”

TGD youth who were not accepted in their family home, however, described difficulty with engaging in HIV care because of logistical and emotional challenges resulting from family rejection. Participants who had been kicked out of homes because of their gender identity explained that lack of stable living circumstances made it difficult to remember appointments and take their medications. One participant who *“ran away”* because their family was not accepting and had since been in and out of HIV care said: *“I always wind up stop taking them [ART medications] cause I never really had stable living.”* Another youth discussed how they tended to avoid their HIV appointments when they were underage because they did not want their mother to overhear discussions about pronouns and gender identity with the provider:

“I did not feel comfortable with her, you know, knowing and, you know, they would ask you about your sexual encounters, they would ask you about, you know, just a lot of different things. A lot of questions that people ask, you know, your ‘What do you go by?’ You know, just stuff like that and at the time I didn’t want my mother so that was kind of a barrier that was kind of hinderin’ me from goin’ to the doctor because I didn’t want to be judged and I still wanted my mother to love me.”

In this example, although the mother was supportive of their child’s HIV care, the child skipped appointments because their mother would not have ‘loved’ her if the doctor revealed their true gender identity. In this way, withdrawal of love and support from parents can be exercised as a form of gendered power over youth.

Opportunity gatekeeping and engagement in HIV P&C. The central difference in opportunity gatekeeping from study A centered around financial support provided to TGD youth. This was exacerbated for youth in the current study by the need to manage medical expenses resulting from their HIV care. Although both sets of participants discussed difficulty obtaining jobs, only participants in study B mentioned the need to turn to illegal means to afford their medical transitions. In these cases, opportunity gatekeeping compounded the typical barriers to HIV P&C engagement, such as legal involvement, school dropout, unemployment, and substance use.

Systemic gatekeeping and engagement in HIV P&C. Youth discussed several institutions and systems that gatekept them from HIV P&C, including schools and healthcare systems. Though many participants received sexual education in school, few participants reported exposure to comprehensive HIV prevention programming prior to acquiring HIV. Even fewer participants reported receiving information about any sort of TGD-specific prevention resources. One participant discussed how they wished for more specific prevention courses that detailed how HIV may be unknowingly spread:

“I wish I would have did the prevention classes. But in school in school they have sex ed and all that, so I had knew about the sex, but you have to understand when a man is, when you have man down with a man. Certain men do certain things to try to give you something and if you’re not, if you’re not knowing, and you just sometimes, you just thinking ‘ok we just having a good time, just a good time’, we’re not knowing that a person actually pumping something inside of us that can hurt us.”

Thus, at the most fundamental level, systemic gatekeeping in schools contributed to youth’s exposure to HIV.

Several participants noted that HIV appointments were difficult to schedule because they would have to prioritize school, employment, or more important appointments, such as food stamp application interviews. Participants with both histories of homelessness and engaging in sex work had struggled with substance use or dropped out or been kicked out of school or employment. These challenges compounded the typical barriers HIV P&C engagement. In this next quote, the participant discusses these multiple challenges:

Interviewer: *“So, what are some of the things that made it harder to go to that first appointment to like start getting care for HIV?”*

Participant: *“I was also underage when I was living on my own and another thing I was on the run, you know what I’m saying, so I felt as though if I linked myself to here it’ll link to something else and I’ll get locked up and go to jail, you dig what I’m saying. So those is the majority of the reasons that me being so underage, you know, certain things they need parental consent to do and something like that and I didn’t have it from nowhere and just from nobody to be able to that or nothing like that so I just said, you know, I left it alone.”*

Finally, youth who lacked access to transition-related resources and obtained hormones or money illegally discussed reluctance to engage in HIV P&C because they were afraid to disclose to providers their involvement in illegal activities. One TGD youth described this experience in the following way:

“Some transgenders that cannot go to regular doctors because they have a lot of, you know, work done and silicone injections and they don’t, they’re afraid of goin to the doctor because they’ve gotten these injections illegally so they can’t really go to the doctor because, of course, you know, they may be scared that once they go, the doctor’s gonna ask them a lot of questions and they’re gonna have to turn the people in that did the illegal work and, you know, stuff like that and, you know, they’re afraid”

Violent control and engagement in HIV care. Participants explicitly cited violence and victimization as barriers to engaging in HIV P&C. Identifying with two marginalized identities (TGD youth and person living with HIV), compounded the potential for violence.

Interviewer: *“How about your family react?”*

Participant: *“Oh, they thought I was going to die [candidly], so they was all in my face for the whole month or two that I was in the hospital, but I mean after when I got out and got better and they figured I wasn’t dying I mean it just went back to the same old ways.”*

Interviewer: *“And what’s that”*

Participant: *“The name calling, the cursing, all that.”*

Interviewer: *“Tell me more about that.”*

Participant: *“Uh, they’ll call me faggots, queers, noodle lovers and all that so.”*

Interviewer: *“What?” [in shock]*

Participant: *“Yeah.”*

Participants outlined three specific ways in which the mental and physical toll of violence make it difficult to seek out and engage in HIV P&C: 1) Fear and avoidance of spaces where violence has historically occurred; 2) negative interactions with providers; and, 3) mental health and coping.

Most commonly, participants’ engagement HIV P&C was disrupted by efforts to avoid verbal violence in their household and in public spaces. In public, participants reported difficulty or avoiding attending HIV medical appointments due to fear of being in settings in which their gender could be policed or scrutinized. This included public settings (e.g., parks, public transportation), medical settings (e.g., hospitals, waiting rooms, HIV testing locations) and anywhere they may encounter a person or form that could invalidate them. In the following quote, one participant describes this experience:

“I didn’t have a car and it was really hard because you don’t want to be in the streets automatically - - you don’t want to take public transportation because you don’t know what anyone’s going to say about your long hair - - you don’t know what they’re going to say about the way you walk. You don’t know if they’re going to like it too much, to the fact that they want to see you as a sexual object or if they hate you so much because they have something - - that have to deal with themselves. So, that’s a really big barrier, is going out in public and trying to go to the doctor because you’re scared of what public’s going to say to you when they see you.”

Like in study A, fear and avoidance of violence and harassment was especially prevalent among youth who were not yet passing or still in transition. As a result, when traveling to and interacting with providers, some participants would revert to dressing like their sex assigned at birth: *“...when I do go in the hospital I always just make sure that I’m presentable. I’m never in, uh, trans clothing or as a trans man or anything like that, but, uh, usually don’t have a problem with getting healthcare.”*

Finally, surviving everyday violence and harassment negatively impacted youth’s emotional and physical health. Exposure to violence led to negative internalizations, severe mental health comorbidities, and substance use, which made engagement in HIV P&C increasingly more difficult. One participant described their experience:

“Hard way cause you know life it, you know, life give you so much and so much negativity. People just throw stuff, you know, they talk bad about you. They talk low about you. You know they step on you. They mistreat you, mis, you know, abusing all the stuff like that, you know, I had a, I used to have it so bad to where, you know, I listened to what people tell me and what people say and, you know, and I sit up and I cried in a little corner and I weep and I cry, won’t eat, won’t sleep, won’t do nothing, won’t even come outside.”

Within healthcare settings, TGD youth reiterated the ways in which ill-informed providers (e.g., pediatricians, general practitioners, emergency room physicians) and policies regarding TGD health removed agency over their bodies and health and reduced feelings of trust and safety. One participant discussed being reluctant to return to a specific clinic where they had previously been mistreated:

“I went in for a physical. I played basketball for [school name]. I went in for a physical and the guy was like, well, um, are you gay. And I was like, yeah. So, he was like, well I don’t want to see you. And I was like why? Because he was like because there should be no gay basketball players. And I was like damn that’s crazy...And it happened that, it happened at [Clinic name], at the clinic right there on the corner. So, I was like, damn so I just left and I never came back.”

In addition to healthcare settings, youth discussed heteropatriarchy within legal and government settings interfering with HIV P&C engagement. For example, one participant discussed how they hated going to the welfare offices because they refused to use their preferred name. Another youth described how challenging it was to get dressed for court appointments:

“I was debating like should I dress up as a girl or should I dress up as a boy. If I dress up as a girl, is they going to take me seriously? I’m thinking ‘are they going to think I’m here to play and joke?’ But if I dress up as a boy, I’m not going to feel comfortable.”

Reifying heteropatriarchy and engagement in HIV care. In this study, the addition of HIV stigma to TGD stigma contributed to youth’s feelings of discomfort for being associated with HIV. Participants feared being seen by someone they knew at an HIV clinic or taking their medicine. This fear was exacerbated by gender identity. Participants desired a future where they would not be ‘*clocked*’ or noticed as being transgender, but rather as women particularly in healthcare settings. One participant discussed how simply picking up HIV medications at the pharmacy could be stressful because the name the pharmacist calls, your ID photo, and your appearance do not match. Additionally, people may notice what medication it is.

For TGD youth, common stereotypes about HIV *and* transgender women created environments in which youth did not feel safe disclosing their HIV status. Most notably, youth were afraid to confirm stereotypes about TGD people contracting HIV and were concerned they would be judged: *“It’s like people think that we already have it, so I was mortified of becomin’ a statistic, okay.”* Another participant discussed how their provider’s assumptions about the ‘*typical*’ lifestyle of a TGD youth clouded the provider’s ability to do their job, and in turn, failed to convince the participant to stay healthy and engaged in care: *“So, I felt that I was bein’ looked at and judged because of that [gender identity], you know? ‘Oh, this is just a transgender, that’s, you know, not ready to change the life that I was livin’.”* Many youth even

felt the need to clarify to the interviewer that they did not get HIV in the way most people assume: *“People, um, are most likely probably to assume that by me being a transgender like I was like the rest of them prostituting and stuff like that when I was far from that.”*

As a result, this fear of confirming stereotypes led youth to keep their HIV status hidden not wanting to confirm these negative stereotypes, leaving youth feeling ashamed, scared, othered, or unsafe. One participant stated: *“...not only are you going through a transgender issue, but you’re also going through an HIV issue. So, it’s both issues at once. So how are you going to accept that yourself and how are other people going to accept that or look at that?”*

Restorative mechanisms and engagement HIV care. In study A, youth participants identified strategies for reclaiming power that restored their autonomy, agency, or control over life decisions. In this study, participants similarly identified ways in which youth fight back, rebuild, or create power over their bodies and decisions. Many of the strategies for reclaiming power in this study were influenced by both the youth’s status as a person living with HIV and as a person with a minority gender identity.

Enacting physical expression. In study A, the most common way participants in this study discussed reclaiming their power was through bodily autonomy and physical expression. Passages highlight each participant’s journey toward *“finding themselves”* and feeling *“like I’m finally really, really in my skin.”* One participant said: *“It’s been awesome. Like I said, I feel like myself now. And it’s like I’m not hiding [participant] anymore. It’s like ‘I’m here! Hello world!’* Participants in this study felt positively toward the changes they had made to their bodies. Furthermore, when they were socially validated by their families, peers, providers or strangers, participants felt powerful and supported: *“I was just my own self. And I didn’t feel like I had to conform to what society says that my gender should be.”* Participants who were more

comfortable in their bodies and their expressions were more active in their HIV care because they encountered fewer barriers accessing HIV P&C.

Lifting up the self and the TGD community. Like in study A, participants in this study discussed supporting and lifting themselves up was a critical step in reclaiming their control and agency and restoring their power, especially in light of their HIV diagnoses. *I've come to a point where I've become. And think I'm unstoppable. And I love the way that I look. I love the way my voice sounds. Everything about me. I've come to a point where I feel like it's flawless. I'm unstoppable. Both boy or a girl.*” Participants spoke about their gender identity and their experiences with strength, courage, and positivity despite many negative experiences with gender-based stigma:

“It [gender identity] helps me, like you have to be strong to go, you have to be very strong to, you know, like go through this. Like you have to have a strong mind to go through this cuz I know some people that haven't so I'm, it has a positive effect on me cuz I feel, it helps me be stronger. It helps me, you know, get to focus more, not get insane, like, it's just, it's just, I don't know, it builds you, it really does from all the stuff that you go through, it builds you.”

Participants built up an incredible sense of strength and resilience in the face of the violence, harassment, and discrimination. Many of these participants had developed a ‘*thick skin*’ to deal with gender-based discrimination and loss of control over their autonomy: *“The way we just, you know, outspoken. We feel free to be who we are and don't worry about what others got to say. That's the most positive thing. Cuz it takes a lot of courage to be who we are, you know, and being judged in society.”* In this next quote, a participant who lost a lot of instrumental and emotional support because of their gender identity discusses how they have been able to persevere without the help of others, highlighting further themes of courage and resilience:

“Like people would bust out and they be like you faggot ass this and that ... done lived the whole different lifestyle and especially when after, of course, being HIV positive. It's

like, I have nobody just really standing in my corner with me. It just me....I have a couple of friends but, at that time it really, I was like, 'what's the point of my friends if I ain't got no family behind me?' And one day I just had a long talk with myself and now when I wake up it's like, I'm happy. I don't care what people say about me. They can throw salt at my name I wouldn't care. I wouldn't care. I am who I am. If you don't like it, you don't like it. I mean, I been rocking this long by myself and I'm going to continue to rock longer... I become a stronger person day by day."

Disrupting imbalance. The majority of youth in this study were receiving care at long-standing HIV treatment centers where providers and personnel are trained in youth and TGD-issues. Therefore, HIV P&C engagement barriers were mitigated when HIV care providers were aware of unique challenges facing TGD youth. For example, a positive experience engaging in care was described as having access to transportation (independently, through support system, or through the HIV program), encountering affirming doctors, and utilizing programming that specifically support TGD youth needs. These participants felt that HIV care providers working in TGD-friendly spaces were generally knowledgeable about TGD issues and were comfortable to talk to. One participant described ways their provider puts them at ease during HIV care appointments:

"The way he respects me. To call me the names that I would prefer as the pronouns I prefer. Um, and he respects me. He makes me feel comfortable. He includes me in a whole lot of decisions. He asks for my ideas instead of just sitting up there saying, you know, really this would be the best choice for you so we're going to take this choice. He gives me options."

Participants were also pleasantly surprised when their HIV care providers were able to also prescribe hormones or advise participants on the medical aspects of their transitions: *"People at the doctor's office staying on me, reminding me, um, it makes me feel wanted you know. Like they really want to see me and take care of me"* Feeling 'in control' with doctor

Educating and advocating. A final mechanism of gendered power in Study A centered around reclamation of power through education and advocacy. In this study, this theme was less

commonly discussed. However, in the final section of the interview several participants did offer recommendations for providers in hopes that they could better support future TGD youth.

Recommendations centered around wishing providers realized that TGD people are also ‘*humans*’ and deserved to be treated as such. One participant said: “*Treat us like people. Don’t look at us like we’re some beast or we’re, somethin’ different, you know, we all the same. We may not be the same color, the same race, the same sex, but we’re all people, human beings, you know, so treat one like you treat the other, that’s how I feel.*” In addition, youth discussed how although providers generally respected them, they wished they took the time to understand their experiences and unique situations, without prejudice or assumption. They wished medical schools covered TGD issues or providers spent time talking to and informing themselves about TGD youth. One youth argued that if providers spent more time understanding TGD youth, the provider would be able to do their job better

Intersectionality and gendered power. One goal of this study was to examine similarities and differences in experiences of gendered power among TGD youth with different gender and ethno-racial identities. In terms of gender identity, approximately 40% of participants identified as gender diverse. However, when drawing comparisons across the gender diverse and transgender groups, it became clear that a majority of the people who identified as gender diverse participants were still in a state of transition towards their goal of identifying as women. Many of these participants did not yet feel comfortable identifying as women or transgender women. As a result, subgroup differences were difficult to ascertain. Furthermore, regarding ethno-racial identities, the final analytic sample was less diverse than I had originally hoped. As a result, there were not enough participants across groups to draw conclusions based on ethno-racial identity.

In summary, this study validates the mechanisms of gendered power described in Study A were similarly discussed in this study. Furthermore, this study supports my hypothesis that gendered power does indeed impact the ability of TGD youth living with HIV to engage in HIV P&C.

CHAPTER 7: REFLECTIONS ON PARTICIPATORY PROCESS

One of the most novel features of this study is that the gendered power framework emerged from TGD youth. Throughout this project, I employed a participatory approach to elevate TGD youth voice in research. The project's conceptualization, design, data collection plan, analytic tools, and dissemination plan were developed in partnership with TGD youth. The purpose of this chapter is to highlight the insights gained from TGD youth's contributing to this project.

Researcher's Reflections on Participatory Approach

Overall, I strongly feel that this project was improved by using a participatory design. Three features of this mixed methods participatory design stand out as central contributors to my confidence in both the research process and findings: 1) collaboration with TGD Youth Research and Advising Team; 2) gender affirming recruitment approach; 3) usefulness of the Youth GO participatory focus group method.

Research and Advisory Team. Consistent with the values of participatory research, those directly affected by the research should play an important role in the research process (Gaventa & Cornwall, 2007; Minkler & Wallerstein, 2003). As a result, I intended equitable collaboration with TGD youth as co-researchers throughout the entirety of this project.

At the beginning of the conceptualization of this project, I recruited and hired TGD youth to serve as paid collaborators and advisers. As discussed in the Chapter 2 (methodology), our team met weekly for over a year to outline project and individual goals, discuss theories of power, design a focus group protocol, attend focus group trainings, pilot-test and implement the focus group protocol, co-analyze data, discuss implications, and plan dissemination and action steps. As of now, we still meet regularly to roll out our dissemination plan for the research.

My consistent and ongoing collaboration with the TGD youth Research and Advisory Team strengthened the research in the following ways. First, as TGD youth, team members brought diverse skills, knowledge, experiences, and expertise to the topic area that I did not possess. Youth were able to speak about their own experiences and their TGD peers' experiences in ways that were beneficial to our research. For example, one important contribution of the team was how to handle situations in which focus group participants did not want to speak. Team members came up with a system by which participants could signal to the facilitators that they wanted to be skipped without calling attention to themselves. With the focus group protocol, the team spent a significant amount of time making sure the wording of our questions and prompts was gender affirming. As a group, we also decided to include prompts about power that would not only elicit negative responses but also positive ones (e.g., *'Has there been a time in your life where you felt powerful or in control over your life or decisions?'*). The inclusion of this prompt led to important findings about restorative mechanisms of power. Without the Research and Advisory Team's input on how to make the focus group sessions more affirming, this important component of gendered power may have been lost, further highlighting the importance of collaborative participatory approaches to research.

In another example, when we needed to quickly change the format of our focus groups to accommodate virtual participation due to COVID-19, one of our advisers came up with a way to use Zoom and Google PowerPoint to mimic a flipchart and sticky notes virtually. Relatedly, team members had access to informational resources (e.g., blogs, internet threads) with relevant information of which I was unaware. For instance, the team encouraged me to purchase the image we used on our recruitment flyers from an artist they found online. Team members also

brought their social networks and connections to the TGD community, which we often drew upon for project recruitment and when seeking out locations to conduct the groups.

Second, due to our prolonged engagement as a team, we were able to spend much of the first few months of the project really getting to know each other and think through the content we were planning to investigate. These few months were instrumental in creating a space in which team members were able to brainstorm freely, be self-reflexive, and engage in critical discussions. Team members learned about one another's strengths, weaknesses, and interests and how to use them in productive ways. For example, at one meeting we drew on the teams' interest in role play games to practice our focus group protocol. Everyone created a character that they played as we tested out our focus group prompts and discussions. Activities like these brought us together as a team, while also contributing important insight to our research.

Finally, the team brought energy and passion to the project. Team members continually helped me connect the meaning of this work back to the community with their fresh ideas and poignant stories. Our team fueled my fire to make sure we were producing something of which we as a team and of which the TGD community could be proud. I believe that without this team, I might have been inclined to cut corners and engage in a less 'participatory' approach. The team kept everyone focused on our goals. It kept me honest, morally grounded, and committed to producing the best work we could for the TGD community. Together we were able to produce a protocol we were proud of, collect data in a gender affirming and safe space, and collaboratively analyze data in a meaningful way.

Recruitment. Another important feature of this project pertained to recruitment. Borrowing from trauma-informed and feminist recruitment strategies, we spent a great deal of time making sure our recruitment materials were explicit and affirming (Campbell, Goodman-

Williams & Javorka, 2019; Campbell, Greeson & Fehler-Cabral, 2013). Given the historical mistreatment of TGD individuals in medical and social research, the advisory team and I were very careful to propose a gender affirming recruitment plan and process. We did not want to deceive participants about the content of the conversations. We wanted to attend to the fact that potential participants might be afraid or uncomfortable even reading our flyer. Framing recruitment challenges in this way encouraged us to consider the following when designing a recruitment and sampling protocol: 1) power differentials between youth and adults that could further take away youth agency over their decisions; 2) stories told by members of a traumatized/vulnerable population could make participation in such a group uncomfortable or re-traumatizing; 3) history of this population with cisgender power figures like me could discourage participation; 4) history of this population being ignored or misrepresented within psychology research could present participation issues; and 5) the safety and well-being of the youth. As a result, our recruitment plan involved a key intermediate step that involved building relationships with key stakeholders and leaders within the TGD community. By taking this step during recruitment, we were able to get our materials distributed by people who and organizations that TGD youth already trusted. We met with these stakeholders and were able to explain our goals for the project and our intentions for the data. These stakeholders then passed along our information through their networks. In doing so, when youth attended our groups, they knew they could be confident that we were going to handle their stories with the care and attention they deserve. Moving forward, we intend to circle back to these stakeholders to collaborate in the dissemination of these findings back to the community.

Youth GO focus group protocol. Finally, the modified Youth GO protocol aided the participatory process significantly. This protocol allowed for a second avenue of TGD youth

participation. During the six primary steps of Youth GO, youth who are participants in the groups generate data, learn qualitative analysis techniques, code and categorize the data, theorize connections across groups, and discuss the findings. This technique was easy to implement and provided a relatively straightforward within group analysis process. Although we lost complexity that might have come from one-on-one interviews, we gained a lot from these discussions and observing interactions among participants, and from the participants' analysis of and conclusions drawn on their own data. Specifically, by structuring the focus group session to first introduce prompts and generate data, then engage participants in organizing, theming, and conclusion drawing, each group was able dig deeply into the concepts and connect their ideas with others in the group. The group setting created a positive and affirming space in which youth could respond to the prompts publicly or anonymously. Further, group members were incredibly validating of other participants' thoughts and ideas, contributing to a space that was inclusive and affirming. We did not encounter any conflict among participants.

We added a 'theoretical exploration' step to the Youth GO protocol. Within this step, youth participants reflected on the data, categories, and themes they created during the focus group session, paying close attention to relationships, commonalities, and differences among the themes. Although these within-group results are not presented in this dissertation, the information that emerged from these conversations significantly informed the cross-group analysis. Deciding to let youth participants discuss, clarify, and draw conclusions from their own data was an important step in this project. Without this step, we might have misinterpreted or poorly represented the experiences of the youth participants, which might have undermined the purpose of involving youth in research to develop theory.

Overall, because of TGD youth involvement, I benefited from the knowledge, skills, and insight of the TGD youth. With their collaboration, I am confident that we have conducted a project that is more robust and valid than could have occurred without using a participatory methodology.

Youth's Research and Advisory Team's Reflection on the Participatory Approach

Through ongoing evaluations, debriefing sessions, and one-on-one discussions, Research and Advisory Team members have been able to voice their opinions about the group and process. Overall, the Research and Advisory Team expressed satisfaction with the project, their involvement, and the skills they have gained. One adviser said:

"I've never done anything with college. I haven't even gotten my GED yet, but it was interesting hearing college age people's thoughts on this. It was really nice to get feedback [from the team] on ideas of mine they thought were really good. I didn't expect to like it as much as I did...I learned research skills, focus group skills, other stuff that I don't have the words for, but I know how to do. It's been a really nice experience. I'm glad I did it."

Another advisor commented on how their involvement shaped how they think about research.

They said: *"I was familiar with psychological studies only from reading the finished products. If you never take the face off a clock, you might never realize how complex the mechanism is."* One advisor discussed how much they enjoyed the space we created for the focus groups. They said:

"...I was really nervous [about facilitating] but, it makes everything easier when you have something in common with them. You know they are not going to judge you for something a lot of other people do. That is a rare space." Finally, an advisor discussed their newfound appreciation for participatory approaches to research:

"The other gift that Dani has given me is an understanding of how compassionate and selfless research should be conducted. While building the process for the focus groups, I was introduced to an entirely different research method. Care was given to making sure that participating in a focus group was worth someone's time. They were compensated for their travel expenses and provided with food. They were allowed to bow out, if they

became uncomfortable. Most importantly, they were given the opportunity to have their voices included in the analysis of their data.”

Youth’s Participants’ Reflections on the Participatory Approach

Moreover, at the end of the focus groups, when time permitted, we asked participants to reflect on how they felt being a part of the focus group. Participants were overwhelmingly pleased with the groups, the facilitators, and their time spent with the project. Youth participants commented on how much “*fun*” they had discussing these topics with other TGD youth and engaging in the group activity together. One participant said: *“I really felt that the researchers had our best interests in mind and wanted to benefit us as much as possible while doing this research, which feels great. I also had a fun time and enjoyed the activities”*.

Similarly, several participants appreciated our transparency about the research method and process. A few participants compared their positive experience in our study to prior experiences with cisgender researchers conducting “*problematic*” studies in which they did not feel that their time, experiences, or stories were valued. One participant said they enjoyed our group because it felt “*equitable*.” They said, it did not feel like I was “*taking their experiences from them, but that we were co-learning and helping each other out*.” Furthermore, at the beginning of the group when we explained their rights and our goals and handed out incentives for their participation and transportation, one participant said: *“Wow, thank you. This is the most respected I have ever felt in one of these studies.”* Another participant said: *“The team did a great job validating and really seeing each and every individual that was in my focus group. We did not feel like research subjects. This experience was great!”* Finally, at the end of every group, without prompting, participants ended up exchanging contact information with each other. A few participants even commented on how nice it was to meet other TGD people like them from their area.

These reflections highlight the importance of being transparent, honest, and ethical with research participants. Furthermore, this project underscores the value of involving TGD youth in research that pertains to their lives. Finally, this participatory process provides important insight for future researchers interested in using participatory approaches on how to do so successfully.

CHAPTER 8: DISCUSSION

Overcoming barriers to equitable healthcare access for TGD youth requires an awareness of the oppressive power structures that impede their well-being and ability to flourish. Yet, research, theory, and programming that impacts the lives of TGD youth has rarely included their perspectives despite calls to action for their inclusion. The absence of their voices has stymied conceptual and empirical research growth and restricted the development of evidence-based programming, practices, and policies. To address this gap, through this dissertation I sought to create an opportunity for TGD youth to define, explore, and theorize about gendered power. I was also interested in documenting how gendered power influenced TGD youth engagement in health care. Using a mixed methods participatory design, I explored gendered power and healthcare access in two unique populations: a diverse community sample of TGD youth and a sample of TGD youth living with HIV (Study A and Study B). Study A used participatory focus group data collection and analysis to understand how youth define and discuss gendered power in the context of their experiences and how, if at all, gendered power influences healthcare access. Study B used secondary data and thematic analysis to explore how gendered power is manifested in discussions about accessing HIV prevention and care services.

Defining Power

A primary aim of this dissertation was to gain youth's opinions and interpretations of gendered power. To my knowledge, this study is the first to ask TGD youth explicitly about their perceptions of power and the relationship of power to their gender identities. Despite the abstract and complex nature of the concept, youth spoke about power in a very robust and profound way and delineated distinct mechanisms of gendered power. Participants were readily able to articulate their thoughts, feelings, and experiences with power. Furthermore, youth were acutely

aware of the ways in which their gender identity was managed and controlled by others. Youth could identify incidents in every aspect of their lives in which someone or something was trying to control their gender identity, and as a result, their actions and decisions. As has been described in existing theories of power (e.g., Gutierrez, 1990; Speer & Hughey, 1995; Walker & Pratto, 2004), youth spoke about power as a multidimensional phenomenon, citing intrapersonal, interpersonal, institutional, and societal examples of gendered power and control. A unique insight that this population brought is the idea that power is about controlling identity. In previous theorizing on gendered power among cis-gender women (Walker & Pratto, 2004; Connell, 1997; Rosenthal & Levy, 2002), power is exercised to control behaviors, decisions, resources, and opportunities. Although these types of control were evidenced here, in this study power was primarily exercised to control or limit someone's identity, eating at the core of who they are.

Mechanisms of Gendered Power

Another central aim of this dissertation was to ascertain how youth's interpretation of gendered power compared to Walker and Pratto's theory of gendered power (Walker & Pratto, 2004). As shown in Table 4, TGD youth's experiences strongly aligned with existing theory. Three out of the four mechanisms identified in Walker and Pratto's (2004) theory of gendered power clearly and distinctly appeared in youth's discussions. 'Allocations and control of resources' corresponds with this study's 'gatekeeping' mechanism. 'Violence and force' align with the 'violent control' mechanism. 'Consensual ideologies about gender' corresponds with the 'reifying heteropatriarchy' mechanism. Although the specific discussion of restrictive mechanisms identified by youth differed from previous literature on cisgender women, these mechanisms operated as theory would suggest. Gatekeeping was used to restrict or limit TGD youth's access to resources that would support their ability to express their gender as they

desired. Violence was used to intimidate or bully youth from living in their affirmed identity, and reification of heteropatriarchy used normative beliefs about gender to legitimize power imbalances and challenge youth's affirmed gender identification. In combination, these restrictive mechanisms operated through attempts to control youth's identity and sense of self, stripping youth of power over their bodies, behaviors, and decisions that affected their health and wellbeing.

Building on Theories of Gendered Power

As expected, my findings did not completely align with existing theory. In this study, I failed to find evidence of Walker & Pratto's final mechanism of gendered power, 'asymmetric social obligations', an individual's obligations to their social systems. Although youth in this study fulfill (or attempt to fulfill) social obligations as children, partners, peers, or coworkers, they do not see it as a form of oppression. In contrast, youth discussed the *inability* to fulfill their social obligations because of their gender identities as contributing to powerlessness. This finding may suggest that oppressive mechanisms for cisgender women paradoxically reflect aspirations for some TGD youth. In this study, young transgender women often viewed the traditional female role as a something worth striving for in their transition journey. Youth viewed those roles, and their corresponding social obligations, as liberating, rather than oppressive. Future research is needed to disentangle how social roles and responsibilities impact subgroups of TGD people.

My findings also suggest that resource control extends beyond constraint and disbursement of material resources. Rather, for TGD youth gatekeeping operates through the gatekeeper's ability to leverage resources, opportunities, and social support, either intentionally or unintentionally, to maintain control of TGD youth's identity. This type of control was

especially pronounced for TGD youth relying on their parents for basic survival needs. Although few studies have specifically investigated this type of parental control, a recent study of familial rejection among TGD youth through the lens of ambiguous loss theory (Caralpa & McFuire, 2018) suggests that parental control, and the corresponding loss that comes from complying with or defying that control may have significant psychological effects. Future research should explore the impact of parental gatekeeping on TGD youth's mental health and overall wellbeing.

Despite the prevalence of violence in TGD youths' lives, only a few recent studies to date have specifically examined violent control, with even fewer paying attention to subgroup differences among TGD youth (Reisner et al., 2016). For some participants, violence was often tied to the idea of 'passing' such that youth who perceived themselves as 'passing' or conforming to society's normative expectation of their desired gender, experienced less violence. This finding closely aligns with a recent study of violence and trauma among TGD youth in the process of transitioning (Burnes, 2016). Burnes and colleagues (2016) present a model of violence throughout the trajectory of TGD youth's transitions, underscoring the differences in experiences of violence throughout transitions. In their model, familial violence typically occurs prior to or at the beginning of transition, followed by self-inflicted violence and interpersonal violence or harassment. Burnes' model of violence and trauma across social and medical transition timelines provides a compelling explanation for differential experiences of violence and trauma in this study and should be further investigated for its ability to explain aspects of gendered powerlessness in TGD youth. In addition, the idea that mechanisms of gendered power may change across developmental milestones highlights another important line of future inquiry. Researchers considering further expansion of a theory of gendered power among this population should strongly consider applying a life course perspective to investigate how gendered power

changes and evolves over the life course, particularly during key developmental and transitional time periods (Clausen, 1986; Lerner & Busch-Rossnagel, 2013).

In contrast to the existing literature, youth rarely described their romantic partnerships as sources of violent control. This was unexpected given how important intimate partner violence is to existing theory and research on gendered power (Walker & Pratto, 2004). Although intimate partner violence is vastly understudied among TGD populations, emerging literature has revealed the many ways in which partners of TGD individuals exercise power and control in harmful ways (Cook-Daniels, 2015; Brown & Herman, 2015; Goldberg, Jadwin-Cakmak & Harper, 2018). One explanation for the lack of discussion about intimate partners may be that youth were too young to have developed relationships with partners on whom they would rely for resources and support. Alternatively, TGD youth may not recognize this type of partner control as a mechanism of powerlessness. As a result, this points to an important future line of inquiry to investigate partner's role in maintaining gendered power. Furthermore, youth in this study rarely discussed self-inflicted violence as a form violent control. The absence of self-inflicted violence was surprising given the high rates of suicide attempts among TGD youth (Pritchard, 2013) and the potential relationship it may have to feelings of power and control. This suggests another important line of future inquiry to investigate the relationship between self-inflicted violence and gendered power among TGD youth.

My findings also highlight how societal norms and expectations about gender remain pervasive. Reification of heteropatriarchy reinforced cisgender privilege, binary gender norms, and traditional gender expressions, creating a culture of erasure, misinformation, and misrepresentation against/of TGD youth. This research expands the conversation among researchers and scholars specifically about our current interpretations of diversity, particularly

gender diversity in our research. As social scientists, we do our work within systems of oppression and may be intentionally or unintentionally enacting power in harmful ways. As such, future research must ensure it does not perpetuate narratives of TGD youth that are unresponsive to the dynamic landscape of gender diversity.

Intersectionality and Powerlessness

Another important aim of this study was to investigate how discussions of gendered power differed based on gender identity and ethno-racial identities. In this study, youth discussed gendered power in tandem with their other social identities, acknowledging and reflecting on how their seen and unseen identities intersect with their gender identity. Many current theories of gendered power discuss intersectionality as an afterthought; however, a novel feature of this study was the attempt to understand how youth's unique gender identities intersect with other identities to impact power. Consistent with prominent intersectionality research (Bowleg, 2012; Buchanan & Ormerod, 2002), we found that gender-based oppression, and consequently gendered power, cannot be neatly separated from other forms of oppression. Rather, multiple forms of oppression converge to impact gendered power. As such, findings confirm the intersectional nature of gendered power.

Relatedly, unique to this study are the differences in the mechanisms of power among subgroups of TGD identities within the larger TGD community. In this study, I found compelling evidence of the differential experiences of subsets of TGD individuals by exploring experiences of nonbinary individuals and individuals who identify or express themselves as masculine or feminine. For example, TGD individuals who appear more feminine discussed experiences with violence and reification of heteropatriarchy differently than individuals with masculine expression. Interestingly, this finding closely aligns with cisgender theories of gendered power,

which suggest that women will experience less power than men in a patriarchal society (Walker & Pratto, 2004). Despite the insight provided by this study, we do not yet fully understand how gendered power operates among TGD youth who do not identify within the larger binary system of gender. Although nonbinary identifying youth discussed mechanisms of gendered power differently than their nonbinary peers, we lack an understanding of the complexities of how these mechanisms function based on individuals' beliefs about gender. These findings imply that to advance developing theory and practice, future research efforts must consider non-cisgender identities as intersectional and worthy of investigation.

Healthcare Access

In this study, I hypothesized that gendered power would influence healthcare access among TGD youth. Findings support this hypothesis. I found that for HIV-positive TGD youth, the mechanisms of gendered power operated to undermine their steady engagement in care. Specifically, gatekeeping caused youth to make difficult choices between managing basic survival needs or the medical aspects of their transitions to the detriment of their HIV care. Violence or fear of violence impacted youth's ability to safely travel from their home to hospitals for healthcare appointments. Finally, the reification of heteropatriarchy converged with HIV stigma to create a culture of shame, fear, and misinformation that undermined youth's trust in their providers. These findings are largely consistent with other prior research on barriers to TGD youth access and engagement in healthcare (Cicero et al., 2019; Goldberg et al., 2019; Hendricks & Testa, 2012; Reisner et al., 2015). However, a novel contribution of this study is the suggestion that said barriers operate through the restrictive mechanisms of gendered power.

Among the few studies in the existing literature that have focused on power among TGD youth (each conducted within the last few years), all have been tightly focused on patient-provider interactions within healthcare systems (Guss et al., 2019; Peitzmeier et al., 2019; Poteat

et al., 2019; Sevelius et al., 2019). In contrast, this study provides a picture of healthcare engagement inside and outside of the medical examination room. In doing so, this study highlights the ways in which healthcare access can be impacted by external forces of power as they have internal consequences on the individual (e.g., shame) and those operating via home, school, work, and the public sphere.

Furthermore, this study is unique in its approach to understanding healthcare access by incorporating the experiences of healthcare access among two populations of TGD youth, one that is not HIV infected or of unknown status and one that is living with HIV. Gendered power impacted both groups' healthcare experiences and limited their desire to access it. HIV care providers were described as more gender affirming and more aware of the unique challenges TGD youth may face when accessing healthcare, when compared to how youth described primary care and other health and social service providers. Negative experiences with providers prior to receiving gender-affirming HIV care still impacted youth's likelihood and ability to seek out care. An important point of intervention for HIV care engagement may be training and supporting gender affirming services outside of trans-specific and HIV-specific healthcare settings.

Reclamation of Power

Another central finding from this study was the emergence of mechanisms in which youth took back power. Although empowerment research has a long tradition of studying the process through which individuals gain great control over their decisions, their lives, and their environments (Rappaport 1981; Zimmerman, 2000), we did not set out to specifically investigate reclamation of power. Surprisingly, youth in both studies described acts of power reclamation in detail. In this study, youth were not powerless in the face of disempowering mechanisms. For

each restrictive mechanism mentioned, youth countered with tactics to reclaim their dignity and self-worth. Findings suggest that although gendered power can be used to oppress, it can be countered. Unlike contemporary theories of gendered power that focus solely on restrictive mechanisms, the current study's findings describe a conceptualization of power reminiscent of Foucault's classic works. More specifically, Foucault argued that power is not only negative, but also a productive and positive force necessary for liberation (Fendler, 2010; Foucault, 1976). Further, Foucault argued against the traditional conception of power as repression, arguing instead that oftentimes power is a positive and productive form of resistance. Foucault writes:

"To challenge power is not a matter of seeking some 'absolute truth' (which is in any case a socially produced power), but 'of detaching the power of truth from the forms of hegemony, social, economic, and cultural, within which it operates at the present time' (Foucault, 1991: 75)."

For youth in this study, finding creative ways to reclaim control and enact autonomy over their lives and decisions signaled to them their power. Youth countered heteropatriarchy through education and advocacy. Youth felt in control when they took control of where their information comes from, when youth advocated for their needs, and when they educated others. Youth felt powerful when they could dress as they please and present themselves in their preferred gender. Youth felt power over their bodies when they decided to change towards an outward reflection of their inner identity, chipping away at the iceberg of cis-normativity and heteronormativity. Youth countered parental gatekeeping by making intentional decisions to move out of their parent's homes, rejecting conditional support. Youth countered systemic gatekeeping by organizing change within oppressive institutions. Youth countered invalidation and rejection when they stood up for themselves, their identities, and their community. Youth countered violence with positivity and compassion for 'haters' and felt power in their ability to brush off negative comments and stand by their truth. Reclamation of power did not only rely on youths' actions,

but also on allied people and systems. Gender affirming services, access to comprehensive and accurate information, policies and protections, accurate representation in the media, all created conditions through which youth felt a new sense of control or a regaining of control over their body and the decisions that affect their lives.

To date, very little has been published on the ways in which power can be reclaimed, resisted, or restored for TGD youth. Other theoretical models within TGD and the larger queer community also document some of these restorative mechanisms (Hendricks & Testa, 2012; Peitzmeier, 2019; Sevelius, et al., 2019; Singh and McKleroy 2010). Resilience literature among TGD youth provides evidence of similar mechanisms, however this body of work does not suggest that these actions are a form of positive power, but of one's ability to survive against an oppressive power structure. Similarly, within empowerment literature, reclamation of power is not specifically tied to the construct of oppressive construction, whereas in this framework, power reclamation is in direct response to oppression. Although research has documented the existence of TGD power empirically, there has been little theorizing about this phenomenon. I suspect that the four mechanisms producing gendered power I identified are not all that may exist. Moreover, although power reclamation mechanisms in both samples of TGD youth were similar, sub-differences did emerge. Participants living with HIV possessed an incredible sense of strength and resilience in the face of the persistent harassment they experienced as a result of stigma due to their gender minority and their HIV status. This toughened skin may suggest that power reclamation mechanisms differ for individuals who have had to overcome tremendous amounts of interpersonal and systemic discrimination above and beyond their gender identity. Future research should continue exploring how and in what ways TGD youth reclaim power from oppressors to have agency over their lives. Theory might also better capture how specific

reclamation strategies operate relative to mechanisms of powerlessness and to the intersectionality of TGD youth's identities.

Limitations

With any exploratory research project, there is always a possibility that relevant themes may have been misinterpreted, overlooked, or over emphasized. Although the framework of gendered power that emerged in this study was derived directly from youth's voices, we still cannot be certain whether we may have overlooked other mechanisms of gendered power. Furthermore, given that this project was informed by Walker and Pratto's (2004) existing theory of gendered power, it is also possible that my knowledge of this theory impacted my ability to identify novel mechanisms. To guard against this, I was sure to develop and analyze this project's data with co-researchers (TGD youth Research and Advisory Team) who were less influenced by Walker and Pratto's original model. As such, given that these findings emerged in focus group discussions with TGD youth participants, within the Advisory Team's cross-group analysis in Study A, and again in Study B's discussions of HIV care access, I remain confident in the mechanisms of gendered power that emerged in this study.

One of the central aims of participatory methodologies are to get to a place where the community partners (TGD youth in this case) and the researchers have shared power and control over the research. In this study, this was not the case. Although I value and respect researchers who can attain ideal levels of pluralistic participation, within the context of an institutional dissertation project, this was not possible. Academic institutions require that this work be primarily conducted alone. As a result, in this project, power was distributed unequally between me, my dissertation committee, and the TGD youth. Although I offered youth several opportunities for more power and control in this study, I did not have the resources, capacity, or

approval to support TGD youth advisers to have more power over the project. Consequently, I could not engage the youth as much as I desired and primarily served in a leadership role rather than distributing leadership equitably.

Relatedly, the resources required for participatory work was limiting. Youth participants and advisers were paid generously for their time and efforts. Additionally, given the importance of long-term engagement with TGD youth, the advisers worked on this project for over a year. That required I raise significant financial resources to compensate them for their time. As an individual graduate student conducting participatory work without major funding sources or institutional buy-in, this impacted the degree of involvement I could support. Although this project was supported by three different funding sources over the year, I still did not have enough funding to support the amount of engagement that I desired. For example, towards the end of the project, I could no longer fund food at every meeting, which likely impacted youth's level of engagement over time.

Additionally, in Study A, I employed structured prompts and probes that may have constrained participant responses in the focus groups. To minimize this possibility, we first tested these prompts in mock focus groups, but that does not ensure participants spoke freely on the topics. Relatedly, we did not account for where TGD youth were at in their transition during the focus groups. We did not ask what point in time relative to that process they were referring to when they commented on feeling powerlessness, for example. Therefore, we cannot know precisely whether youth were speaking about before they came out, after they came out, or somewhere along their journey of coming out. Although this was an intentional decision to encourage broader discussion of gendered power, future research might consider investigating how gendered power changes over the developmental trajectory for TGD youth.

Second, we did not intentionally set out to study restorative mechanisms of gendered power. Prior theorizing on this topic primarily focuses on the negative impacts of power (Rosenthal & Levy, 2010; Connell, 2013; Walker & Pratto, 2004). As such, The Research and Advisory Team and I only included prompts about feelings of powerfulness and control to create a space for the focus groups that was not only negative, but also empowering and affirming. As such, we did not expect for such rich and detailed discussions on taking back and creating power. Considering this limitation, a more detailed exploration into the mechanism of restorative power is necessary to examine nuances of mechanisms identified in this study as well as uncover additional mechanism that may exist.

Furthermore, although we strived to be inclusive of multiple identities in the design and implementation of our focus group protocol, we did not explicitly apply a critical race or intersectionality lens. Only one out of our five prompts explicitly encouraged discussion of identities other than gender. Although I found racial and other identity-based differences, a more explicit examination of these other identities (perhaps with additional prompts) would likely have yielded richer and more informative results. Furthermore, our TGD youth Research and Advisory Team was not ethnically or racially diverse which may have impacted the design, data collection, and analysis. As a group, we often reflected on this limitation by discussing potential biases, particularly when facilitating predominately Black focus groups. Therefore, during recruitment and screening, we decided to reach out to the LGBT center we recruited from to inquire about co-facilitators. One young Black queer woman was interested and experienced in facilitating focus groups about race and power. She completed her MSU IRB and ethics training and attended a brief training about the study and protocol with our group before co-facilitating the focus groups with our team. I hope that her involvement assisted us in limiting the potential

biases of our racial makeup on racial minority participants. The positive remarks youth made about their groups gives me some confidence that who we were did not severely undermine our ability to obtain youth's candid observations on the topics discussed.

Focus groups in Study A were also limited by time and resources. In all groups, we did not account for how much discussion would occur during data generation phase of the focus group session. In many cases, this forced the second half of the session (group analysis) to move more rapidly than we would have preferred. With more time and financial support, the analytic phase of the focus groups may have benefited from an additional hour of time. Future researchers using this method should budget 3 to 4 hours, rather than 2 hours. Additionally, one focus group had to be conducted virtually due to the Covid-19 pandemic, which likely impacted the quality of interpersonal interaction and rapport building that comes with in-person group facilitation. We tried to minimize this by ensuring the same amount of interaction virtually as we had in person, using online facilitation tools that mimicked flip charts and sticky notes.

Finally, in Study B, use of a secondary dataset limited our analyses of gendered power and access to general healthcare services. These data were a part of a larger project that was not intended to study gendered power. Therefore, although these data provide rich, organic discussions of interactions with healthcare providers and systems, interviewers were not trained to probe on issues of gendered power. Although several questions in the interview protocol for these data focus on TGD-specific healthcare and general healthcare access, the bulk of the interview focused on HIV healthcare. HIV service seeking is an important issue but may not generate a generalizable picture of gendered power's impact on healthcare service seeking for TGD youth. Furthermore, for feasibility I decided to sample a subset of the larger data corpus. Our sampling method retained the youth from moderate states based on a measure of state-level

structural stigma (Miller et al., 2018). As a result, this sample lacks youth who reside in highly accepting and highly conservative states. Despite these limitations, however, these data provide a uniquely diverse and large sample of TGD youth experiences navigating healthcare.

Furthermore, I remain confident that these data in combination with the data from Study A provide a foundational framework of gendered power for TGD that can be incorporated into HIV programming and future studies can build upon.

Implications

Central to this study was theorizing and defining gendered power in concert with TGD youth. This study extends Walker and Pratto's theory of gendered power (Walker & Pratto, 2004) by offering an empirically based theoretical framework that is intersectional, developmentally appropriate, and attentive to the unique needs of TGD youth. This framework supports major theoretical ideas about gendered power within the current literature base. Furthermore, the mechanisms that comprise our framing of gendered power among TGD youth generally align with emerging knowledge of TGD populations. The major advance from this project is a novel conceptualization of gendered power as focused explicitly on controlling one's expression of identity. Existing theories based on evidence from studies of cisgender female adult populations conceptualize gendered power as controlling behaviors to support the supremacy of one group (e.g., men) over another (e.g., women). In other words, prior theories focus on 'power over others', not 'power over the self'. Rarely are existing conceptualizations of gendered power theorized as attempts to control who someone is at their core. Furthermore, we advance theory by providing a conception of gendered power that highlights reclamation of power. In contrast to existing theory, reclaiming power for TGD youth was not about reclaiming power over others, rather, reclaiming power over the self.

This type of gendered control impacts many aspects of TGD youths' lives including healthcare access. Despite these important theoretical advances, this study also highlights important future trajectories for development of theories of gendered power. Namely, there is still much work that can be done in understanding the theoretical underpinnings of gendered reclamation of power. Findings from this study underscore the many ways in which intersectional identities moderate mechanisms of gendered power. To refine and hone this theory, future research should dig deeper into these complexities and explore how gendered power relates to other facets of TGD youth's lives (e.g., mental health, trauma, physical health, social support, sense of community).

This study also points to implications for how we go about research with TGD populations. In carrying out this study, I made a conscious effort to recruit participants with a wide variety of gender identities, which allowed for cross-group comparisons among subgroups of TGD youth rather than combining all TGD into one group. In this study we were able to gain initial insight into how various mechanisms of gendered power functioned for groups of non-binary versus binary TGD youth and for masculine expressing, androgynous and/or feminine expressing TGD youth. Research among TGD youth often draws the distinction between TGD populations and cisgender populations, grouping all TGD individuals into one group (Bauer et al., 2009). This has the potential to erase or minimize the experiences of various groups. Intersectionality scholars argue that intersectional research should avoid essentializing groups (Bowleg, 2012). One strategy to avoid essentializing within TGD is to attend to other social identities, such as race, class, and gender during analyses both within and across distinct gender identities of TGD youth. In this study, by highlighting intersectionality and attending to our participants' multiple social identities, we were able to delineate differences in the execution and

functioning of gendered power across gender identity, gender expression, race, and socioeconomic status, even if not to the degree necessary for a robust understanding of these issues. Consequently, future research that wishes to understand the experiences of TGD youth should consider employing similar intersectional approach from project conceptualization through data collection and analysis. Given the exploratory nature of this study and the small sample of youth, future research must examine these differences more fully and closely to verify the patterns observed here.

In this study, participants disclosed surviving tremendous amounts of early and ongoing trauma and violence. These experiences often contributed to feelings of fear and anxiety when seeking out services. These findings are consistent with Hendricks and Testa's gender minority stress theory which argues that increased exposure of victimization among transgender people contributes to is related to their gender identity or presentation, which in turn has an impact on mental health (2012). This suggest that research with TGD populations should be both gender-affirming and trauma-informed. Trauma-informed research practices emphasize the importance of giving participants a sense of agency, choice, and control over the research at multiple stages throughout the process (Campbell, Goodman-Williams & Javorka, 2019). Therefore, future research and interventions with TGD youth should be trauma-informed in design and practice, paying attention to the ways in which experiences of violence and trauma may impact help seeking (Elliott et al., 2005; Harris, & Fallot, 2001).

Finally, findings point to policy and practice interventions that would promote TGD youth reclamation of gendered power and engagement in healthcare. This study provides evidence that power and oppression are not too abstract or complex for young people to understand. Interventions should build on the existing strategies youth already engage in to

reclaim power. Future programming needs to create opportunities that help youth reclaim power by supporting youth to reduce self-stigma, engage in advocacy and education on TGD health concerns, and create conditions that support TGD youth autonomy in key decision making. To illustrate, reclamation of power might be facilitated through the creation or use of youth advisory boards and councils in schools, organizations, cities, communities, and healthcare settings. Youth in this study were eager to enact change and advocate for their needs and the needs of other TGD youth. Furthermore, youth felt powerful when they were successful in making individual or structural changes. Youth also felt powerful when they were provided the opportunity to educate and be educated on topics that concerned their lives. As such, the development of more TGD youth advisory or support groups throughout communities show promise as an avenue to promote power reclamation.

Restrictive mechanisms of power similarly point to policy and practice interventions. We urgently need interventions that undermine mechanisms of powerlessness and create opportunities for reclamation. Interventions should be multi-level and multi-sectoral in nature and geared toward both TGD youth and cisgender individuals. Interventions should attend to those who interact with TGD youth (teachers, employers, providers) to redress gender-based oppression and create opportunities for TGD youth to regain control of their identities and their decisions. For instance, we must create and expand programming and support structures for parents and adults who interact with youth. Such programming should highlight the consequences of gatekeeping and violent control on the health and wellbeing on TGD youth. Healthcare institutions should consider educating providers who interact with both youth and parents on the unique dynamics that may be occurring between TGD youth and their parents and teach providers how to support youth in the face of the unequal power dynamics in healthcare

settings. For example, providers might speak to parents and youth separately in healthcare interactions to ensure they obtain the full picture of the TGD youth's healthcare needs.

Alternatively, youth advocates or medical advocacy programs may be a beneficial approach to addressing power dynamics in healthcare settings. In other health contexts (e.g. sexual assault medical examinations), medical advocates have been found to be incredibly helpful in: 1) helping patients voice their needs; 2) supporting patients in reclaiming control over their body and decisions; and 3) reducing physical and emotional stress of interacting with healthcare providers (Campbell, 2006).

Results also highlight the need for gender affirming policies within youth-serving institutions that promote the validation, inclusion, and safety of TGD youth. Within schools, intervention and programming should be geared primarily toward administrators, teachers, staff, and parents to educate on the needs of TGD youth and the ways in which current rules and regulations in schools may be perceived as violent or silencing to TGD youth. Within healthcare settings, findings point to the need for revised medical training curriculum for practitioners of family medicine, pediatrics, and reproductive health on gender diversity and affirming TGD care. More specifically, healthcare institutions should consider training providers in motivational interviewing techniques or other strength-based methods that put the decision-making power and healthcare behavior changes back into the hands of the patient. Motivational interviewing is an evidence-based intervention that centers on the client or patient and their specific goals through efforts to change behaviors or adhere to treatment recommendations (Miller & Rollnick, 2002). Prior research has found substantial evidence of the positive impact of motivational interviewing in HIV prevention, HIV care engagement, substance use prevention, and mental health treatment among youth (Gray & Strang, 2005; Naar-King, Outlaw, Green-Jones, Wright & Parsons, 2009;

Westra, Constantino & Antony, 2016). However, most work on motivational interviewing highlights behavior change (e.g., increasing medication adherence), rather than the positive changes that may come with giving patients back decision-making power over their bodies and health. Future interventions should consider exploring how motivational interviewing in health care settings increases power and agency over TGD youth's bodies, and in turn, increases their likelihood to engage in healthcare. Relatedly, findings suggest greater implementation of gender affirming documents and protocols that allow youth to feel welcome and validated when filling out legal, medical, or employment-related paperwork.

Finally, an important forward step in TGD research has been the shift away from research that is solely concentrated on changing individual behaviors. We need both individual-level and structural-level interventions. Findings from several structural change initiatives with youth find that reducing individual risk behaviors is insufficient to respond to healthcare access disparities (Kurth et al., 2015; Miller, et al., 2017; Prato et al., 2013). Ecological approaches focused on structural determinants of health, health system navigation, interpersonal relationships, individual behavior change, and organizational capacity building, rather than pathologizing or blaming youth have shown promise in affecting widespread community change (Blankenship, Bray & Merson, 2000; Bronfenbrenner, 1978; Mugavero, 2013). Therefore, to achieve the goals outlined in the current study, we need community mobilization efforts that span multiple settings and stakeholders (e.g., parents, youth, teachers, administrators, providers, politicians) and multiple ecological levels, to support the creation of gender-affirming and gender-literate communities (Rahilly, 2015).

Conclusion

Taken together, this dissertation provides a foundation for a preliminary framework of gendered power specific to TGD youth. TGD youth encounter manifestations of gendered power in every aspect of their lives, where internal and external forces control youth's ability to define themselves and make critical decisions about their life, health, and wellbeing. These findings help to inform our understanding of how gendered power impacts identity and access to healthcare among TGD youth. Further, this study underscores the value of applying an intersectional lens to research among TGD populations. Finally, I hope this project highlights the importance of intentionally including TGD youth voice in research and programming that concerns TGD youth.

APPENDICES

Appendix A: IRB Determination of Exempt Research – Study A

MICHIGAN STATE UNIVERSITY

EXEMPT DETERMINATION Revised Common Rule

July 15, 2019

To: Robin L Miller

Re: **MSU Study ID:** STUDY00002696
Principal Investigator: Robin L Miller
Category: Exempt 2ii
Exempt Determination Date: 7/15/2019
Limited IRB Review: Not Required.

Title: Gender and Power: Exploration of how power dynamics impact the health and well-being of gender diverse youth.

This study has been determined to be exempt under 45 CFR 46.104(d) 2ii.

Principal Investigator (PI) Responsibilities: The PI assumes the responsibilities for the protection of human subjects in this study as outlined in Human Research Protection Program (HRPP) Manual Section 8-1, Exemptions.



**Office of
Regulatory
Affairs
Human Research
Protection Program**

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www.hrpp.msu.edu

Continuing Review: Exempt studies do not need to be renewed.

Modifications: In general, investigators are not required to submit changes to the Michigan State University (MSU) Institutional Review Board (IRB) once a research study is designated as exempt as long as those changes do not affect the exempt category or criteria for exempt determination (changing from exempt status to expedited or full review, changing exempt category) or that may substantially change the focus of the research study such as a change in hypothesis or study design. See HRPP Manual Section 8-1, Exemptions, for examples. If the study is modified to add additional sites for the research, please note that you may not begin the research at those sites until you receive the appropriate approvals/permissions from the sites.

Please contact the HRPP office if you have any questions about whether a change must be submitted for IRB review and approval.

New Funding: If new external funding is obtained for an active study that had been determined exempt, a new initial IRB submission will be required, with limited exceptions. If you are unsure if a new initial IRB submission is required, contact the HRPP office. IRB review of the new submission must be completed before new funds can be spent on human research activities, as the new funding source may have additional or different requirements.

Appendix B: Recruitment Flyer



PAID FOCUS GROUPS

*Trans and gender diverse young people
Ages 18 to 24*

Come discuss gender and power with us!

Participants will attend an interactive focus group session where we will discuss how power impacts the lives of young transgender and gender diverse folks.

Logistics:

- Travel voucher (via Lyft) to and from the focus groups will be provided
- A \$30 dollar incentive will be provided for your valuable time and effort
- Lunch will be provided!
- Focus groups should take 60 to 90 minutes

Eligibility:

- Age 18-24
- Do not identify with sex assigned at birth
- Comfortable engaging in a discussion with other transgender/gender diverse young people from your community

Contact information:

- If interested please contact the Coordinator of this project (Gender and Power Project):
 - Dani Chiaramonte (she/her/hers)
 - Email – chiaram1@msu.edu
 - Cell – 708-334-8331 (call, text, or WhatsApp)



Appendix C: Informed Consent Form

Research Participant Information and Consent Form

Title: Gendered Power: An exploration into the experiences of transgender and other gender diverse youth

Researcher: Danielle Chiaramonte, M.A. –Doctoral Candidate

Institution and Dept: Michigan State University – Ecological-Community Psychology

Sponsor: Robin L. Miller, Ph.D.

BRIEF SUMMARY

- You are being asked to participate in a research study. Researchers are required to provide a consent form to inform you about the research study, to convey that participation is voluntary, to explain risks and benefits of participation including why you might or might not want to participate, and to empower you to make an informed decision. You should feel free to discuss and ask the researchers any questions you may have.
- You are being asked to participate in a research study of experiences of gendered power among transgender and other gender diverse youth. Your participation in this study will take about between 60 to 90 minutes. You will be asked to participate in a focus group session with 4-5 other transgender and gender diverse youth wherein we will ask about times in which you felt powerful or powerless.
- The most likely risks of participating in this study are a violation of confidentiality. We cannot guarantee that another focus group participant will not share information outside of the focus group. One benefit of participating is that the focus group includes a mini-workshop in which you will learn how to analyze focus group data.

PURPOSE OF RESEARCH

- The main purpose of this research is to understand how gendered power dynamics that are maintained through relationship, institutional, and societal norms impact transgender and other gender diverse youth's experiences, particularly when navigating health care systems.
- This research study is part of a dissertation being conducted by Danielle Chiaramonte who is a graduate student at Michigan State University. She is supervised by Dr. Robin Lin Miller.

WHAT YOU WILL BE ASKED TO DO:

- You are being asked to participate in a research study about gender and power among transgender and other gender diverse youth.
- If you agree to participate in this study, you will be asked to participate in a focus group. A focus group is a facilitated discussion with 4-6 other people led by 2 facilitators. The other participants will be other youth who do not identify with the sex they were assigned at birth.
- If you choose to participate, we expect you to maintain the confidentiality of all participants.

- The focus group will ask about your thoughts on the ways in which power operates in your life and how that intersects with your gender identity. Your participation will take about 60 to 90 minutes.
- This study will use a participatory focus groups approach. This means that during a single focus group session (60 to 90 minutes) you will be engaged in both the data generation (e.g. sharing thoughts, ideas, responding to prompts) as well as the data analysis (e.g. interpreting and making sense of the focus group discussion).
 - Two trained facilitators will explain the focus group protocol and introduce you to the other focus group participants (3-5 other youth).
 - Next, you will be asked to discuss experiences in which you felt powerful or powerless.
 - After the discussion, there will be a mini-workshop to demonstrate how to analyze and organize focus group data.
 - Then, you and the facilitators will work together to organize the data into themes and interpret findings.
 - Finally, you will engage in a discussion about the findings and debrief with the facilitators.
- You must be at least 18 years old to participate in this research.

POTENTIAL BENEFITS

- We hope these focus groups will be a space in which participants can feel welcome to contribute their unique perspective on their experiences.
- In addition, the participatory nature of the focus group protocol facilitates co-learning among both the researchers and the participants. This means, that we (the researchers) are afforded the privilege of learning from you through discussions about your unique experiences. You (the participant) will be afforded the opportunity to learn and apply techniques for focus group research that you can take with you into your future endeavors.
 - Part of the focus group will include a mini-workshop where you will learn how to organize and analyze focus group data, as well as interpret findings.

POTENTIAL RISKS

- This research project poses minimal risk to participants. Although topics of gender and power can be sensitive, we do not expect the conversations during the focus group session will cause any psychological or emotional distress.
- The most likely risks of participating in this study are a violation of confidentiality. We cannot guarantee that another focus group participant will not share information that offer outside of the group. As a result, we request that you not to share any information you do not feel comfortable sharing in the event that a breach occurs and someone in the group fails to protect the privacy of the focus group participants and nature of our discussion.
- We request that you do not use your real name in the focus groups. Rather, we recommend you choose a pseudonym for facilitators and other participants to refer to you by.

PRIVACY AND CONFIDENTIALITY

- You do not need to share your name with us or the other members of the focus group. We highly encourage using a pseudonym instead of your real name.
- Recordings from the audio recorders will be immediately uploaded to a secure server after the focus group session and subsequently deleted from the recorder. Therefore, no recorder will ever have a focus group recording stored on it outside of the focus group session room. Only

study personnel will have access to these audio files. They will only be used to transcribe the discussion verbatim. However, any names or identifying locations (e.g. school names) will be changed in what we type out to protect your confidentiality.

- Information collected during the screening process (contact information, gender identity, pronouns, race/ethnicity) will be stored in a password protected Excel file on a secure server at MSU. This document will not include your name, only the pseudonym that you want to use in the focus group. This document will not be linked with the focus group audio recording or transcript. It will be destroyed once the focus groups are completed.

YOUR RIGHTS TO PARTICIPATE, SAY NO, OR WITHDRAW:

- Participation in this research project is completely voluntary. You have the right to say no, change your mind or withdraw from the study at any time. For example, if mid-focus group, you no longer feel comfortable, you may excuse yourself and leave. Your decision to not participate will not result in any penalty.
- In addition, if you arrive at the focus group and are not comfortable with the other members in the group, you may choose to withdraw from the study, attend a different focus group, or have a one-on-one session with a facilitator instead.
- You may choose how much or how little you want to speak during the group. You may choose not to answer specific questions or to stop participating at any time. You should never feel compelled to share something during the focus group that you do not feel comfortable sharing.
- The focus groups will be audio recorded in order to capture what is said accurately. If you participate in the study, you may request that the recording be paused at any time.

COSTS AND COMPENSATION FOR BEING IN THE STUDY:

- We do not envision any significant risks related to participation in this study. However, you may feel some pressure to reveal feelings or experiences to the group.
- It is possible that you may already know someone in the focus group or that you may interact with someone from the group at some point in the future.
- The information you share with will be kept completely confidential to the full extent of the law. You will not be asked to use your name during the focus group. The research team will take every precaution to maintain confidentiality of the data.
- There is an expectation of confidentiality regarding conversations in the focus group meeting. Although we ask everyone in the group to respect everyone's privacy and confidentiality and not to identify anyone in the group or repeat what is said during the group discussion, please remember that other participants in the group may repeat what was said outside of the focus group. To safeguard your privacy to the extent possible, we encourage you not to use your real name during the focus group sessions.
- You will be compensated \$30 for your participation in the focus group.
- Participants will be provided a transportation voucher to get to and from the focus group.

RESEARCH RESULTS

- Findings and updates for the aggregated results of the study will be made available to all participants through email.

CONTACT INFORMATION FOR QUESTIONS AND CONCERNS:

If you have concerns or questions about this study, such as scientific issues, how to do any part of it, or to report an injury, please contact the primary investigator Robin Lin Miller, 316 Physics Rd. Office 132, East Lansing MI 48824, mill143@msu.edu, 517-432-3267.

If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail irb@msu.edu or regular mail at 4000 Collins Rd, Suite 136, Lansing, MI 48910.

6. DOCUMENTATION OF INFORMED CONSENT.

Your signature below means that you voluntarily agree to participate in this research study.

Signature

Date

I acknowledge that the focus group will be audiotaped.

Initials _____

Appendix D: Youth GO Protocol

Youth GO: Implementation Fidelity Checklist

Facilitator(s): _____ Date: _____ Site: _____

Please check if you used each of the materials:

- Nametags
- Markers/pens
- Flipchart paper
- Post-it notes
- Colored papers
- Assorted candy
- 2 Focus Group Facilitators (FGF)

Step One, Climate Setting

- **Facilitators introduced themselves and youth introduce themselves**
 - Thank everyone for attending
 - *“First off, I’d like to thank you all for attending this focus group. We hope we can have a good conversation today about power and representation, among trans and gender diverse folks.*
 - Introductions
 - *We’d like to begin with some introductions. If everyone can share a name, nickname or pseudonym you’d like to use during this session, your preferred pronouns, and what brought you to this space today.*
 - *“My name is ... Pronouns are I’m working with this project because....*
- **Facilitators explained the purpose and goals of the Youth GO session**
 - Explain Purpose
 - *Today we are going to spend the next hour discussing gender, power, and health among our community (transgender and gender diverse youth)*
 - *We are often left out of the conversations about policies, programming and changes that directly affect us, and we want to change that norm.*
 - *We are particularly interested in hearing your perspectives about spaces or situations where you felt like you had power over a decision you made about your life.*
 - *We are also interested in the opposite, meaning, situations where you felt you didn’t have power or control? Maybe it was taken away from you?*
 - *Some of the most pressing needs facing our community center around access to quality and affirming health services. Within healthcare settings,*

we are often met with people and systems that are unaware of, accommodating to, or unable to meet their needs.

- Remind that they do not have to talk if they don't want to
 - *There is no right or wrong answer. This should feel like a relaxed discussion around peers.*
- Youth created a community agreement
 - *Before we begin, we'd like to set some group rules or guidelines for the room. We want to make sure this is a safe space for everyone*
 - *Lead towards*
 - *Vegas Rule - what happens here stays here*
 - *Every comment is valuable and important*
 - *Try not to interrupt*
 - *Use correct pronouns and names*
 - *Point to pass/be skipped*
 - *Parking Lot*
- Make sure all agree to abide by the community agreement

Ice Breaker Questions

Q1: *What is something about yourself or something you really like that you wish people asked you about more? daily life?*

Step 2 - Generating

PROMPT 1

Prompt 1: *What comes to mind when you think of the word power? What does power mean to you? [display on flip chart]*

- *Don't worry about being wrong, we want to hear your gut responses to this question.*
 - *[After prompts have been placed, present a definition of power for this study]*

Define Power: *In this project, we define power as the ability or opportunity to make a decision about your life or circumstances in your life and follow through on that decision.*

- *Given this definition, is there anything you want to add or change from what you already wrote?*

When all prompts are placed, have participants read a post-it note that IS NOT their own back to the group]

- *Do people identify with, relate to, or understand what others wrote for this prompt?*
- *Is there anything anyone wants to clarify, add, or comment on?*
- *Can you talk about that ___ more?*

PROMPT 2

Prompt 2: *In what ways do you feel that people's perceptions of you and your identity affect the amount of power have?*

- *If it doesn't come up, probe on gender identity, gender expression*

When all prompts are placed, have participants read a post-it note that IS NOT their own back to the group]

- Do people identify with, relate to or understand what others wrote for this prompt?
- Is there anything anyone wants to clarify, add, or comment on?
- Can you talk about that ____ more?

PROMPT 3

Prompt 3: Has there been a time throughout your life where you felt powerful or in control over your life and decisions?

- What were the circumstances or actions that contributed to this feeling?"
- Is there a person/place/thing that comes to mind when you think of power/being powerful?
- Are there physical or social spaces where you feel your power is restricted or you feel you have less control? Why?"

[When all prompts are placed, have participants read a post-it note that IS NOT their own back to the group]

- Do people identify with, relate to, or understand what others wrote for this prompt?
- Is there anything anyone wants to clarify, add, or comment on?
- Can you talk about that ____ more?

PROMPT 4

Prompt 4: Has there been a time in your life where you felt your power or control over your life and decisions was restricted or diminished?

- What were the circumstances or actions that contributed to this feeling?"
- Are there systems that you feel have been deliberately created to take power from you?
- "Are there physical or social spaces where you your power is restricted or diminished? Why?"

When all prompts are placed, have participants read a post-it note that IS NOT their own back to the group]

- Do people identify with, relate to, or understand what others wrote for this prompt?
- Is there anything anyone wants to clarify, add, or comment on?
- Can you talk about that ____ more?

PROMPT 5

Prompt 5: "Now we'd like you to think about how your gender identity has impacted power of your health or ability to access health-related resources?"

When all prompts are placed, have participants read a post-it note that IS NOT their own back to the group]

- Do people identify with, relate to, or understand what others wrote for this prompt?
- Is there anything anyone wants to clarify, add, or comment on?
- Can you talk about that ____ more?

Step Three - Organizing

- Explain data organization game with candy
 - *Now we are going to play a game -- once we have learned how to play the game, we will apply it to the questions we just discussed*
 - *Imagine that your team owns a new store that has a small inventory of candy. Your team buys four bins to organize the candy for the customers and must come up with a name for each bin. The names must be clear enough so that customers who can't see the candy still know what type of candy is inside each bin.*

[Facilitators distribute small bags of assorted candy and colored paper for categorizing the candy and let the youth work on the task, helping only when needed]

- Facilitators give new task
 - *Now imagine that two of your bins broke. Organize the candy again, but using only 2 bins and come up with a name for each bin. The names must still be clear enough so that customers who can't see the candy know what type of candy is inside each bin*
- Facilitators give 2 new sheets of paper to represent the bins and let the youth work on the new task, helping only when needed.
- Youth grouped responses for individual prompts
 - *Now we are going to take what we just learned about how to create groups with candy and apply it to our answers that everyone gave to the questions we discussed earlier.*
 - *We are going to organize the responses into meaningful groups and create names for the groups, which are called themes*
- Youth created names/themes for the groups

Step Four, Selecting

- Youth discussed or reviewed the themes created
 - *You just worked to group the question responses (themes). Now we are going to create big groups for all the questions and responses. This will help us determine what we think is MOST important to describe all the questions and responses we discussed today. These will be called categories*
- Youth presented/proposed categories for the themes. Allow youth to present suggestions and have the group come up with consensus using thumbs up/down process.
 - *What is the most important thing we discussed today?*
 - *Can you group any of these themes together?*
 - *What would be a good name for these similar responses?*
 - *What are the most important to you?*
 - *It sounds like there was a lot of discussion about ____ today. Is this important to include*
- Youth voted on the categories
- Youth and facilitators cross-checked the categories with the themes

Step Five, Debrief & Discussion

- Facilitators reminded youth of the purpose and goals of the Youth GO session
 - *Thank you so much for participating in this discussion today, we hope that the information we learn can help to make positive changes for transgender and other gender diverse youth in this community*
 - *We will leave you with a card where you can contact us about any questions, concerns or ideas you have and*
- OPTIONAL: Facilitators revisited the "Parking Lot"

- Youth were given time to reflect on their experience
- Youth were reminded of the value of their perspective

Step Five, Theoretical Exploration

- Facilitators will post the themes generated and labeled on the white board
 - *How are these themes similar?*
 - *How are these themes different?*
 - *Which themes overlap and why?*
 - *Do you think any of these themes would be different if different TGD youth were in our discussions? Why?*
 - *How/why is this type of information important?*
- Note taker will summarize back the main points of the theoretical exploration discussion
 - *Do folks agree with this summary?*
 - *Anything to add/change/delete?*
- Facilitators will ask for final thoughts or additions to our themes and conclusions

Step 6: Debrief, discussion and closing

- Facilitators reminded youth of the purpose and goals of the Youth GO session
 - *Thank you so much for participating in this discussion today, we hope that the information we learn can help to make positive changes for transgender and other gender diverse youth in this community*
 - *We will leave you with a card where you can contact us about any questions, concerns or ideas you have and*
- Youth were given time to reflect on their experience
- Youth were reminded of the value of their perspective
- Facilitators post 2 questions in which youth with one question in which they can respond on an index card on their way out
 - What wishes do you have for other transgender and gender diverse young people in this country? What do you wish researchers and policy makers could do?
 - Would you like to be contacted about study findings and future opportunities?

Appendix E: ATN 130 Interview Protocol – Study B

ATN130

QUALITATIVE INTERVIEW GUIDE – YOUTH LIVING WITH HIV

Font Key

Section Titles	<u>SECTION TITLES</u>
Main Content and Questions	These concepts are always covered. Note that they do not need to be read word for word like a script.
Alternative Scripts or Questions	• Probing questions to be used as appropriate • You will not use all of these with each participant
Interviewer Notes, Skips, and Instructions	<i>Note: things that aren't necessarily said out loud, but ought to be covered or considered.</i> <i>If: text that guides to skip certain questions or to read certain questions, depending upon participant answers.</i> <i>Instructions for interviewer are italicized.</i>
Interview Concept Notes	Descriptions of the goals and intent of sections.

Reminders about using the Interview Guide

Remember, the interview guide is just that – a guide. Alter the language to sound natural for you and as appropriate for the participant and your setting.

Not all probing questions will be asked of all participants, but are included to provide guidance on obtaining additional information from participants. Other probes can and should be used as appropriate given the participant's response.

If a participant thoroughly discusses a topic that is later in the interview guide, you do not need to cover it again later. Remember that bolded content and questions should always be covered in the interview, but do not necessarily need to be in that order.

ATN 130: IN-DEPTH QUALITATIVE INTERVIEW GUIDE: YOUTH PARTICIPANTS LIVING WITH HIV

I. INTRODUCTION

This section is designed to:

Let the individual know why they are here and how the discussion will be structured.
Make sure they understand the purpose of the interview and emphasize the need for honest feedback.

Hi. My name is _____, I use the pronouns _____, and I will be conducting this interview today. I am a _____ and I work at _____. I would first like to thank you for taking the time to talk with me today—your thoughts and opinions are very valuable, and I appreciate your willingness to help us in our efforts to design new programs and services for young people.

The purpose of this interview is to learn more about your experiences as a transgender or gender nonconforming young person. We are going to talk about your experiences with getting HIV-related prevention and treatment services, your sources of strength and support (what or who has helped you), and challenges or difficulties you’ve faced. We will then talk about things that should be included in new programs designed specifically for transgender and gender nonconforming youth. By transgender and gender nonconforming youth, we mean young people whose current gender identity or gender expression differs from their sex assigned at birth. As I ask you to describe your opinions and experiences, please keep in mind that there are no right or wrong answers to these questions, since people have a lot of different views on these topics. I’m simply interested in what you think about these different issues. I don’t know exactly what it’s like to “be in your shoes” or to deal with the pressures people like yourself are confronted with every day. I am looking forward to learning more about these experiences from you. You are in the role of a teacher today and I am here to learn from you since you are an expert in your own life experiences, opinions, and viewpoints. Thank you for giving me your time. This interview should take around 1.5 hours to complete. If at any time you have questions or something I say is not clear, please let me know and I’ll try to clarify. Also, if at any time you need to take a break, please let me know.

- 1. Do you have any questions?**

If yes, answer participant’s questions.

- 2. Do you give me permission to audio-record today’s interview?**

3. Are you ready to begin?

II. WARM-UP/BUILDING RAPPORT

This section is designed to:

Develop rapport with the participant, creating a comfortable environment for discussion.

Develop a relaxed conversational style of communication.

1. What would you like me to call you during the interview?

Please note name: _____

2. What pronouns do you use?

If participant doesn't understand what is being asked:

For example, he/his, she/her, ze/zir, they/them.

Please note pronouns used: _____

Note: Spend about 2 minutes on these next rapport-building questions. If their response is approximately two minutes and you feel you've built rapport with only question 3, skip question 4.

3. So, tell me what do you do most of the time?

- What are some of the activities that you participate in?
- What do you do for fun?
- What do you and your friends like to do?

4. How long have you lived in [AMTU city]?

- *[If a living in city a long time] How do you like living in [AMTU city]?*
- *[If living in city less time] What brought you here?*

Thanks for sharing. People identify or think of themselves in a lot of different ways in regard to their gender. Some people identify in different ways in different situations. For this interview, I want to know how you usually identify in terms of gender to make sure that I am using the term that's most comfortable for you.

5. How do you identify yourself in terms of your gender?

If having difficulty understanding what you're talking about:

Here I'm talking about terms like woman, man, trans woman, trans man, genderqueer, gender nonconforming, gender fluid, two-spirit, agender, non-binary, transfeminine, or transmasculine.

Please note participant's gender identity [GI]: _____

6. At what age did you begin to identify as [GI]?

7. When did you first recognize that your gender was different than the sex you were assigned at birth?

Thank you. In some parts of this interview, the questions I'll ask you will be different depending on whether or not you are living with HIV, or do not know your HIV status. So, before we get started:

8. Please tell me, are you living with HIV?

Please note participant's HIV status: _____

Note: If participant reports not living with HIV or not knowing their HIV status, switch to interview guide for youth not living with HIV or of unknown status.

III. RESILIENCE

This section is designed to:

Explore participants' perceptions of positive aspects of their gender identity.

Explore resilience related to participants' gender identity, including intrapersonal, interpersonal, community, and institutional level factors.

Transgender and gender nonconforming young people often face many challenges, and sometimes that leads researchers and others to focus only on the negative things about being a transgender or gender nonconforming person. However, today I would like to ask you some specific questions about the factors that you think help people with your gender identity be successful in their lives.

- 1. Many transgender and gender nonconforming youth experience stress in different areas of their lives because of their gender identity or gender expression. What are some of the things that help you deal with the stress that comes along with your gender identity?**
- 2. What do you think are some of the positive things about being a person with your gender identity?**
 - What about that makes it an important part of being a person with your gender identity?
 - What about this factor makes it desirable/helpful?
 - What, if anything, is there about your gender identity that helps you see or experience the world differently?
- 3. How has your gender identity positively affected the way you think or feel about yourself?**

IV. GENDER AFFIRMATION

This section is designed to:

Get a general sense of participants' experiences with gender affirming changes.

Explore where participants are currently at with these changes, what the process of these changes has been like, and what plans, if any, they have for gender affirming changes in the future.

So now I'd like to change topics a little bit. You have already answered questions about some of the topics we're going to talk during the online survey, but now I want to hear more about this in your own words. Also – I don't have access to your survey answers (they are kept private) so I will have to ask you a few of those questions again.

When people feel that their gender doesn't match the sex that they were assigned at birth, some people make changes. These changes might include things like what you call yourself, how you dress, changing your ID and other legal documents, or taking hormones, as well as some other things.

- 1. What changes, if any, have you made?**
 - Some people talk about making social changes, like what you call yourself, how you dress, or the pronouns you use. Have you made any social changes?
 - Some medical changes that people make include taking hormones, getting silicone injections, or having gender affirmation surgery (i.e., top or bottom surgery). Have you made any medical changes?
 - Some legal changes that people make include changing their gender marker on their birth certificate or ID and changing their name legally. Have you made any legal changes?

Note: Skip to Q3 if they say they've made no changes.

2. What have these changes been like for you?

- Have you felt comfortable with these changes?
- In what ways have you felt comfortable/uncomfortable?
- How have others responded to these changes?

3. Describe what, if any, gender-related changes you would like to make but have not been able to.

- What things or circumstances have kept you from making this change?
- What changes, if any, do you plan to make in the future?
- When do you plan on making this change?
- Why is this change important to you?
- What benefits do you anticipate from making this change?

V. HEALTH CARE EXPERIENCES & INTRODUCTION OF SOCIO-ECOLOGICAL MODEL

This section is designed to:

Get a general sense of participants' experiences with health care services not related to HIV prevention and care.

Explore barriers and facilitators to accessing health care services, both generally, and at different levels of the socio-ecological model.

The next set of questions will be about your experiences with health care services. I would like you to focus on health care experiences you have had that are not related to HIV care or prevention, because we'll talk specifically about those related to HIV later. These could be experiences you've had trying to get health care, or while you were using health care services. You could tell me about positive or negative experiences, or both.

1. Tell me about some experiences you've had while trying to use or while using health care services in general.

- How did they benefit you, if at all?
- In what ways did these services make you feel supported? In what ways did they not?
- How comfortable were you with these services? What made you comfortable/uncomfortable?
- How, if at all, does your gender identity affect your experiences with health care services?
- Tell me about any services you've received that are specific to transgender and gender nonconforming youth.

Thank you for sharing your experiences with me. Sometimes when we talk about experiences we also talk about barriers. Barriers are those things that make it harder for us to do the things we want to do. For example, imagine that it's raining really hard outside and you need to go to the store, but you don't want to get wet. The rain is a barrier because it's making it harder for you to get to the store.

2. Tell me about any barriers you have experienced while using health care services, or while trying to use health care services.

Note: If the participant already mentioned some barriers in responding to Q1, mention them while asking Q2. E.g., "You mentioned some barriers that you faced trying to access health care, such as X and Y. Tell me about any other barriers you may have experienced while using health care services."

- Tell me about a time that you wanted to use health care services but were unable to.
- What about that experience made it more difficult for you?

Sometimes when we think about health issues, we can look at it from different levels of our lives. Here is a picture of the different levels that we want to think about today. Since we are talking about your experiences, you are the person in the middle of the chart. This level is all about your own thoughts, feelings, and behaviors. The circle just outside of you are people you interact with. This level is about your interactions and your relationships with other people, for example, people that you may be close with like your friends, family, or partners, as well as all of other people that you interact with, from health care providers to bus drivers. The third level is called the institutional or community level. This level includes any communities you interact with, as well as the places where you have those interactions, such as schools, community centers, or medical clinics. This outer level holds the big picture things such as religion, culture, politics, common beliefs, and laws – the things that affect the way we understand the world.

Note: Use the graphic of the socio-ecological model as a reference when explaining the different levels. Indicate each level as you talk through them with the participant.

When thinking about the rain example, an intrapersonal level barrier would be not wanting to get wet or not having an umbrella. An example of an interpersonal level barrier would be a friend not letting you borrow their umbrella. If people in your community did not view umbrellas as an appropriate way to stay dry that would be an example of an institutional or community level barrier. A socio-cultural or policy level barrier would be a law that didn't allow the use of umbrellas.

3. After seeing this, what, if anything, new comes up for you when thinking about barriers to accessing health care in general? Again, these are things not related to HIV related prevention or care, which we will talk about next.

Note: If you notice participants are only talking about barriers at one level, probe for barriers at other levels. Help participants understand the levels by talking through which levels the barriers they've already discussed fit into. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears - makes it harder for you to use general health care services?
- What, if anything, related to your interactions with different people makes it harder to use health care services? (Could be family, friends, partners, providers, employers, etc.)
- What things in the communities you're a part of that help you or make it harder to use or try to use health care services?
- What things about the places where you receive health care make it harder to use those services?
- What sort of big picture things like policies, politics, religion, or common beliefs make it harder to use or try to use health care services?

Ok, now we are going to talk about facilitators. The opposite of barriers, facilitators are those things that help us do what we want to do. Imagine that it's still raining very hard outside and you would still like to go to the store. An example of a facilitator would be using an umbrella, a friend giving you a ride in their car, or deciding that you don't mind getting wet and walking to the store in the rain. These are things that would help you get to the store even though it is raining outside.

We can also think about facilitators at different levels like we did when talking about barriers. Thinking back to the rain example again, deciding that you don't mind getting wet or using an umbrella is an example of an intrapersonal level facilitator because it's a decision within yourself that helps you get to the store even though it's raining. A friend giving you a ride to the store is an example of an interpersonal level facilitator, because another person you know is providing support that helps you do what you need to do. If a community organization gave out free umbrellas to everyone in the community, that would be an example of a facilitator at the community level. And, if the state government built covered sidewalks that protected people from the rain, that would be an example of a facilitator at the socio-cultural or policy level.

4. Tell me about any facilitators or things that have helped you access health care services.

- Tell me about a time you needed to use health care services and there was someone or something that helped you do so.
- What made that experience easier for you?

Note: If you notice participants are only talking about facilitators at one level, probe for facilitators at other levels. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears - makes it easier for you to use general health care services?
- What, if anything, related to your interactions with different people makes it easier to use health care services? (Could be family, friends, partners, providers, employers, etc.)
- What things in the communities you're a part of make it easier to use health care services?
- What things about the places where you receive health care make it easier to use those services?
- What sort of big picture things like policies, politics, religion, or common beliefs make it easier for you to use health care services?

5. In general, how do you think your experiences using health care services are similar to or different from the experiences of other transgender or gender nonconforming youth?

6. Thanks for sharing. Before we move on, is there anything else about general health care services that you would like to share with me?

VI. HIV CONTINUUM OF CARE

Note: Use the flipbook to explain the HIV Continuum of Care. Use the first page of the flipbook when explaining the continuum, and flip to each corresponding page when explaining the different stages.

The next set of questions will be about the HIV Continuum of Care. The HIV Continuum of Care includes different parts of HIV care that might help someone not get HIV or help someone living with HIV to become virally suppressed or ‘undetectable’. The different stages of the continuum are prevention, testing, diagnosis, linkage to care, engagement in care, retention in care, initiation of antiretroviral therapy or ART, adherence to ART, and viral suppression. We’ll be talking about what each of these stages means and I’ll ask you about your experiences with each stage of HIV care. I’ll also ask you how you think your experiences compare to the experiences of other transgender and gender nonconforming young people you know.

1. Do you have any questions before we get started?

Note: Answer participant’s questions before beginning the next section.

HIV PREVENTION

This section is designed to:

Get a general sense of participants’ experiences with HIV prevention services and programs.

Explore barriers and facilitators to accessing HIV prevention programs and services, both generally, and at different levels of the socio-ecological model.

Note: Show the participant the page of the flipbook on HIV Prevention Programs and Services.

We’re going to start out talking about the first stage of the HIV Continuum of Care, which is HIV prevention. This stage includes HIV prevention services and programs, such as counseling, educational workshops, information on how to properly use condoms, and programs for individuals, couples or groups focused on reducing the risk of acquiring HIV by changing behaviors or through taking medicines such as pre-exposure prophylaxis or PrEP.

For this stage, I’d like you to think about any HIV prevention services, programs, or events you might have been a part of BEFORE you learned you were living with HIV.

1. Tell me a little bit about your experiences with HIV prevention programs and services.

- How did they benefit you, if at all?
- In what ways did these make you feel supported? In what ways did they not?
- How comfortable were you with these? What made you comfortable/uncomfortable?
- How, if at all, does your gender identity affect your experiences with HIV prevention programs and services?
- Tell me about any services, programs, or events you’ve been a part of that are specific to transgender and gender nonconforming youth.

Thank you for sharing your experiences with me. Now I would like to hear about any barriers you have experienced when trying to access or while using HIV prevention programs and services. Remember that barriers are those things that make it more difficult for us to do the things we want to do.

2. What things made it harder or kept you from using HIV prevention services?

[Or, if participant said they never used any prevention services] Tell me about what kept you from using HIV prevention services.

- Tell me about a time that you wanted to use HIV prevention programs or services but were unable to.

- What about that experience made it more difficult for you?

Note: If you notice participants are only talking about barriers at one level, probe for barriers at other levels. Help participants understand the levels by talking through which levels the barriers they've already discussed fit into. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears - made it harder for you to use HIV prevention services?
- What, if anything, related to your interactions with different people made it harder to use HIV prevention services? (Could be family, friends, partners, providers, employers, etc.)
- What things in the communities you're a part of made it harder to use HIV prevention services?
- What things about the places where HIV prevention services are offered made it harder to use those services?
- What sort of big picture things like policies, politics, religion, or common beliefs made it harder to use HIV prevention services?

Ok, now we are going to talk about facilitators. Remember, facilitators are those things that help us do what we want to do.

3. What things helped you use prevention HIV programs and services?

[Or, if participant said they never used any HIV prevention services] Tell me about what would have helped you use HIV prevention services.

- Tell me about a time you wanted to use HIV prevention programs and services and there was something or someone that helped you do so.
- What made that experience easier for you?

Note: If you notice participants are only talking about facilitators at one level, probe for facilitators at other levels. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears - made it easier for you to use HIV prevention services?
- What, if anything, related to your interactions with different people made it easier to use HIV prevention services? (Could be family, friends, partners, providers, employers, etc.)
- What things in the communities you're a part of made it easier to use HIV prevention services?
- What things about the places where you receive health care made it easier to use those services?
- What sort of big picture things like policies, politics, religion, or common beliefs made it easier for you to use HIV prevention services?

4. In general, how do you think your experiences using HIV prevention programs and services are similar to or different from the experiences of other transgender or gender nonconforming youth?

5. Thanks for sharing. Before we move on, is there anything else about HIV prevention services that you would like to share with me?

HIV TESTING

This section is designed to:

Get a general sense of participants' experiences with HIV testing services.

Explore barriers and facilitators to accessing HIV testing, both generally, and at different levels of the socio-ecological model.

Note: Show the participant the page of the flipbook on HIV Testing.

We are going to move on to the second stage of the continuum which is HIV testing. The testing stage of the HIV Continuum of Care refers to being tested for HIV, whether using a traditional or rapid test. This stage does not refer to receiving the results of an HIV test.

1. Tell me a little bit about your experiences with HIV testing.

- Tell me about the first time you went for HIV testing.
- If you've been tested more than once, tell me about your best or worst testing experience.
- In what ways did these experiences make you feel supported? In what ways did they not?
- How comfortable were you with these testing experiences? What made you comfortable/uncomfortable?
- How, if at all, did your gender identity affect your experiences with HIV testing services?
- Tell me about any testing services you've used that were specific to transgender and gender nonconforming youth.

2. What things made it harder or kept you from getting tested?

- Tell me about a time that you wanted to get tested but were unable to.

Note: If you notice participants are only talking about barriers at one level, probe for barriers at other levels. Help participants understand the levels by talking through which levels the barriers they've already discussed fit into. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears - made it harder for you to get tested for HIV?
- What, if anything, related to your interactions with different people made it harder to get tested? (Could be family, friends, partners, providers, employers, etc.)
- What things in the communities you're a part of made it harder to get tested?
- What things about the places where HIV testing is offered made it harder to get tested?
- What sort of big picture things like policies, politics, religion, or common beliefs made it harder to get tested?

3. What things helped you or made it easier to get tested?

Note: If you notice participants are only talking about facilitators at one level, probe for facilitators at other levels. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears - made it easier for you to get tested?
- What, if anything, related to your interactions with different people made it easier to get tested? (Could be family, friends, partners, providers, employers, etc.)
- What things in the communities you're a part of made it easier to get tested?
- What things about the places where you got tested made it easier?

- What sort of big picture things like policies, politics, religion, or common beliefs made it easier for you to get tested?
4. In general, how do you think your experiences with HIV testing are similar to or different from the experiences of other transgender or gender nonconforming youth?
 5. Thanks for sharing. Before we move on, is there anything else about HIV testing that you would like to share with me?

HIV DIAGNOSIS

This section is designed to:

Get a general sense of participants' experiences receiving the results of their HIV tests.

Explore barriers and facilitators to learning one's HIV status, both generally, and at different levels of the socio-ecological model.

Note: Show the participant the page of the flipbook on HIV Diagnosis.

Now we are going to move on to the third stage of the continuum, which is Diagnosis. The diagnosis stage of the continuum refers to learning your HIV status or receiving the results of an HIV test, whether positive, negative, or indeterminate.

1. Tell me a little bit about your experiences receiving HIV test results.

- Tell me about when you first learned you were living with HIV.
- In what ways did this experience make you feel supported? In what way did it not?
- How comfortable were you with this service? What made you comfortable/uncomfortable?
- How, if at all, did your gender identity affect this experience?

It's not always easy talking about this, so thank you again for sharing that with me. Now I would like to hear about any barriers you experienced when receiving your HIV results.

3. What things made it more difficult to receive your results?

Note: If you notice participants are only talking about barriers at one level, probe for barriers at other levels. Help participants understand the levels by talking through which levels the barriers they've already discussed fit into. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears - made it harder for you to receive your test results?
- What, if anything, related to your interactions with different people made it harder to receive your test results? (Could be family, friends, partners, providers, employers, etc.)
- What things in the communities you're a part of made it harder to receive your results?
- What things about the places where HIV testing is offered made it harder to receive your results?
- What sort of big picture things like policies, politics, religion, or common beliefs made it harder to receive your results?

4. What things made it easier to receive your test results?

Note: If you notice participants are only talking about facilitators at one level, probe for facilitators at other levels. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears - made it easier for you to receive your results?
- What, if anything, related to your interactions with different people made it easier to receive your results? (Could be family, friends, partners, providers, employers, etc.)
- What things in the communities you're a part of made it easier to receive your results?
- What things about the place where you receive your results made it easier?
- What sort of big picture things like policies, politics, religion, or common beliefs made it easier for you to receive your results?

6. In general, how do you think your experiences receiving HIV test results are similar to or different from the experiences of other transgender or gender nonconforming youth?

7. Thanks for sharing. Before we move on, is there anything else about receiving your HIV test results that you would like to share with me?

LINKAGE TO CARE

This section is designed to:

Get a general sense of participants' experiences with linkage to HIV care.

Explore barriers and facilitators to being linked with HIV care, both generally, and at different levels of the socio-ecological model.

Note: Show the participant the page of the flipbook on Linkage to Care.

We are going to move on to the fourth stage of the continuum, which is Linkage to Care. A person is considered linked to HIV care if they have attended an HIV-specific medical appointment since receiving a positive test result.

1. When, if ever, did you attend your first HIV medical appointment?

Note: If participant reported never had an HIV medical appointment, skip to Q3.

2. Describe what happened in between the time that you were diagnosed with HIV and when you attended your first HIV medical appointment.

- Who helped you make your first appointment?
- What kind of provider did you first see?
- How, if at all, did your gender identity affect your first HIV medical care appointment?

Thank you again for sharing that with me.

Note: Skip now to Q5 if participant said that they attended an HIV-related medical appointment.

3. Tell me about your experiences as a person living with HIV who has not received any kind of HIV medical care.

- Are there times you've wanted to access HIV care but haven't? Tell me about that.

4. What has prevented you from getting HIV medical care?

- How, if at all, has your gender identity affected you not getting HIV care?

Thank you again for sharing that with me. Now we would like to talk more specifically about the barriers that kept you from getting into HIV care.

5. [If participant has been linked to care] What made it more difficult to attend your first HIV medical visit after you learned you were living with HIV?

[If participant has never been linked to care] Tell me about what's kept you from going to an HIV medical appointment after you learned you were living with HIV.

Note: If you notice participants are only talking about barriers at one level, probe for barriers at other levels. Help participants understand the levels by talking through which levels the barriers they've already discussed fit into. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears - made it harder for you to attend your first HIV medical appointment?
- What, if anything, related to your interactions with different people made it harder to attend your first HIV medical appointment? (Could be family, friends, partners, providers, employers, etc.)
- What things in the communities you're a part of made it harder to attend your first HIV medical appointment?
- What things about the places where HIV medical care is provided made it harder to go to your first appointment?
- What sort of big picture things like policies, politics, religion, or common beliefs made it harder to attend your first HIV medical appointment?

6. [If participant has been linked to care] Tell me about what things made it easier for you to go to your first HIV medical appointment.

[If participant has not been linked to care] Tell me about any facilitators at the different levels that would have helped you get linked to HIV care.

Note: If you notice participants are only talking about facilitators at one level, probe for facilitators at other levels. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears - made it easier for you to attend your first HIV medical appointment?
- What, if anything, related to your interactions with different people made it easier to attend your first HIV medical appointment? (Could be family, friends, partners, providers, employers, etc.)
- What things in the communities you're a part of made it easier to attend your first HIV medical appointment?
- What things about the places where HIV medical care is provided made it easier to go to your first appointment?
- What sort of big picture things like policies, politics, religion, or common beliefs made it easier to attend your first HIV medical appointment?

7. In general, how do you think your experiences around linking to HIV care are similar to or different from the experiences of other transgender or gender nonconforming youth?
8. Thanks for sharing. Before we move on, is there anything else about linking to HIV care that you would like to share with me?

If participant never had any HIV medical care, skip to Section VII. Program Recommendations.

ENGAGEMENT IN CARE

This section is designed to:

Get a general sense of participants' experiences engaging with HIV care.

Explore barriers and facilitators to engaging in HIV care, both generally, and at different levels of the socio-ecological model.

Note: Show the participant the page of the flipbook on Engagement in Care.

We are going to move on to the fifth stage of the continuum, which is Engagement in Care. A person is considered engaged in HIV care once they have had a second HIV-specific medical visit.

1. When, if ever, did you attend your second HIV medical appointment?

Note: If participant never had a second HIV medical appointment, skip to Q3.

2. Tell me a little bit about your experiences going to a second HIV care visit after you learned you were living with HIV.

- Tell me about where you received HIV care.
- How long after your first HIV medical appointment was your second appointment? What happened in between the two appointments?
- In what ways did this experience make you feel supported? In what ways did it not?
- How, if at all, did your gender identity affect your experiences going to a second HIV medical appointment?

Thank you again for sharing that with me.

Note: Skip now to Q4 if participant attended a second HIV medical appointment.

3. Can you tell me why you did not go to another appointment?

Thank you again for sharing that with me.

Note: Refer to the graphic of the socio-ecological model to remind participants about the different levels. If you notice participants are only talking about barriers/facilitators at one level, probe for barriers/facilitators at other levels.

4. [If participant had second visit] **What things made it harder for you to go to a second HIV care appointment?**

[If participant did NOT have second visit] **What things kept you from getting to a second HIV care visit?**

Note: If you notice participants are only talking about barriers at one level, probe for barriers at other levels. Help participants understand the levels by talking through which levels the barriers they've already discussed fit into. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears - made it harder for you to attend your second HIV medical appointment?
 - What, if anything, related to your interactions with different people made it harder to attend your second HIV medical appointment? (Could be family, friends, partners, providers, employers, etc.)
 - What things in the communities you're a part of made it harder to attend your second HIV medical appointment?
 - What things about the places where HIV medical care is provided made it harder to go to your second appointment?
 - What sort of big picture things like policies, politics, religion, or common beliefs made it harder to attend your second HIV medical appointment?
5. *[If participant had second visit]* **Tell me what helped you go to your second HIV medical appointment.**
[If participant did NOT have second visit] **Tell me about what things would have helped you go to a second HIV medical appointment.**

Note: If you notice participants are only talking about facilitators at one level, probe for facilitators at other levels. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears - made it easier for you to attend your second HIV medical appointment?
 - What, if anything, related to your interactions with different people made it easier to attend your second HIV medical appointment? (Could be family, friends, partners, providers, employers, etc.)
 - What things in the communities you're a part of made it easier to attend your second HIV medical appointment?
 - What things about the places where HIV medical care is provided made it easier to go to your second appointment?
 - What sort of big picture things like policies, politics, religion, or common beliefs made it easier to attend your second HIV medical appointment?
8. **In general, how do you think your experiences around going to a second HIV medical appointment are similar to or different from the experiences of other transgender or gender nonconforming youth?**
9. **Thanks for sharing. Before we move on, is there anything else about going to your second HIV medical appointment that you would like to share with me?**

If participant never went to a second HIV medical appointment, skip to Section VII. Program Recommendations.

RETENTION IN CARE

This section is designed to:

Get a general sense of participants' experiences staying in HIV care.

Explore barriers and facilitators to being retained in HIV care, both generally, and at different levels of the socio-ecological model.

Note: Show the participant the page of the flipbook on Retention in Care.

We are going to move on to the sixth stage of the continuum, which is Retention in Care. A person is considered retained in HIV care if they attend at least one HIV-specific medical visit every six months. Many people do see their provider every six months and many people do not. We're interested in learning about your experiences after your first two medical visits following your HIV diagnosis and the things that affect whether you do or do not see a health care provider consistently.

- 1. First, how often do you go to HIV medical appointments?**
- 2. Do you consider yourself to be retained in HIV care?**
- 3. Tell me a little bit about what your experiences have been continuing with HIV care after your initial two visits.**
 - How long has it been since you first started receiving HIV care?
 - How would you describe the quality of your doctor's visits?
 - Where do you go for care? Have you ever changed where you go for HIV care?
 - Who do you see for care? Have you ever changed your HIV care provider?
 - How, if at all, has your gender identity affected your experiences with continuing HIV care?
 - In what ways did the HIV care services you've received make you feel supported in your gender identity? In what ways did they not?
- 4. It can be difficult to always attend medical appointments. Are you usually able to go to your doctor's visits?**
 - How often do you miss your HIV medical appointments?
 - *[If participant has been in care >2 years]* How, if at all, has how often you miss your HIV medical appointments changed over time?
 - What kinds of things make it hard to go to your doctor's visits?
- 5. Tell me about any times that you've gone longer than six months between HIV medical appointments.**
 - Describe what else was going on in your life at that time.
 - Did you consider yourself 'out of HIV care' during this time?
 - What made you go back for another appointment?
 - How, if at all, did your gender identity affect this gap in doctor's visits?
 - How, if at all, did your relationship with your medical provider affect how often you went to doctor's visits?
- 6. What things have made it difficult to regularly go to your HIV medical appointments?**

Note: If you notice participants are only talking about barriers at one level, probe for barriers at other levels. Help participants understand the levels by talking through which levels the barriers they've already discussed fit into. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears – have made it harder for you to go to appointments regularly?

- What, if anything, related to your interactions with different people have made it harder to go to appointments regularly? (Could be family, friends, partners, providers, employers, etc.)
- What things in the communities you're a part of have made it harder to go to appointments regularly?
- What things about the places where HIV medical care is provided have made it harder to go to appointments regularly?
- What sort of big picture things like policies, politics, religion, or common beliefs have made it harder to go to appointments regularly?

7. Thank you again for sharing that with me. Now I'd like you to tell me about a time period since diagnosis when you were able to attend your HIV care visits on a regular basis.

- At this time, how long was it between your doctor's visits?
- Describe what else was going on in your life at that time.
- What kinds of things made it easier to go to your doctor's visits?
- How, if at all, did your gender identity help you to regularly go to appointments?
- How, if at all, did your relationship with your medical provider help you to regularly go to appointments?

8. What things have made it easier to regularly go to your HIV medical appointments?

Note: If you notice participants are only talking about facilitators at one level, probe for facilitators at other levels. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears – have made it easier for you to go to appointments regularly?
- What, if anything, related to your interactions with different people have made it easier to go to appointments regularly? (Could be family, friends, partners, providers, employers, etc.)
- What things in the communities you're a part of have made it easier to go to appointments regularly?
- What things about the places where HIV medical care is provided have made it easier to go to appointments regularly?
- What sort of big picture things like policies, politics, religion, or common beliefs have made it easier to go to appointments regularly?

9. In general, how do you think your experiences around going to HIV appointments regularly are similar to or different from the experiences of other transgender or gender nonconforming youth?

10. Thanks for sharing. Before we move on, is there anything else about attending your HIV appointments that you would like to share with me?

INITIATION OF ART

This section is designed to:

Get a general sense of participants' experiences initiating ART.
Explore barriers and facilitators to initiation of ART, both generally, and at different levels of the socio-ecological model.

Note: Show the participant the page of the flipbook on Initiation of ART.

Now we're going to move on to the seventh stage of the continuum, which is Initiation of Antiretroviral Therapy, or ART. Initiation of ART refers to being prescribed antiretroviral therapy and beginning to take it for the first time.

1. Tell me a little bit about your experiences receiving a prescription for ART.

- Tell me about the first time you received a prescription for ART.
- How, if at all, did your gender identity affect your experience of first being prescribed ART?
- *[If participant never received a prescription for ART]* Tell me about why you think you've never been prescribed ART.

Note: If participant never received a prescription for ART, skip to Q3.

2. Tell me about beginning to take ART for the first time.

- How did starting to take ART make you feel? (Physically? Emotionally?)
- *[If participant never began taking their prescribed ART]* Tell me about why you didn't start taking ART after receiving a prescription.

3. *[For participants who were prescribed ART]* Tell me about the things that made it harder for you to start ART.

[For participants who were NOT prescribed ART] **What things have kept you from starting ART?**

- What, if anything, made it difficult to receive your first prescription?
- What, if anything, made it hard to start taking the medication?

Note: If you notice participants are only talking about barriers at one level, probe for barriers at other levels. Help participants understand the levels by talking through which levels the barriers they've already discussed fit into. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears - made it harder for you to start ART?
- What, if anything, related to your interactions with different people made it harder to start ART? (Could be family, friends, partners, providers, employers, etc.)
- What things in the communities you're a part of made it harder to start ART?
- What things about the places where HIV medical care is provided made it harder to start ART?
- What sort of big picture things like policies, politics, religion, or common beliefs made it harder to start ART?

4. *[For participants who were prescribed ART]* What things made it easier for you to start ART?

[For participants who were NOT prescribed ART] **What things would make it easier for you to start ART?**

- What, if anything, made it easier to start ART?
- What, if anything, made it easier to start ART?

Note: If you notice participants are only talking about facilitators at one level, probe for facilitators at other levels. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears - made it easier for you to start ART?
 - What, if anything, related to your interactions with different people made it easier to start ART? (Could be family, friends, partners, providers, employers, etc.)
 - What things in the communities you're a part of made it easier to start ART?
 - What things about the places where HIV medical care is provided made it easier to start ART?
 - What sort of big picture things like policies, politics, religion, or common beliefs made it easier to start ART?
5. **In general, how do you think your experiences around linking to HIV care are similar to or different from the experiences of other transgender or gender nonconforming youth?**
 6. **Thanks for sharing. Before we move on, is there anything else about linking to HIV care that you would like to share with me?**

Note: If participant never received a prescription for ART, skip to Section VII. Program Recommendations.

ADHERENCE TO ART

This section is designed to:

Get a general sense of participants' experiences with adherence to ART.

Explore barriers and facilitators regarding adherence to ART, both generally, and at different levels of the socio-ecological model.

Note: Show the participant the page of the flipbook on Adherence to ART.

The eighth part of the continuum of care is Adherence to Antiretroviral Therapy or ART. Adherence to ART refers to someone regularly taking their ART as prescribed. You already answered some questions earlier on the survey about taking your ART. Now we're going to talk a little more about this so that we can understand more about what taking this medicine has been like for you.

1. **Tell me a little bit about your experiences taking your ART medications.**
 - Describe your usual routine, in terms of taking your meds.
 - How comfortable are you with taking your medications as prescribed?
 - How, if at all, has your gender identity affected how regularly you take your ART?

Thank you for sharing your experiences with me.

Note: Use the graphic of socio-ecological model to remind participant of the levels that we want to address. If you notice participants are only talking about barriers/facilitators at one level, probe for barriers/facilitators at other levels.

2. **What things make it harder to take your ART as prescribed?**
 - Tell me about a time that you wanted to take your meds regularly but were unable to.

Note: If you notice participants are only talking about barriers at one level, probe for barriers at other levels. Help participants understand the levels by talking through which levels the barriers they've already discussed fit into. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears - makes it harder for you to take your meds regularly?
- What, if anything, related to your interactions with different people makes it harder to take your meds regularly? (Could be family, friends, partners, providers, employers, etc.)
- What things in the communities you're a part of make it harder to take your meds regularly?
- What things about the places where HIV medical care is provided make it harder to take your meds regularly?
- What sort of big picture things like policies, politics, religion, or common beliefs make it harder to take your meds regularly?

3. What things help make it easier to take your ART regularly?

- Describe what you do regularly to help you remember to take your meds.

Note: If you notice participants are only talking about facilitators at one level, probe for facilitators at other levels. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears - makes it easier for you to take your meds regularly?
- What, if anything, related to your interactions with different people makes it easier to take your meds regularly? (Could be family, friends, partners, providers, employers, etc.)
- What things in the communities you're a part of make it easier to take your meds regularly?
- What things about the places where HIV medical care is provided make it easier to take your meds regularly?
- What sort of big picture things like policies, politics, religion, or common beliefs make it easier to take your meds regularly?

4. In general, how do you think your experiences around taking meds are similar to or different from the experiences of other transgender or gender nonconforming youth?

5. Thanks for sharing. Before we move on, is there anything else about taking your meds that you would like to share with me?

VIRAL SUPPRESSION

This section is designed to:

Get a general sense of participants' experiences with viral suppression.

Explore barriers and facilitators to achieving viral suppression, both generally, and at different levels of the socio-ecological model.

Note: Show the participant the page of the flipbook on Viral Suppression.

Now we're going to move on to the ninth and final stage of the HIV Continuum of Care – Viral Suppression or being undetectable. A person is considered undetectable if their viral load is <200 copies/ml for the most recent value reported.

1. What, if anything, have you heard about being virally suppressed or undetectable?

- Tell me what, if anything, your health care provider has told you about being undetectable.
 - i. What does this mean to you?

2. Do you know what your viral load is?

- *[If No, ask]* Do you know whether or not you are undetectable?
- *[If Yes, ask]* What is it?
- Is becoming virally suppressed or undetectable a goal you've talked about with your doctor?

3. What, if any, experiences do you have with being undetectable or trying to be undetectable?

4. What things make it harder to become undetectable, or to stay undetectable?

Note: If you notice participants are only talking about barriers at one level, probe for barriers at other levels. Help participants understand the levels by talking through which levels the barriers they've already discussed fit into. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears - makes it harder to be undetectable?
- What, if anything, related to your interactions with different people makes it harder to be undetectable? (Could be family, friends, partners, providers, employers, etc.)
- What things in the communities you're a part of make it harder to be undetectable?
- What things about the places where HIV medical care is provided make it harder to be undetectable?
- What sort of big picture things like policies, politics, religion, or common beliefs make it harder to be undetectable?

5. Tell me about what things [have made/would make] it easier to be undetectable.

Note: If you notice participants are only talking about facilitators at one level, probe for facilitators at other levels. Example probes for the different levels are below.

- What, if anything, related to just to yourself – that is, your own thoughts, feelings, hopes, and fears – [makes/would make] it easier to be undetectable?
- What, if anything, related to your interactions with different people [makes/would make] it easier to be undetectable? (Could be family, friends, partners, providers, employers, etc.)
- What things in the communities you're a part of [make/would make] it easier to be undetectable?
- What things about the places where HIV medical care is provided [make/would make] it easier to be undetectable?
- What sort of big picture things like policies, politics, religion, or common beliefs [make/would make] it easier to be undetectable?

VII. PROGRAM RECOMMENDATIONS

This section is designed to:

Explore programs and services that participants' have participated in to find out what aspects of those programs were beneficial.

Obtain participants' recommendations on programs and services for transgender and gender nonconforming youth.

Thank you for all of the helpful information that you have provided us with today. That finishes our section on the stages of the HIV Continuum of Care. Before we wrap up, we are going to talk a little bit about what kinds of programs, activities, or events that could be developed to promote the health of transgender and gender nonconforming youth.

1. What kinds of programs, activities, or events would you like to see for transgender and gender nonconforming youth, or specifically for young people who share your gender identity?

If time permits, these are additional questions that could be asked:

- What would be a dream program or event, something you'd love to see?
 - Who should the program include? (All transgender and gender nonconforming youth? Just specific groups?)
 - Where would it take place?
 - What about it would be really appealing to you or your peers?
 - What kinds of things would really draw youth in? What's something you'd see and say, "That sounds useful," or "I'd go to that"?

3. What HIV-specific programs would you like to see?

If time permits, these are additional questions that could be asked:

- What would be a dream program or event, something you'd love to see?
 - Who should the program include? (All transgender and gender nonconforming youth? Just specific groups?)
 - Where would it take place?
 - What about it would be really appealing to you or your peers?
 - What kinds of things would really draw youth in? What's something you'd see and say, "That sounds useful," or "I'd go to that"?

4. What recommendations do you have for providers who work with transgender and gender nonconforming youth?

- What can health care providers like doctors, nurses, and mental health care professionals do to better serve transgender and gender nonconforming youth?
- What can social service providers like social workers, case managers, health educators, and HIV test counselors do to better serve transgender and gender nonconforming youth?

5. Before we finish up, are there any other recommendations for programs or providers you'd like to share with me today?

VIII. INTERVIEW WRAP-UP

Thank you so much for taking the time to talk to me today. We talked about a lot of different issues today.

1. Is there anything else that you would like to share with me?
2. Is there anything that you thought I should have asked about that I didn't?
3. Is there anything that I could have asked differently?

This concludes the formal part of the interview. I really appreciate how much time and energy you have put into this interview. The information that you have offered today will be very helpful in our efforts to create and run programs to improve lives of transgender and gender nonconforming young people.

Complete appropriate portions of Section IV. DEBRIEFING INTERVIEW with participant prior to compensation and dismissal. ALL participants will complete at least one section of the debriefing interview.

IV. DEBRIEFING INTERVIEW

Several questions in the interview asked you about personal and sensitive information. Some of the questions in the interview may have caused you to think about situations or feelings that I would like to check in with you about. I want to check in with you to make sure that when you leave here today you are feeling okay and that you are safe.

IV-A. DEBRIEF RELATED TO SUICIDE

Complete this portion of the debriefing interview if follow-up is needed related to suicide.

Note: If there is no follow up needed related to suicide, skip to section IV-B.

If participant discussed suicidal thoughts/ideation/attempts, ask:

1. **At one point in the interview, you mentioned thoughts or feelings of wanting to end your life. I want to ask you now how you are feeling, and if you are having thoughts of hurting yourself.**

If answer indicates suicidal thoughts, feelings, or plan, the interviewer should say:

It's my responsibility to make sure you are safe. I need you to meet with a counselor to make sure you are safe. I will stay with you until they arrive.

Interviewer should follow clinic/agency procedures for acute mental health referrals. Interviewer should contact supervisor immediately and stay with the participant until supervisor or mental health professional arrives.

IV-B. DEBRIEF RELATED TO ABUSE

Complete this portion of the debriefing interview if follow-up is needed related to abuse.

Note: If there is no follow up needed related to abuse, skip to section IV-C.

If participant discussed experiencing some form of abuse, ask the following – if the abuse is perpetrated by a custodial parent or guardian and the participant is under the age of 18, then follow procedures for child abuse reporting.

2. **At one point in the interview, you mentioned someone in your life hurting you or abusing you. I would like to ask you about those experiences, to make sure you are safe and to see if you would like to talk to anyone further about what has happened. Is there anything you would like to say about anyone hurting or abusing you?**

If yes, interviewer should say:

I'm sorry that happened to you. It's my responsibility to make sure you are safe. I would like you to meet with a counselor to make sure you are safe. I will stay with you until they arrive.

Interviewer should follow clinic procedures for mental health and/or potential abuse referrals.

Interviewer should contact supervisor immediately and stay with participant until supervisor or mental health professional arrives. In addition to mental health services/referrals, the supervisor or mental health professional will provide appropriate information regarding legal protections and services related to the abuse.

IV-C. DEBRIEF RELATED TO SEXUAL RISK

Complete this portion of the debriefing interview if follow-up is needed related sexual risk.

Note: If there is no follow up related to sexual risk, skip to section IV-D.

If participant discussed HIV sexual risk behaviors and exhibited a lack of knowledge about how to prevent transmitting HIV to others, or held misconceptions about HIV:

- 3. At one point in the interview, you mentioned doing some things that might be putting yourself at risk for STIs (sexually transmitted infections) and potential HIV re-infection, as well as putting others at risk. I'd like to share some information about HIV, STIs, and condoms, if that's okay.**

If participant agrees, provide information about sexual risk behaviors / safer sex practices.

IV-D. DEBRIEF RELATED TO MISCONCEPTIONS ABOUT HIV

Complete this portion of the debriefing interview if follow-up is needed related to misconceptions about HIV.

Note: If there is no follow up related to misconceptions about HIV, skip to section IV-E.

If participant mentioned beliefs related to HIV that were incorrect:

- 4. At one point in the interview, you mentioned some things about HIV that I'd like to discuss a bit more. I'd like to share some information with you about HIV if that's okay.**

If they agree, proceed with giving the participant needed information and resources.

IV-E. DEBRIEF FOR PARTICIPANTS NOT IN CARE

Complete this portion of the debriefing interview with participants who are living with HIV and who are not currently in care.

Note: if participants are in care, skip to section IV-F.

- 5. In your interview today, you talked about not currently being in HIV care. Would it be okay if I told you about the services we provide here, or provide some information about other places nearby that offer HIV care?**

If participant gives permission, provide information about HIV care services available.

If participant does not give permission, interviewer should say:

OK. If you decide you would like to speak to someone about HIV care later, here is the person you should contact.

Provide name and contact information about the appropriate person to contact at your site.

IV-F. DEBRIEF FOR ALL PARTICIPANTS

Complete this portion of the debriefing interview with all participants.

Ask this question of ALL PARTICIPANTS regardless of their reporting of abuse, suicidal thoughts, and/or HIV sexual risk behaviors.

6. Is there any (other) part of the interview you would like to discuss further?

If response indicates the participant is in urgent need of mental health assistance, the interviewer should follow clinic/agency procedures for acute mental health referrals. Interviewer should contact the supervisor immediately and stay with the participant until supervisor or mental health professional arrives.

If no signs of distress, interviewer should say:

If you decide that you would like to speak with a counselor later, here is a list of agencies in the community that provide this service.

Give final appreciation for participation, offer compensation, and see participant out.

Appendix F: Determination of Non-Human Subjects Research – Study B

MICHIGAN STATE UNIVERSITY

DETERMINED NOT “HUMAN SUBJECTS”

August 28, 2018

To: Danielle Marie Chiaramonte

Re: **MSU Study ID: STUDY00001277**
Principal Investigator: Danielle Marie Chiaramonte
Determination Date: 8/28/2018

Title: Qualitative Examination of Factors Impeding HIV Care Engagement for Transgender Youth Living with HIV

The activity described in this submission was determined not to meet the definition of “human subjects” as defined by the U.S. Department of Health and Human Services (DHHS) regulations for the protection of human research subjects.

Definition of Human Subject

For DHHS, “human subject” means “a living individual about whom an investigator (whether professional or student) conducting research obtains: (1) Data through intervention or interaction with the individual, or (2) Identifiable private information.” [45 CFR 46.102(f)].



Determination

This project will conduct an analysis of secondary, de-identified data. No further data will be collected through an interaction or intervention with human subjects.

Hence, the activity does not involve human subjects.

Therefore, the federal regulations for the protection of human subjects would not apply to this project and Michigan State University (MSU) IRB approval is not needed to proceed. However, please note that while MSU IRB approval is not required, other federal, state, or local regulations or requirements or ethical or professional standards may still be applicable based on the activity.

Modifications: If any of the activities described in this submission change, please contact the IRB office as the activity may involve human subject research and require IRB approval. For example, this determination is not applicable to activities that may be regulated by U.S. Food & Drug Administration (FDA), such as those involving drugs, medical devices, human food additives, color additives, electronic products, or any other test articles regulated by the FDA.

Modifications to Project Funding: Changes in project funding may alter this determination. For example, MSU IRB review and approval is required if MSU receives an award through a grant, contract, or cooperative agreement directly from

**Office of
Regulatory
Affairs
Human Research
Protection Program**

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