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A QUALITATIVE STUDY ABOUT THE RESISTANCE AND RESILIENCE OF

TRANSGENDER YOUTH OF COLOR NAVIGATING PARENT/GUARDIAN SUPPORT

AND SOCIETAL OPPRESSIONS

by

Linda M. Wesp

A Dissertation Submitted in

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ABSTRACT

IT'S A PROCESS:
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by

Linda M. Wesp

The University of Wisconsin-Milwaukee, 2019
Under the Supervision of Professor Peninnah Kako, PhD

Transgender youth of color experience alarming rates of marginalization and victimization within society, including experiences of rejection from parents/ guardians, which has been associated with various adverse health outcomes. Health care providers are encouraged to facilitate parent/guardian support for transgender youth to improve long term health, however nurses report feeling underprepared to care for transgender populations and nursing transgender health research is lacking. Therefore, the purpose of this study was to describe how transgender youth of color experience and navigate parent/guardian support, considering the broader societal context.

This study was informed by critical and intersectionality theory. A qualitative secondary approach was used to analyze previously collected semi-structured qualitative interviews from a nation-wide study with transgender youth (n=24). Data was analyzed using narrative inquiry to describe stories of transgender youth of color age 16-18 years and their experiences regarding parent/guardian support related to their overall health and well-being, while navigating intersecting marginalization. The overarching theme *It's a Process* described the ways that transgender youth of color navigated various barriers and milestones in pursuit of living their

lives with authenticity. Additional subthemes emerged, including *We Need Your Help, I'm Lucky to Have Support, Self-Advocacy/Resistance,* and *Having Hope/Resilience.* This study was the first to explore the pivotal experiences of transgender youth turning 18, a turning point when youth were finally able to consent for their own health care, but may face limited access if still on their parent/guardian's insurance without parent/guardian support.

Findings of this study have important implications for nursing education, practice, and research as well as health care policy. Increased understanding about the ways transgender youth of color navigate intersecting barriers can improve nursing education and clinical care. Future research can develop clinical tools that will facilitate resistance and resilience processes for transgender youth of color, as well as parent/guardian support, ensuring culturally and developmentally appropriate interventions. Future research can also explore the structural causes of health inequities found in this study to inform policy change.

To Paige Clay,

and all trans youth who have lost their lives

as a consequence of violence

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LIST OF ABBREVIATIONS

ATN	Adolescent Medicine Trials Network for HIV/AIDS Research
AVA	Affirming Voices for Action
HIV	Human Immunodeficiency Virus
IRTHJ	Intersectional Research for Transgender Health Justice
LGBT	Lesbian, Gay, Bisexual, and Transgender
PG	Parent/Guardian
QSA	Qualitative Secondary Analysis
U.S.	United States

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"Stories are about human plights, personally experienced. Stories of those who experience human plights every day tend to get buried. The role of narrative inquiry then is to excavate those stories and use them as seeds for social justice" (Kim, 2016, p. 238).

CHAPTER 1: INTRODUCTION

Statement of Problem

Transgender people experience alarming rates of marginalization and victimization, which are associated with poor health outcomes (Reisner et al., 2016). Experiences of stigma occur at the individual, interpersonal, and structural level, and negatively impact health (White Hughto, Reisner, & Pachankis, 2015). For transgender youth, support from parents and legal guardians have been identified as an important interpersonal factor, having a positive impact on health and well-being (Katz-Wise et al., 2017). Yet, almost 50% of transgender adults surveyed in the United States (U.S.) reported experiencing negative interactions and a lack of support from parents or legal guardians during their childhood or adolescence (James et al., 2016). Transgender adults who had experienced this lack of parent/guardian (PG) support were more likely to be from communities of color, and more likely to have experienced homelessness, engaged in sex work, and have attempted suicide (James et al., 2016). Transgender youth from communities of color are overall at disproportionate risk for adverse and preventable health outcomes such as HIV, substance use, and depression (Institute of Medicine, 2002; Institute of Medicine, 2011; NIMHD, 2016).

Support from parents/guardians is particularly important for transgender youth who are not yet 18 years, because it directly impacts access to gender affirming interventions, mental health care, housing, education, and employment, and thus their opportunities for health and

wellbeing during crucial stages of growth and development (Olson-Kennedy et al., 2016; Simons, Schrager, Clark, Belzer, & Olson, 2013). Minor adolescents are most likely still in the legal custody of their parent or guardian, and thus are especially vulnerable to the effects of acceptance or rejection when it comes to transgender-related health care that requires parental consent. Furthermore, transgender youth of color may also be experiencing discrimination and inequality due to racism, classism, adultism, heterosexism, and/or transphobia, and must therefore navigate marginalization from multiple angles, along with the experiences within their family unit. And finally, transgender youth are still proceeding through stages of adolescent development,

Overall, there is a paucity of research on transgender health in general, but especially about transgender youth of color in the U.S. and the various interpersonal and structural factors that impact their health (Institute of Medicine, 2011; Olson-Kennedy et al., 2016). Health professionals are urged to facilitate parent/guardian acceptance and support of transgender youth (Levine, 2013); however, evidence based information and clinical tools for fostering acceptance and support for transgender youth do not yet exist. Furthermore, nurses' knowledge of transgender care is limited (Carabez, Eliason, & Martinson, 2016; Eliason, Dibble, & Dejoseph, 2010) and health care providers without appropriate training about the needs of transgender populations are more likely to have uncertainty about their care for transgender patients, which contributes to stigmatizing interactions and inadequate care provision (Poteat, German, & Kerrigan, 2013)

Few descriptions exist about the lived experiences of transgender youth of color in the U.S. and how they navigate parent/guardian support, while also taking into consideration the potential impacts of structural level factors. *Structural competency* is the idea that disease,

behavior, and attitudes connected with stigma are often downstream consequences of a number of upstream influences such as ideologies, policies, and socio-structural processes that create the status quo (Metzl & Hansen, 2014). Inequalities in income, incarceration, employment, housing, education, and access to health care can be traced to structural factors such as racism, nationalism, and colonialism that directly impact communities of color and immigrant communities in the U.S. (Birn, Pillay, & Holtz, 2017). Many of these structural factors impact adult parents and guardians who are themselves people of color, as well as transgender youth of color themselves. Rigid and binary ideologies about gender contribute to structural processes that create inequality today, and these ideologies stem from historical processes of colonization that produced new gender orders and destroyed indigenous knowledges and ways of being (Connell, 2012). Understanding youths' experiences of parent/guardian support within this historical and structural context requires an intentional focus on experiences of the interpersonal dynamics that also considers structural influences.

Purpose of Study and Research Questions

Therefore, the overall purpose of this study was to generate a deeper understanding about the role of parent/guardian support in the lives of transgender youth, with a focus specifically on youth of color. A qualitative inquiry approach provided a comprehensive and detailed description of the stories from transgender youth of color in the U.S. about how they experience support from their parents/guardians, as well as navigate societal oppressions.

Maintaining awareness of potential structural level factors, this research sought to answer the following questions: 1) How do transgender youth of color age 16-18 in the United States experience support from their parents/guardians? 2) How does parent/guardian support relate to the health and well-being of transgender youth of color? 3) How do transgender youth

experience parent/guardian support within the context of navigating structural inequalities and intersecting marginalization?

Significance of Study

Nurses are the largest health profession in the U.S. and we focus on the range of human experiences and responses that occur within interpersonal and social environments (American Nurses Association, 2010). The number of transgender youth age 13-17 in the United States is roughly 150,000, which is roughly 1 out of every 137 youth (Herman, Flores, Brown, Wilson, & Conron, 2017). The transgender population in the U.S. is also estimated to be more racially and ethnically diverse, meaning transgender people are more often from communities of color when compared to the non-transgender population (Flores, Brown, & Herman, 2016). Yet, nursing research has been alarmingly silent on the topic of transgender health or the needs of transgender people of color (Eliason et al., 2010). This study begins to fill a major gap in nursing literature, enhancing our understanding of and care for this population.

Additionally, a national panel of expert transgender health researchers have identified that a critical research priority for transgender youth is research that describes the lived experiences of transgender youth with an emphasis on understanding the social environments within which they live (Olson-Kennedy et al., 2016). Results from this dissertation aligns with this priority, providing contextualized information that informs clinicians, educators, policy makers, and researchers about next steps for intervention development and policy changes to reduce health inequities and increase access to care for this population. More specifically, this study demonstrated an application of intersectionality theory in health research that seeks to enhance structural competency as a way to understand the social environment. An intentional structural approach, whereby the topic and population are considered within the larger context of

stigmatization and socio-structural processes, exemplifies a structurally competent approach to research with transgender populations who experience intersecting oppressions.

Finally, the qualitative secondary analysis (QSA) approach of this study provided an updated synthesis of best practices for re-use of qualitative data. Previous work in the area of qualitative secondary analysis methodology has laid a foundation for the viability of this method (Szabo & Strang, 1997) and outlined how health researchers can address potential issues that may arise (Heaton, 2004). The case exemplar provided with this study operationalizes the QSA approach, making it even more attainable for future use in nursing research, expanding our use of existing qualitative data with marginalized populations who may face limited resources for research funding and reduced accessibility for participation in qualitative research (Tate & Happ, 2018).

Definitions of Terms

Transgender Youth of Color- Transgender is a term used to describe a diverse population of people who have a gender identity and/or expression that does not align with the sex assigned at birth. *Youth* is a broad term to describe individuals who may still be dependent on older adults, which for the U.S. usually includes children, adolescents, or young adults of any age under 25 years. For the purposes of this study, the focus will be on individuals age 16, 17, or 18 because they are currently or have very recently experienced being minors and depending on their parent or legal guardian for consent to medical care. *People of color* refers to individuals who experience racialization, the socially constructed process of delineating people into social groups because of certain human traits, skin color, or country of origin (Bonilla-Silva, 1997).

Parents/Guardians – The terms parent and guardian used throughout the study describe the adult(s) who are legally responsible for raising and supporting a young person (financially,

materially, emotionally, and/or developmentally) through childhood and adolescence. This may include the biological parents, adoptive or foster parents, foster care systems, or other relatives/friends who have legal custody of the participant, meaning that they are the primary person responsible for caretaking, but they are also legally responsible for decision making and consent for medical care until the young person turns 18. The age of 18 is significant because it is the age of legal majority in the U.S., where the study was conducted. The study also recognizes that there are many definitions for family and as such, the term family may refer to a wide variety of supportive people who provide support, beyond genetic relation or legal definitions. However, the operationalization of the terms "parent/guardian" for this study will be limited to the individual who has/had legal custody of the participant until age 18, due to the nature of the problem and inquiry at hand.

Assumptions

Theoretical assumptions for this inquiry stem from the study's philosophical underpinning of critical theory, intersectionality, and critical race theory. The assumptions will be briefly explained here. *Critical theory* informs the epistemological assumption that knowledge is co-created and contextual and the ontological assumption that there are multiple truths and thus life is full of complexity (Lincoln, Lynham, & Guba, 2011). Therefore, the underlying philosophical approach to this inquiry will be remain open to many complex truths. This also means as the primary researcher, I remain aware that, as a nurse practitioner who has worked with transgender youth of color for over a decade, I may have already created some of my own assumptions about the answers to the research questions. Therefore, I will also seek to bracket any ideas I may bring from my own experiences, to allow the voices of participants to take precedent.

Intersectionality theory emphasizes the interrogation of how the multiple layers of power relations work together to create and sustain inequities (Collins & Bilge, 2016; Crenshaw, 1991), as well as how collectively, people experiencing marginalization have embodied knowledge that can disrupt, resist, and dismantle these systems of power (Weber, 2006). Intersectional thinking is rooted in women of color and indigenous resistance activism against slavery, settler colonization, and violence (Clark, 2016; Crenshaw, 1989, 1991; Hancock, 2016). Intersectionality theory suggests that structures of domination, such as colonialism, racism, heteropatriarchy, and capitalism, create and mutually constitute one-another to sustain a complex matrix of power to limit opportunity and marginalize various groups (Collins & Bilge, 2016; Dhamoon & Hankivsky, 2011). Indigenous scholar Linda Tuhiwai Smith describes how settler colonialism has devalued and marginalized indigenous ways of knowing, resulting in the domination of Western epistemologies and research methods that are profoundly exploitative for indigenous people and communities of color today (Tuhiwai Smith, 2012a). Western ideologies continue to determine what "counts" as research, and "deeply embedded in these constructs are systems of classification and representation which lead themselves easily to binary oppositions, dualisms, and hierarchical orderings of the world" (Tuhiwai Smith, 2012b, p. 58). Intersectional approaches take into consideration these and many other processes of power that co-occur to influence the status quo and create social marginalization – in health care systems and research (Dhamoon, 2011). This marginalization is especially important to address because of the ways these systems of domination create and maintain a strict male/female gender binary and racialized gender norms (Spade & Willse, 2015). Therefore, another assumption underlying this study is that both academic research and the health care system continues to be impacted by systems of domination, including but not limited to white supremacy, cisgenderism,

heteropatriarchy, capitalism, and neoliberalism. Furthermore, this study assumes that people moving through society today are navigating strict binary gender expectations, which permeate our every-day interactions and institutions. Research informed by intersectionality theory will name, interrogate, and disrupt these systems (Dhamoon, 2011), as well as center the strategies that transgender youth of color use to disrupt these intersecting forms of oppression in their lives.

Finally, *critical race theory* explains that "race" is a social construct manipulated for the benefit of whites, both historically and currently (Delgado & Stefancic, 2017). Simultaneously, racism is an everyday experience for people of color, yet not acknowledged by the dominant group and therefore difficult to eliminate or even address (Bell, 1991). Yancy calls upon white people to remain "unsutured" and self-critical of the socialization that privileges white bodies and lives over the bodies and lives of people of color (Yancy, 2014). As a white, cisgender person, I sought to return regularly to these truths throughout this study. I recognized, and had to remind myself often, that as a white person I have been socialized to gloss over complex and ugly realities about racism. I have been socialized to ignore certain truths in order to remain comfortable. I sought to bring this awareness to other systems of domination as well, including cissexism and ageism. In order to disrupt status quo patterns, I tried to lay out uncomfortable truths as I uncovered them in the data, remaining "unsutured" and uncomfortable, in hopes of disrupting the status quo approach to these issues.

Detailed discussion about the application of intersectionality and critical theory for the overall dissertation is discussed further in Chapter 2 (Manuscript I).

Chapter Summary and Organization of the Dissertation

This introductory chapter describes the need for structurally competent nursing research with transgender youth of color, and the importance of understanding more about the role of

parent/guardian support and other factors that may impact their access to health care and overall health outcomes. This chapter has also outlined an overview of the problem, purpose of the study, research questions, significance, definition of important terms, and assumptions. Moving forward, this dissertation will be organized using the non-traditional manuscript format. Therefore, some ideas and language may be repeated out of necessity, because the manuscript-chapters were designed to stand alone for submission to peer-reviewed journals.

Chapter 2 (Manuscript I) presents a novel theory-based conceptual framework that applies broadly to all transgender health inequities research, and also provides the theoretical framing for this dissertation. The manuscript provides an in-depth overview of the main tenets of intersectionality theory and the theory of structural injustice, providing a theoretical backbone for research that seeks to examine health inequities in a structurally competent way.   The manuscript then outlines a framework called Intersectional Research for Transgender Health Justice (IRTHJ), which illustrates how social inequality is not random or accidental, but systematically produced over time through and across actively maintained structures of domination, institutional systems, and socio-structural processes. *Structures of domination* include historical processes of settler colonization, white supremacy, heteropatriarchal family structures, and adultism that shape the *institutional systems* transgender youth of color must navigate, including health care, immigration, education, and foster care systems. Additionally, the framework names ongoing *socio-structural processes* that influence daily status quo interactions and create marginalization within these systems. These socio-structural processes include the colonization of knowledge, pathologization of identities, and the racialization and criminalization of bodies. Thus, chapter two provides a theoretical overview of the structures,

systems, and processes that should be examined when conducting structurally competent research with transgender youth of color.

Chapter 3 (Manuscript II) is a systematic literature review about parent/guardian support for transgender youth. This systematic review sought to identify 1) how "support" and "parent/guardian" are each currently defined in the literature; 2) what we currently know about the relationship between PG support and the health and well-being of transgender youth; and 3) whether the literature discusses structures of domination, institutional systems, and socio-structural processes in relation to PG support for transgender youth. This review found that PG support is broadly defined in the literature as affirming gender identity, protecting the child, and providing feelings of closeness and acceptance. PG support has been found to improve mental health, as well as decreases HIV risk and risk for victimization among transgender youth. Studies found several structural factors influencing PG support for transgender youth, including ideologies of cisgenderism, heterosexism, and racism that influence various institutional systems and everyday socio-structural processes, which parents/guardians must navigate. In addition, this manuscript identifies several gaps where future research is needed to further explain the complexities of parent/guardian support, especially among transgender youth from racial/ethnic minority communities and those under age 18.

Chapter 4 (Manuscript III) describes best practices for conducting rigorous qualitative secondary analysis research through a three-step approach. This approach was developed after a thorough review of qualitative secondary analysis methodology literature. The purpose of this manuscript is to describe the three iterative steps (describing the QSA project, epistemological assessment, and ethical assessment) and illustrate how they were applied to conduct this dissertation study. This chapter adds an important contribution to the qualitative methodological

literature and exemplifies how nursing researchers are well poised to conducted secondary analyses of qualitative data sets, especially with marginalized populations where nurses' professional experiences providing patient-centered care can ensure trustworthiness and rigor.

Chapter 5 (Manuscript IV) is a data-based manuscript, presenting the results from the narrative inquiry data analyses completed to answer the dissertation research questions. The chapter includes a description of the detailed narrative inquiry approach that was used to analyze semi-structured qualitative interviews with transgender youth of color age 16-18 in the U.S. (n=24), according to study aims described earlier. Participant narratives coalesced around the main theme, *It's A Process,* describing complex experiences of seeking to live authentically while navigating intersectional barriers to health care, especially access to gender affirming interventions. Subthemes included *We Need Your Help, I'm Lucky to Have Support, Self-Advocacy/Resistance,* and *Having Hope/Resilience.* This study was the first to describe pivotal experiences of transgender youth turning 18, a point when youth were finally able to consent for their own health care but may still face limited access if still on parent/guardian's insurance without parent/guardian support. Findings of this chapter can inform our understanding about the ways transgender youth of color demonstrate resistance and resilience, as well as the role of health care professionals in supporting transgender youth and their parents/guardians.

Finally, chapter six presents a synthesis of the overall dissertation. A brief review of each chapter is presented, followed by personal reflections and a discussion about the implications of this dissertation for nursing practice, future research, and health care policy.

Table 1.1 Manuscripts and Target Journals

Manuscript	Title	Target Journal
I - Theory	"Intersectionality Research for Transgender Health Justice: A Theory-Driven Conceptual Framework for Structural Analysis of Transgender Health Inequities"	*Global Public Health (submitted awaiting decision)*
II - Review of Literature	"Parent/Guardian Support and Health Outcomes Among Transgender Youth: A Critical Review of the Literature"	*Journal of Family Nursing*
III - Methods	"Secondary Analysis in Qualitative Nursing Research: Best Practices and Case Exemplar"	*Global Qualitative Nursing Research*
IV - Results	"It's A Process: A Narrative Inquiry of Transgender Youth of Color Navigating Parent/Guardian Support"	*Qualitative Health Research*

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CHAPTER 2: THEORY AND CONCEPTUAL FRAMEWORK

Chapter two is an overview of the theoretical underpinnings and conceptual framework for the dissertation study. This chapter is a manuscript that has been formatted for and submitted to *Global Public Health (decision pending)*. The manuscript first provides an overview of intersectionality theory and the theory of structural injustice. Then, it introduces a theory-driven conceptual framework to inform transgender health research, filling a gap in the transgender health literature. The manuscript is broad in scope and is designed to provide a theoretical and conceptual foundation for an approach to health inequities research with a variety of transgender populations. As a standalone manuscript, the overall focus of this chapter broadens beyond a focus on transgender youth of color populations; however, the critical and structural approach explicated in this chapter provides the theoretical underpinning informing the review of literature, methodological approach, and data analysis discussed in subsequent chapters of this dissertation.

TITLE

Intersectionality Research for Transgender Health Justice:

A Theory-Driven Conceptual Framework for Structural Analysis

of Transgender Health Inequities

by

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Abstract

Transgender people experience intersecting forms of social marginalization and are disproportionately affected by health inequities. We elucidate a novel conceptual framework for transgender health research that theorizes the constructs and pathways through which social inequities produce health inequities for transgender populations. Drawing on theories of intersectionality and structural injustice, the Intersectionality Research for Transgender Health Justice (IRTHJ) framework posits that social and health inequities affecting transgender populations are the result of status quo power relations produced within and between oppressive structures, institutional systems, and socio-structural processes. The IRTHJ framework delineates three main actions for improving transgender health research: i) name intersecting power relations, ii) disrupt the status quo, and iii) center embodied knowledge. The authors show how the IRTHJ framework provides tools for researchers to transform the design, implementation, and interpretation of transgender health research, and they discuss implications for programs, policy, and action for transgender health justice.

Background

Transgender people globally experience intersecting forms of social marginalization and are disproportionately affected by health inequities (Reisner et al., 2016). Despite greater ill health, transgender people face significant barriers in accessing health care due to discrimination, harassment, and refusal of care from health care providers (James et al., 2016). Among the 27,715 respondents to the 2015 U.S. Transgender Survey, 24% reported past-year transgender-related housing discrimination and 30% of employed respondents reported job-related discrimination, with transgender people of color reporting even higher rates (James et al., 2016). Sex work is often a means of survival for transgender people, and transgender women sex workers are vulnerable to HIV because of a complex interaction of systemic, interpersonal, and individual discrimination and violence (Poteat et al., 2015). Worldwide, HIV is higher among transgender women when compared to all adults of reproductive age (Baral et al., 2013), and in the U.S., African American transgender women experience a disproportionately higher burden of HIV (Becasen, Denard, Mullins, Higa, & Sipe, 2018).

Transgender populations worldwide also face significant inequities in violence and mental health concerns. For example, transgender women in Cambodia with depressive symptoms were significantly more likely to report gender-based violence and sexual assault (Yi et al., 2018). Another study with a national sample from the Dominican Republic found that individuals with histories of sexual abuse, torture, or attempted murder were significantly more likely to have attempted suicide (Budhwani et al., 2018). In the U.S., compared to non-transgender people, transgender people had disproportionately higher prevalence of suicide attempts (Grossman, Park, & Russell, 2016) and substance use (Keuroghlian, Reisner, White, & Weiss, 2015), with even higher rates among transgender people of color and transgender people

with disabilities (James et al., 2016). Estimates suggest that U.S. Black and Latina transgender women account for nearly 93% of all transgender homicide victims, and that these women are murdered at higher rates than Black and Latina cisgender women (Dinno, 2017).

The U.S. National Institutes of Health has identified transgender people as a 'health disparity population,' due to their disproportionate burden of mental and physical ill-health (NIMHD, 2016) and the World Health Organization has called for a global health agenda inclusive of transgender people (Thomas et al., 2017). Transgender health research requires a theoretical foundation that can inform inquiry into relationships among these layers of marginalization, discrimination, and health inequities. Syndemic theory has been utilized in the transgender health literature to analyze social factors that underlie co-occurring health outcomes (Brennan et al., 2012; Reisner, White Hughto, Pardee, & Sevelius, 2015; Wilson et al., 2015). However, a recent review of HIV and related syndemics among transgender populations, which found that multiple co-occurring psychosocial conditions were associated with HIV risk, called for future research to employ a more complex analysis of structural level factors that create and sustain these conditions (Poteat, Scheim, Xavier, Reisner, & Baral, 2016).

Purpose

This paper elucidates a new theory-driven conceptual framework for research on transgender health inequities. Drawing on intersectionality (Collins and Bilge, 2016) and structural injustice (Young, 2011), we theorize the constructs and pathways through which social inequities produce health inequities for transgender populations. We outline key theoretical tenets and provide actions and tools for researchers to elucidate the structural production of transgender health inequities, thereby producing intentional and actionable research that can transform inequities into transgender health justice.

Part 1 - Theoretical Foundation

Introduction to Intersectionality Theory

Intersectionality theory asserts that various oppressions create and mutually constitute one another to sustain a complex matrix of power that is rooted in, and actively maintained by, social structures and institutional systems (Collins and Bilge, 2016; Dhamoon and Hankivsky, 2011). Intersectional thinking originated within various women of color resistance movements from the 19th and 20th centuries, including abolitionists Maria Stewart and Sojourner Truth, and the Black feminist lesbian organization Combahee River Collective (Hancock, 2016). As well, early Indigenous feminists, such as Zitkala-Sa in the late 1800's, fought against violence that 'has always been gendered, aged, and linked to access to land' (Clark, 2016, p. 49). Crenshaw (1989, 1991) first coined the term 'intersectionality'; her early scholarship on the complexity of oppression emphasized a shift in analytical thinking about relationships between and within the social categories of race and gender. Likewise, Collins (2000) described a 'matrix of domination,' arguing that power cannot be reduced to only one oppressive structure or one dominant group, but instead functions as an 'intangible entity that circulates within a particular matrix' of intersecting oppressions (2000, p. p. 274).

Queer and transgender activists have for some time emphasized the importance of seeking justice through intersectional resistance that prioritizes multi-axis analysis, such as disrupting institutional systems that perpetuate racialized-gendered violence (Spade, 2013). Yet, although intersectionality has been applied to health research (Bauer, 2014; Bowleg, 2012; Dhamoon and Hankivsky, 2011; Hankivsky et al., 2010; Weber and Parra-Medina, 2003), seldom has it informed research with transgender populations (Lacombe-Duncan, 2016). Next

we outline four tenets of intersectionality most applicable to understanding transgender health inequities.

Four Tenets of Intersectionality

First, an intersectional analysis attends to multiple *intersecting structures* of domination, such as cisgenderism, heteropatriarchy, racism, and colonialism (Dhamoon & Hankivsky, 2011). Cisgenderism is the 'cultural and systemic ideology that denies, denigrates, or pathologizes self-identified gender identities that do not align with assigned gender at birth as well as resulting behavior, expression, and community' (Lennon and Mistler, 2014, p. p. 63). Pertinent to cisgenderism is Connell's argument that gender structures are macro level patterns found across institutions worldwide that are socially embodied, dynamic, and highly influenced by colonial processes over the past 500 years (2012). Gender hierarchies, *in concert with* other structures of power that interlock and sustain social inequities, shape intersecting social identities and experiences at the micro level (Bowleg, 2012). For example, intersectionality research on high rates of sex work, HIV, and incarceration among Black transgender women might consider how systemic anti-Black racism, heteropatriarchy, and transphobia operate within a capitalist economy to produce housing segregation, mass incarceration, precarious employment, and extreme vulnerability to violence for this population, as well as how these structures perpetuate the objectification and criminalization of Black femininity (Sevelius, 2013).

Second, intersectionality elucidates how structures of domination manifest through '*processes* of differentiation,' which *create* both *categories* of difference and *identities* marked as different by the dominant group (Dhamoon & Hankivsky, 2011). Intersectionality-informed health inequities research is explicit in defining which of these concepts (i.e., processes, categories, identities) are being studied and why, as well as how they are rooted in structures of

domination (Bowleg, 2012; Dhamoon, 2011). Examining processes of differentiation (e.g., gendering, racialization, pathologizing) draws attention to the ideologies embedded in structures of domination that inform societal norms and standards (Dhamoon & Hankivsky, 2011). Categories of difference (e.g., gender, race, social class, ability) are the result of these everyday social processes that demarcate groups as "other" and create and sustain power differentials between them (Collins, 1991; Dhamoon & Hankivsky, 2011). Thus, constructs such as gender or race are not considered unidimensional or naturally occurring properties of individuals, but instead a result of the active production of socially marked and intersecting categories of difference (Dhamoon, 2011; Morgen, 2006; Muntaner, Ng, Chung, & Prins, 2015).

A pertinent example of this second tenet concerns racialized gender norms. As Spade and Willse (2015) explain, racialized gender norms 'govern sexual behavior, speaking styles, diet, emotional range, punctuality, manners, dress, and much more. Discourses in the social and medical sciences, popular media, criminal and immigration systems, education, and social services industries produce and uphold these norms' (p. 3). Applying intersectionality, transgender health researchers might examine discourses and other practices that (re)produce these norms, along with how they are enforced and internalized.

Third, intersectionality posits that social inequities are reflections of *power* differentials that negatively impact people with marginalized identities while privileging dominant groups (Dhamoon, 2011). Intersectional health scholars thus emphasize the need to understand social categories as relational and indicative of intersecting power relations (Dhamoon and Hankivsky, 2011; Weber, 2006). For example, if health disparities researchers were to compare transgender women of color to white transgender women, they would conceptualize and interpret identities derived from the social categories of race and gender as effects of structurally produced power

relations tied to racism and cisgenderism (Dhamoon & Hankivsky, 2011). Likewise, intersectionality informed research clarifies that categories considered normative (e.g., 'white' or 'cisgender') are also those with more social power (Dhamoon, 2011; Spade and Willse, 2015).

Fourth, intersectionality *centers* the *embodied knowledge* of people who experience and resist multiple intersecting oppressions (Chown and Malcoe, 2017). Within intersectional scholarship, embodied knowledge 'emphasize[s] and celebrate[s] the voices, experiences, situated knowledge, and perspectives of those traditionally marginalized and erased' (Dhamoon, 2011, p. 233). An intersectionality informed approach values embodied knowledge because it is essential for meeting social justice aims, including understanding how processes of oppression work and how to resist them, and requiring researchers to be accountable to people who live in the margins of society (Chown and Malcoe, 2017). For example, scholars interested in researching transgender health inequities related to incarceration could begin by learning about specific experiences of transgender prisoners, as depicted in anthologies such as *Captive Genders: Trans Embodiment and the Prison Industrial Complex* (Stanley and Smith, 2015), written by current and former transgender prisoners, activists, and academics. These writings are a collection of experiences and plans for action, offering an analysis of the ways that 'regimes of normative sexuality and gender are organizing structures of the prison industrial complex' (Stanley & Smith, 2015, p. 10). However, this is only a start; fully centering embodied knowledge requires participatory research approaches where people situated at the intersection of multiple oppressed identities are included as decision-makers in research and knowledge production (Chown and Malcoe, 2017; Wallerstein, Duran, Oetzel, & Minkler, 2018).

Introduction to Theory of Structural Injustice

Green, Evans, & Subramanian state that 'intersectionality will be most effective where combined with social theory on the production of health inequalities' (2017, p. p. 215). Young's theory of structural injustice provides a framework for understanding how unjust social processes have become the status quo and create and maintain social inequities via institutional systems (2011). The theory of structural injustice posits that individuals act according to societal laws, rules, and other accepted practices that operate together as the 'norm' to directly benefit some, while indirectly or directly harming others (Young, 2011). As Young states, the 'structures are produced and reproduced by large numbers of people acting according to normally accepted rules and practices, and it is in the nature of such structural processes that their potentially harmful effects cannot be traced directly to any particular contributors' (2011, p. 100). The theory of structural injustice identifies the status quo itself as an oppressive vehicle of power. Institutions are held in place by laws, implicit social rules, perceived advantages, or simply by nature of habit, and institutional systems appear objective and permanent in part because the individuals within them follow standard operating procedures (Young, 2011, p. 55). Applying Young's theory to social inequities in health, researchers are directed to consider how the status quo functions and ways that everyday practices of multiple institutional systems (re)produce inequities.

Young (2011) further asserts that when we understand injustice as *structural*, i.e., the result of various institutional systems and socio-structural processes in which we participate, it leads us, morally, to address our collective responsibility for justice. Young argues that the responsibility for justice lies with each person in society, even though each individual person may not be at fault. Responsibility is essentially shared and 'can be discharged only through

collective action' (Young, 2011, p. 105). Collective action, according to Young, is a forward-looking responsibility that manifests through actions intent on changing interrelated institutions and processes to make them more just. No single person can change the structures, systems, or processes on their own. Thus, research informed by the theory of structural injustice advances an ethics that encourages many people at a wide variety of positions within institutions and society to take collective responsibility for problematizing, analyzing, and disrupting the structures of injustice.

Part II – Conceptual Framework

Drawing on the theories of intersectionality and structural injustice, Intersectionality Research for Transgender Health Justice (IRTHJ) provides tools for researchers to transform the design, implementation, and interpretation of transgender health research, as well as to address implications for programs, policy, and action. IRTHJ assumes that social inequities and the distribution of societal determinants of health are not random or accidental, but rather are structural injustices that have been systematically produced over time through actively maintained structures of power. The main tenet of IRTHJ is that *social and health inequities affecting transgender populations are the result of status quo power relations produced within and between oppressive structures, institutional systems, and socio-structural processes*.

IRTHJ Conceptual Framework

The IRTHJ framework is illustrated in Figure 2.1. Three main layers, depicted as concentric circles, demonstrate how relations of power (structures of domination, institutional systems, and socio-structural processes) work together in a continuous interlocking manner, to produce transgender health inequities.

Intersectional Causes
of Health Inequities

Layer 1: STRUCTURES OF
DOMINATION

Racism
Cisgenderism
Hetero-patriarchy
Capitalism
Colonialism
Adultism/Ageism
Ableism

Layer 2:
INSTITUTIONAL SYSTEMS

Housing
Immigration-Refugee
Health Care
Education
Criminal-Legal
Foster Care
Welfare

Layer 3: SOCIO-STRUCTURAL
PROCESSES

Colonizing
Gendering
Class Exploitation
Racialization
Pathologizing
Criminalizing

STRUCTURES OF
DOMINATION

INSTITUTIONAL
SYSTEMS

SOCIO-STRUCTURAL
PROCESSES

Transgender Health
Inequities

NAME
INTERSECTING
POWER
RELATIONS

DISRUPT THE
STATUS QUO

CENTER
EMBODIED
KNOWLEDGE

Transgender
Health
Justice

Fig 2.1 Intersectionality Research for Transgender Health Justice (IRTHJ) Framework

Structures of domination (Figure 2.1, Layer 1) include the various forms of structural

oppression and underlying ideologies that we argue ultimately cause social health inequities for

transgender populations. Social structures involve 'a way of looking at the whole society, one

that sees patterns in relations among people and the positions they occupy relative to one

another' (Young, 2011, p. 70). When considered through an intersectionality lens, transgender

populations are seen to experience heightened vulnerabilities because of their structurally

produced marginalized social positions at the intersections of race, ethnicity, citizenship, gender,

sexuality, age, ability, and class.

Structures of domination are enacted through, and reinforced by, *institutional systems*

(Figure 2.1, Layer 2), which converge to create structural injustice for transgender populations.

For example, cisgenderism permeates every institution in the U.S., conferring privileges to those

classified as cisgender while penalizing, pathologizing, and erasing transgender populations (Bauer et al., 2009). These systems intersect in the policies, regulations, and laws that perform state surveillance and regulation of gender identification (Spade, 2008). A transgender person often must navigate both the health care and legal systems to change gender markers on their birth certificate, driver's license, and passport because some states or jurisdictions require medically certified documentation confirming that an individual has undergone or is undergoing gender transition through cross-gender hormones and/or surgery (Spade, 2008). In addition to being onerous and dehumanizing, such policies restrict options for those who do not desire or cannot access hormones or surgery, and for people whose bodies are disproportionately criminalized because of interlocking oppressive structures such as racism and ableism (Spade, 2008).

Socio-structural processes (Figure 2.1, Layer 3) are everyday social practices that (re)produce inequality in service of the status quo by, for example, enforcing norms within and across institutional systems. Sevelius' (2013) study of self-identified transgender women of color found that they faced societal norms and expectations about femininity shaped by racism and sexism, which led to experiences of objectification, victimization, and identity threat. Transgender identities are pathologized through use of a medical diagnosis (gender dysphoria) that is still widely categorized as a mental health condition, yet is required for accessing various health care services (Dewey and Gesbeck, 2017). Additionally, interventions such as hormones and surgery are often only obtainable when someone has the economic means to access a lengthy diagnostic process (Dewey and Gesbeck, 2017).

IRTHJ Actions

IRTHJ identifies three actions to advance transgender health justice. Table 2.1 translates these actions into specific questions and steps for implementing IRTHJ:

	Questions to Ask	Steps to Take
NAME INTERSECTING POWER RELATIONS	What are the key intersecting power hierarchies that shape constraints & opportunities for our study participants? How do structures of domination, institutional systems, & socio-structural processes produce the inequities under study?	Diagram the pathways through each layer of the intersectional causes of health inequities to theorize how inequities are produced. Apply a structural analysis to frame the study aims & hypotheses.
DISRUPT THE STATUS QUO	How are my worldview & social positions affecting my research decisions? How can the knowledge produced by this research foster collective action for transgender health justice?	Practice self-reflexivity about how we as researchers participate in structural production of social/health inequities, including how we are advantaged or penalized by status quo power relations. Diagram how research findings can disrupt ongoing socio-structural processes that foster unjust social relations.
CENTER EMBODIED KNOWLEDGE	How can this research center the voices, situated knowledge, & perspectives of the transgender populations of focus? How are we being accountable to people who experience & resist multiple intersecting oppressions?	Involve transgender community members, activists, & organizations in all stages of research, from formation of study aims through interpretation & dissemination of findings. Employ principles & methods from participatory action research traditions.

Table 2.1 IRTHJ Actions

First, *naming intersecting power relations* requires that researchers consider the structural production of transgender health inequities within and across each layer of the IRTHJ framework. At all stages of research – from initial study framing and development of research questions, to methods and analysis, and through interpretation and dissemination of findings – researchers can ask *how* the interlocking structures of domination, institutional systems, and socio-structural processes produce the transgender health inequities under study. IRTHJ requires researchers to theorize *intersecting* relations of power at *multiple* layers of analysis. An excellent example of this action in practice is Sevelius' Gender Affirmation Framework (2013), which diagrams how the intersecting experiences of racism, transphobia, and sexism create

internalized stigma leading to an increased need for gender affirmation; at the same time these structures of domination influence institutional systems that restrict access to the resources needed for gender affirmation.

Second, researchers seeking health justice *disrupt the status quo* by through self-reflexivity and action towards building health equity. Power relations can unintentionally influence our language choices, study measures, analysis variables, and suggestions for policy interventions (Choo and Ferree, 2010). In concert with Young's theory of structural injustice, researchers have a responsibility to disrupt hierarchies of power. Reflexivity requires researchers to analyze our everyday participation in the structural production of social and health inequities, including how we are advantaged or penalized within various institutions by status quo power relations. Reflexivity also calls upon researchers to take account of the epistemological and ontological underpinnings that inform our worldviews, as well as how our intersecting social positions may impact our decisions throughout the research process (Hall and Stevens, 1991; McCabe and Holmes, 2009). Disrupting the status quo is especially important when conducting community engaged research, where hierarchies and marginalization are often reproduced in the process of engaging community members as peer researchers and may cause more direct harms if not addressed (Guta, Flicker, & Roche, 2013).

Here we share with readers a bit about our experiences and positionalities that have influenced our thinking and approach to generating this framework. [Anonymous Initials] identifies as a white cisgender woman from a working-class background, a nurse researcher and nurse practitioner with 15 years of experience working with transgender youth and adults in urban U.S. settings. [Anonymous Initials] identifies as a cisgender woman who is racialized as white and was reared in a U.S. working-class, biracial/biethnic (Ashkenazi Jewish and Black)

family; she is a social epidemiologist with over 20 years of experience conducting health inequities research that draws on community knowledges as well as critical race, intersectional, and decolonial scholarship. [Anonymous Initials] identifies as a Black woman with some lived transsexual experience and from a working middle-class background, a doctorally-prepared nurse practitioner, advocate, policy developer and researcher with expertise in comprehensive care for transgender adults for 12 years. [Anonymous Initials] identifies as a Black queer woman from a working-class background; she has provided medical care for transgender adults for more than 20 years and has conducted research with transgender communities for eight. Collectively, we seek to employ IRTHJ in our work, and carefully consider how our research activities will disrupt status quo power relations to advance health justice for transgender populations.

Third, *centering embodied knowledge* calls on researchers to value and be accountable to – in all research activities – the voices, situated knowledge, and perspectives of transgender populations, especially those who experience and resist multiple intersecting oppressions. Centering embodied knowledge is an acknowledgement that the margins of society 'have been both a site of repression and a site of resistance' (hooks, 1989, p. p. 208). This approach argues that confronting the intersecting structural and institutional harms experienced by multiply marginalized groups has the greatest potential for eliminating power hierarchies and thereby producing social and health equity for all (Spade, 2011). Participatory research approaches that are grounded in collaborative relationships with transgender communities are most effective for centering embodied knowledge. These approaches emphasize trust-building as a continuum, while acknowledging historically unjust relationships between marginalized communities and researchers (Lucero, Wright, & Reese, 2018). To center embodied knowledge, researchers can draw from core principles of community-based participatory research and participatory action

research, such as building meaningful relationships, acknowledging and sharing power, encouraging participation, privileging the community's knowledge, and making equity-oriented change (Grant, Nelson, & Mitchell, 2008).

Discussion and Application

IRTHJ is designed to apply broadly to health inequities research across an array of transgender populations and health outcomes. In this section we apply IRTHJ to three previously published studies of HIV among diverse groups of transgender women, all of whom represent communities situated at the intersection of multiple oppressed identities. We illustrate ways that this research has begun to explore structural causes of transgender health inequities, and discuss how use of IRTHJ can strengthen future research and interventions.

We begin by briefly describing the three studies. Brennan et al. (2012) were the first to apply syndemic theory to investigate HIV risk among young transgender women. The authors conducted a secondary data analysis of a cross-sectional study of transgender women (15-24 years) in the Chicago and Los Angeles metro areas. They explored whether there was an 'additive' or dose-response relationship between four syndemic factors and two study outcomes: condomless anal intercourse and self-reported HIV serostatus. They also examined associations between their syndemic index and three indicators of social marginalization. Participants (n=151) reported their racial/ethnicity as Black/African American (39%) or Latina (38%), and 34% were employed. The findings showed positive associations between two syndemic factors (intimate partner violence and polysubstance use) and the study outcomes, and an association between two indicators of social marginalization (sex work and incarceration) and the syndemic index. The authors concluded with a call for a 'multisystems approach' to prevention that targeted 'both social and health-related factors' (Brennan et al., 2012, p.1756).

Wilson et al. (2015) applied syndemic theory to a cross-sectional survey of young (ages 16–24) transgender women (n=282) in the San Francisco area; they examined racial/ethnic differences in sociodemographic factors including racial discrimination, HIV-related risk behaviors, and syndemic factors. Among participants 36.8% were white, 21.9% Latina, 15.2% mixed race, 13% African American, 5.9% Asian, and 7.1% 'other.' The investigators collapsed the sample into two groups, 'white' and 'racial/ethnic minority.' They found significantly lower education and significantly greater levels of racial discrimination (but nearly identical levels— 80%—of trans-related discrimination), greater childhood housing instability, and greater engagement in condomless receptive anal intercourse (CRAI) among racial/ethnic minorities compared to whites. The paper concluded with a call for prevention efforts that address 'racial inequalities to reduce stressors' (p. e46) and 'macrolevel disparities' particularly impacting young transgender women from racial/ethnic minority groups (p. e41).

Utilizing a gender minority stress framework, Arayasirikul et al. (2017) examined transphobic discrimination and 'race' in relation to two HIV risk factors (binge drinking and CRAI) among HIV negative transwomen (n=149) in San Francisco. In bivariate analyses, the authors compared white transwomen to 'transwomen of color' – the latter included Black (22.8% of sample), Latina (33.6%), and 'other' (18.1%) transwomen. Results showed that white transwomen were disproportionately older, college educated, U.S. born, insured, and reported more transphobic discrimination measures (e.g., ever been denied housing or evicted because of gender identity or presentation). In multivariate analyses, higher levels of transphobic discrimination were associated with recent binge drinking but not with CRAI; transwomen of color status (used synonymously with 'race') was associated with CRAI but not with binge

drinking. The authors concluded that 'interventions informed by racial equity and social justice to specifically target transwomen of color may be effective in preventing [C]RAI' (p. 2632).

Name Intersecting Power Relations

The three papers do important work to examine how social factors (e.g., homelessness, discrimination, sex work) and social stressors (e.g., victimization, parental rejection) are associated with health outcomes, providing a dual focus on psychosocial and social determinants of transgender health inequities. However, we can go a step further to ask *why* transgender populations have a worse *distribution* of these social determinants. IRTHJ calls for theorizing, through each IRTHJ layer, the intersecting structural causes of the social patterning of study measures. For example, looking to layer 3 of Figure 2.1, research that names social-structural processes (such as class exploitation, racialization, and criminalization) leads to deeper understanding about why transgender women of color have an increased vulnerability to homelessness, incarceration, and sex work, as Sevelius highlighted in their grounded theory study (2013). Layer 2 of Figure 2.1 depicts how researchers can examine how the lack of non-discrimination laws limit housing and employment options for transgender people as was done in the Virginia Transgender Health Initiative Study (Bradford, Reisner, Honnold, & Xavier, 2013). Additional questions include: How do cisgenderism, racism, and capitalism intersect to severely limit housing and education for transgender women of color? How do housing, education, and criminal-legal policies – at local, state, and national levels – interlock to cause racial inequities in incarceration, sex work or street economies, and in exchange of sex for food or housing? How do racialized gender norms influence the ways Black, Latina, and other young trans women of color are expected to look, act, and behave within society, thus creating an increased need for gender affirmation (Sevelius, 2013)? Asking these types of questions can lead to specific

interventions and intersectoral policies that could disrupt the structural production of transgender health inequities.

Naming intersecting power relations also prompts researchers to explain the meaning of their social variables, including race/ethnicity. Arayasirikul et al. (2017) do an excellent job of situating their transphobic discrimination measures within a gender minority stress framework and they mention heteronormativity and heterosexism. However, they state an intention 'to examine the effects of … race on HIV risk factors' without explaining how they conceptualize 'race;' absent other explanations, this language of race effects is suggestive of biological determinism. Likewise, in their regression analysis of syndemics and social marginalization, Brennan et al. controlled for race/ethnicity "because of significant correlations with indicators of social marginalization" (p. 1754). Instead, IRTHJ theorizes race as a product of racialization processes and racism (Ford and Airhihenbuwa, 2010) and encourages researchers to theorize and diagram how race and racism interrelate causally with other study measures of social marginalization.

Disrupt the Status Quo

All three papers focused on what the World Health Organization Commission on Social Determinants of Health (CSDH) has referred to as *intermediary* social determinants of health (2008, p. 6). A consequence of this focus at the level of causation is that the interventions proposed are likewise limited to action on intermediary determinants, which Solar and Irwin (2007) argue is insufficient:

> Arguably the single most significant lesson of the CSDH conceptual framework is that interventions and policies to reduce health inequities must not limit themselves to intermediary determinants, but must include policies specifically crafted to tackle the

> social mechanisms that systematically produce an inequitable distribution of the
>
> determinants of health among population groups. (Solar and Irwin, 2007, p. 7)

The IRTHJ action of disrupting the status quo further identifies ways to eliminate transgender health inequities at the structural level. The authors call for intervention and prevention efforts that address 'macrolevel disparities' (Wilson et al., 2015), 'multisystems approach' (Brennan et al. 2012), and 'racial equity and social justice' (Arayasirikul et al., 2017). We can go further to advocate for specific policy changes that disrupt the inequitable distribution of social and psychosocial determinants of health. For example, Wilson et al. advocated for '[p]ublic health efforts that prioritize access to housing, education, and jobs' (p.e46) for transgender young women. IRTHJ encourages examining the specific policies and operational practices within and across institutional systems that result in the inequitable social patterning of housing, education, and jobs for transgender populations. One example includes Hill et al. (2017) who explored employment among transgender women of color who had received no-cost legal name change support, and found that those who had legally changed their name had greater odds of being employed. Supporting transgender people with accessible legal name changes can address the everyday marginalization that occurs within various institutional systems due to cisgenderism, thereby directly impacting social factors, such as housing and jobs that we already know are connected to HIV risk.

Center Embodied Knowledge

Centering embodied knowledge asks researchers to use participatory methodologies that involve collaboration and power sharing with transgender community members throughout the research process. Unlike many observational studies, transgender research projects often include community members on advisory boards or in focus groups to guide study development. Wilson

et al. (2015) used focus groups comprised of transgender youth as part of their 'formative assessment' and Brennan et al. (2012) used a transgender advisory committee at one of their research sites to inform survey development, recruitment strategies, and study protocols. These practices allow for some inclusion of embodied knowledge in research design. However, IRTHJ calls for greater involvement of transgender community members, activists, and organizations - not only advisors or key informants on study design, but as full research collaborators with decision-making power over all aspects of the research from idea generation through dissemination. Local grassroots research organizations, such as Black Youth Project 100: Agenda to Build Black Futures (Black Youth Project, 2016), provide examples of how to center marginalized voices and perspectives through action-oriented research that values embodied knowledge throughout the research process, including data analysis, dissemination, and action. Using models such as this, transgender health research can privilege the experiential knowledge of transgender people to promote strategic approaches for achieving transgender health justice.

Conclusion

When researchers do not acknowledge the complex ways that power operates to create inequities in health outcomes, we are complicit in the making of structural injustice. Transgender health inequities research must instead move towards an agenda of health justice. IRTHJ is a novel, theory-driven conceptual framework to inform transgender health research that seeks to illuminate and disrupt structural causes of health inequities. Through application of IRTHJ actions, researchers can illuminate power hierarchies, bring an awareness of intersecting structural causes of health inequities to the research process and dissemination of findings, and work in solidarity with transgender populations to collectively seek to not only understand, but disrupt injustice and resulting inequities in health.

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CHAPTER 3: SYSTEMATIC REVIEW OF THE LITERATURE

This chapter is stand-alone manuscript providing a systematic review of the literature exploring the phenomenon of parent/guardian support for transgender youth. Specific attention is given to the ways parent/guardian support has been currently defined and measured in the literature, as well as how support from parents/guardians was related to health outcomes in research to date. The review also takes a structural approach, examining how the extant literature has taken into consideration structural level factors that influence the family system and/or the interpersonal relationships between transgender youth and their parents/guardians. A synthesis of the current literature, gaps in the research, and suggestions for future studies will be outlined.

TITLE

Parent/Guardian Support and Health Outcomes Among Transgender Youth:

A Systematic Review of the Literature

Abstract

Transgender youth face multiple challenges that require support from their parents/ guardians. Nurses are urged to facilitate parent/guardian (PG) support in order to improve health outcomes. However, nurses lack information about what support should look like and how to facilitate it. This systematic review of the extant literature provides an overview of parent/guardian support and how it relates to health outcomes for transgender youth. A systematic search of PubMed, CINAHL, Medline, and PsycInfo was conducted, with a total of 21 articles meeting inclusion/exclusion criteria. A synthesis of these studies found that PG support for transgender youth is currently defined a multi-faceted way, which includes affirmation of the child's gender identity, protection for the child, and a feeling closeness and acceptance between the parent/guardian and child. Additionally, the literature has identified three main health outcomes that are related to parent/guardian support: mental health, risk for HIV, and experiences of victimization. Structural factors influencing PG support for transgender youth include ideologies of cisgenderism, heterosexism, and racism. These ideologies impacted PG support and also made it more difficult for parents/guardians to advocate for and protect their transgender child. Future research needs to include transgender youth of color under age 18, consider structural factors, and create culturally safe and developmentally appropriate interventions to facilitate parent/guardian support for transgender youth.

Keywords: transgender youth, parent/guardian support, structural factors, gender affirmation, transgender health

Introduction

Transgender is a broad term that refers to a diverse group of people who have in common the fact that their gender identity differs from the sex they were assigned at birth. Transgender people have existed throughout time and across all cultures, and may be referred to using different terms across the globe, such as kathoey in Thailand, waria in Indonesia, and travesties in Latin America (World Health Organization, 2016). Transgender people face significant structural and interpersonal stigmatization throughout their lives, due to a gender identity and/or expression that does not conform to societal or cultural norms and expectations (White Hughto, Reisner, & Pachankis, 2015).

Societal stigma can take the form of human rights violations, physical abuse or harassment, discrimination in schools or the workplace, and microaggressions in everyday social interactions (Winter, Diamond, et al., 2016; Winter, Settle, et al., 2016). A growing body of literature has begun to connect these experiences of stigma to a host of health burdens, yet the specific structural factors impacting long term health are often unnamed or understudied (Reisner et al., 2016). *Interpersonal stigma* often surfaces as rejection from family members, which especially impacts transgender youth who will face significant stress and health impacts when rejected by their parents or legal guardians (Ignatavicius, 2013). The U.S. Transgender Health Survey found that transgender people of color reported higher rates of family rejection as well as significantly greater barriers to accessing health insurance, health care, employment, and housing when compared with White participants (James et al., 2016).

An important area for research is the role of parent/guardian (PG) support for transgender youth, especially because they may face multiple challenges that require attention from their

legal guardians and medical or mental health care. A growing body of literature is beginning to document the importance of PG support for transgender adolescents, because PG consent is often required for the gender affirmation treatments that relieve gender dysphoria, the psychological distress associated with an incongruence between gender identity and physical sex characteristics (American Psychiatric Association, 2013). Significant morbidity and mortality are associated with untreated gender dysphoria in transgender youth, and of utmost concern are increased rates of suicidal ideation and suicide attempts. Suicide is the second leading cause of death among all youth ages 10-19, with 17% of high school age youth considering suicide and 8% of high school age youth attempting suicide (Centers for Disease Control, 2013). However, transgender youth have much higher rates: between 45-51% of transgender youth have reported suicidal ideation (Grossman, Park, & Russell, 2016; J. Olson, Schrager, Belzer, Simons, & Clark, 2015) and 30-51% have engaged in lifetime suicide behavior, i.e. attempting suicide (Toomey, Syvertsen, & Shramko, 2018). Transgender children and pre-pubescent youth who received interventions that supported a transition to the affirmed gender were found to have decreased levels of depression and suicidality, on par with rates among of non-transgender age-matched controls (K. R. Olson, Durwood, DeMeules, & McLaughlin, 2016).

Professional organizations and experts across the U.S. have noted the medical necessity of gender affirming interventions when a transgender child is experiencing dysphoria, and thus urge health care providers to facilitate PG support of transgender youth (American Academy of Pediatrics, 2015; Reitman et al., 2013). In addition to facilitating access to essential health care for youth in general, PG support is widely known to improve the overall health and well-being of all adolescents, especially with relation to mental health outcomes (Scholte, Van Lieshout, & Van Aken, 2001). A thorough understanding of the specific role parents/guardians play in the

health and well-being of transgender youth can improve health care providers care of the youth and their parents, as well as facilitate education for families of transgender youth on what the support should look like.

Family nurses and health professionals can ask several important questions to enhance our understanding about PG support for transgender youth: what exactly is "support" and what do we know about how PGs and youth navigate accessing life-saving health care and gender affirming interventions? What do we know about the relationship between PG support and the health and well-being of transgender youth? What is the best way for family nurses to facilitate this support to improve long term health outcomes? Finally, what are the gaps in our knowledge about PG support, and how can they be addressed through future nursing research?

Additionally, the theoretical perspective informing this literature review emphasizes a structurally competent approach (Metzl & Hansen, 2014; Young, 2011). A structurally competent approach acknowledges that the downstream factors (such as the interpersonal relationships with parents/guardians and individual health outcomes discussed above) are seen as inevitably influenced by a number of upstream factors (Metzl & Hansen, 2014). Thus, the approach was informed by the Intersectional Research for Transgender Health Justice (IRTHJ) conceptual framework (Wesp, Malcoe, Elliot & Poteat, n.d., Ch. 2). The IRTHJ framework theorizes that upstream factors consist of three layers: structures of domination (ideological processes such as colonialism, racism, hetero-patriarchy, or cisgenderism); institutional systems (such as health care, foster care, or welfare systems); and socio-structural processes (including racialization, gendering, and pathologizing of identities). These layers work interchangeably and continually to create societal norms and a status quo of limited opportunities and inequality, influencing interpersonal relationships and health outcomes (Wesp et al., n.d., Ch 2). Therefore,

a secondary aim of this review was to explore if current literature addresses the ways that PG support for transgender youth is related to these "status quo power relations produced within and between oppressive structures, institutional systems, and socio-structural processes" (Wesp et al, n.d., Ch. 2, p. 25). Taking this structural approach, several additional questions guiding this review included: what are the unique needs and experiences of PGs and youth occupying marginalized social positions, for example transgender people of color in the U.S. who experience marginalization of multiple aspects of their identity? To what extent does current research exploring PG support for transgender youth include discussions about power, inequality, and social structural processes that influence overall ideas about gender, for both youth and their parents/guardians?

Literature Search Methods

A systematic search was conducted of PubMed, CINAHL, Medline, and PsycInfo using MeSH terms and keywords including: transgender youth; gender minority youth; parent/guardian support, acceptance, and rejection. See Appendix A for verbatim search strategy and terms used. Duplicates were removed and specific inclusion criteria were applied to the abstracts and then the full text articles. Articles were included if they were: research-based studies that explored any aspect of the phenomenon of parent/guardian support for transgender youth, with youth being defined as age 25 and younger; published in English language peer-reviewed scientific journals between January 1, 2007 and December 31, 2017. Non-research based articles, expert opinion, or clinical vignettes were excluded. Upon full text review, articles that did not provide findings about transgender youth specifically were excluded. For example, if the sample included lesbian, gay or bisexual individuals only and/or older participants and information specific to transgender youth could not be ascertained, these articles were excluded.

Furthermore, articles that did not clearly address the issue of parent/guardian support, acceptance, or rejection were also excluded. The PRISMA diagram of included and excluded studies can be found in Appendix B.

A total of 21 articles met inclusion criteria and were included in this review. The articles were read in full to determine: 1) how the study conceptualized or defined "Parent/Guardian" 2) how they measured and/or defined "support" and 3) the main findings of the study, specifically what (if any) significant relationship was found between PG support and health outcomes for transgender youth. Finally, each article was then re-read to determine if the authors discussed macro level factors such as structures of domination, institutional systems or socio-structural processes that may contribute to understanding PG support for transgender youth. An evidence table summarizing the 21 articles and above findings can be found in Appendix C.

Terminology

A wide variety of terminology is utilized in transgender health literature that may not be familiar to a broader audience. Additionally, transgender health research is in nascent stages and guidance around appropriate language has only recently been provided for clinicians and researchers (Bouman et al., 2016). Therefore, definitions of terminology used in the literature and throughout this paper are summarized below for reference in Table 3.1.

Table 3.1 Terminology

Cisgender – A term that refers to people who are not transgender; people who have a gender identity that aligns with the sex assigned at birth.

Cisgenderism – An ideology that denies and pathologizes gender identities that do not align with societal expectations, and places higher value on cisgender identities.

Gender Dysphoria - Psychological distress associated with a discrepancy between gender identity and sex assigned at birth. Distress often results from an incongruence with the expected gender role due to sex assigned at birth and/or primary or secondary sex characteristics.

Gender Expression - Visible expression and presentation of gender or gender role (such as clothing, hairstyle, accessories). People may have a gender expression that differs from societal expectations, but a gender identity that aligns with sex assigned at birth.

Gender Identity – The deeply-felt sense of self as a male, female, neither, or both, which may or may not align with a person's sex assigned at birth or physical secondary sex characteristics.

Gender Nonconformity or Gender Variance - General terms used to describe an incongruence between gender identity and/or expression and the sex assigned at birth. Most often used to describe children who may or may not have been diagnosed with gender dysphoria.

House/Ballroom Scene – A collective of Black and/or Latino youth who participate in dance performance competitions (aka "balls") that take place within House communities, where Houses compete against one another. Houses are created family structures where members hold specific identities such as mother, daughter, father or son (with older members taking parental roles).

Kathoey – The term used to describe transgender women (people who were categorized as male at birth and identify as female) in Thailand.

LGBT – An acronym that stands for "lesbian, gay, bisexual, and transgender" and refers to a community of people that have a sexual orientation that is not heterosexual and/or a gender identity that is not cisgender.

Sex Assigned at Birth – Categorization of biological sex as male or female that is conventionally assigned to a newborn child based on external examination of genitalia, chromosomes, and gonads. Societal expectations and cultural norms traditionally dictate sex assigned at birth to align with a binary male or female gender identity.

Sexual Orientation – Describes the way someone identifies as being sexually and/or romantically attracted to other people. Includes a diverse number of identities such as lesbian, gay, bisexual, queer, pansexual, straight, among others.

Transgender – An umbrella term that refers to a diverse group of people who have a gender identity that does not align with sex assigned at birth. Gender identities may include male, female, trans male, trans female, genderqueer, gender non-binary, among others.

Findings

Overview of Research Studies

Overall, our current state of knowledge on the phenomenon of PG support for transgender youth is descriptive in nature. Most studies described the nature of PG support or how it was associated with various health outcomes. No intervention studies or controlled trials have been conducted with regards to best practices for facilitating parent/guardian support. Studies have been conducted in the fields of psychology, public health, and medicine. No nursing research was found to be published to date.

Study designs included both qualitative studies (Gray, Sweeney, Randazzo, & Levitt, 2016; Katz-Wise et al., 2017; Koken, Bimbi, & Parsons, 2009; Kubicek et al., 2013; Nemoto et al., 2016; Platero, 2014; Riley, Clemson, Sitharthan, & Diamond, 2013; Wilson, Iverson, Garofalo, & Belzer, 2012) and quantitative studies (Clark et al., 2014; Grossman & D'Augelli, 2007; Le, Arayasirikul, Chen, Jin, & Wilson, 2016; Ryan, Russell, Huebner, Diaz, & Sanchez, 2010; Simons, Schrager, Clark, Belzer, & Olson, 2013; Sterzing, Ratliff, Gartner, McGeough, & Johnson, 2017; Watson, Veale, & Saewyc, 2017; Wilson, Chen, Arayasirikul, Raymond, & McFarland, 2016; Yadegarfard, Meinhold-Bergmann, & Ho, 2014). Two studies used a mixed method (Birnkrant & Przeworski, 2017; Nemoto et al., 2012) and two studies conducted secondary analyses, one quantitative (Le et al., 2016) and one qualitative (Wilson et al., 2012). One study used a randomized, population-based sample (Clark et al., 2014), while the remainder of the research was cross-sectional with convenience samples derived mostly from youth in care at gender clinics. One study was a factor analysis of a measurement tool seeking to measure parental attitudes (Hidalgo, Chen, Garofalo, & Forbes, 2017). Four studies were conducted

entirely online (Birnkrant & Przeworski, 2017; Riley et al., 2013; Riley, Sitharthan, Clemson, & Diamond, 2011; Sterzing et al., 2017).

Two studies recruited transgender adults and asked them to recall childhood experiences of support with their families (Koken et al., 2009; Riley et al., 2013), and therefore may be discussing experiences that differ somewhat from youth today. Several of the studies had parents as participants (Birnkrant & Przeworski, 2017; Gray et al., 2016; Kubicek et al., 2013; Platero, 2014) and one study included family units, with an adult parent and a transgender youth dyad (Katz-Wise et al., 2017). Most of the studies recruited parents from U.S. venues where they were already engaged in supportive clinical services or groups for themselves or their child (Birnkrant & Przeworski, 2017; Gray et al., 2016; Kubicek et al., 2013; Platero, 2014). Platero (2014) was the only study that enrolled parents from outside of the U.S., looking at experiences of parents in Spain. Kubicek et al. (2013) was the only study in the U.S. to capture the perspective of parents from communities of color.

Defining Parent/Guardian

Overall, the literature refers to "parents" generally referred to variety of adults including mothers, fathers, grandmothers, adoptive parents, or legal guardians/foster parents that were significantly involved with caring for the transgender young person as their family of origin (Birnkrant & Przeworski, 2017; Clark et al., 2014; Gray et al., 2016; Katz-Wise et al., 2017; Kubicek et al., 2013). However, transgender youth also have "chosen family," which refer to other adults, such as house/ball parents in Kubicek et al. (2013), who were not legally or biologically related but played a significant nurturing role in youths' lives. For example, the Clark et al. (2014) study with New Zealand high school students allowed for this broad type of definition by asking youth about their "mum (or someone who acts as your mum) or dad (or

someone who acts as your dad)." Some studies simply used the term "family" (Watson et al., 2016) or "caregivers" (Yadegarfard et al., 2014) and did not define what this meant specifically or if/how they explained a definition to the participants. Therefore, in current research with transgender youth, use of the word "parent/guardian" or "family" or "caregiver" might be describing a variety of adult individuals who are significantly involved in a child's life and acting as the primary provider to raise and support the young person.

Defining "Support"

Delving further into the content of the literature, our analysis revealed that the concept of support is not succinctly or consistently defined in the current literature. Some authors used the word "support" (Gray et al., 2016; Grossman & D'Augelli, 2007; Katz-Wise et al., 2017; Kubicek et al., 2013; Le et al., 2016; Nemoto et al., 2012; Simons et al., 2013; Wilson et al., 2012), but the rest did not, even though they discussed similar ideas (Birnkrant & Przeworski, 2017; Koken et al., 2009; Riley et al., 2013; Ryan et al., 2010; Sterzing et al., 2017). None of the qualitative studies with transgender youth participants asked them for their definition of parental support. Ryan et al (2010) used focus groups to develop their measure of family acceptance, however most participants were LGB youth and not transgender. Another study involved two content experts, a transgender young adult and an experienced clinician, in their development of a measure about perceived parental attitudes (Hidalgo et al., 2017).

Not surprisingly, due to the lack of consistent conceptual definition, a variety of measurement tools have been used to measure the phenomenon of PG support. Hidalgo et al. (2017) published a factor analysis of a novel measurement tool specific to transgender youth, the Parental Attitudes of Gender Expansiveness Scale for Youth (PAGES-Y), measuring perceived parental attitudes towards the child's gender identity. The 14-item PAGES-Y was tested with a

clinical sample of mostly White transgender youth seeking care at a gender clinic the U.S. They found two separate constructs were being measured: perceived parental non-affirmation of gender identity and perceived parental acceptance. No other studies have utilized this measurement tool to date. The Family Acceptance Measure was another tool used by Le et al. (2016), Ryan et al. (2010), and Wilson et al. (2016) and looked at various ways parents were supporting LGBT youth in general, but the questions from the tool do not seem to be transgender specific. The family subscale of the Multidimensional Scale of Perceived Social Support (MSPSS) was adapted to ask about transgender specific experiences and used in two studies (Simons et al, 2013; Wilson et al., 2016). Le et al (2016) also measured perceived social support, without mentioning a specific tool, by asking youth participants to identify where it was coming from, either parents or non-parents (i.e. friends or partners). Watson et al. (2016) used 7-items that measured family connectedness, by asking youth how much their family cared about their feelings. Overall the concept of support was not based on a theoretical framework in any of articles and was not consistently measured or defined.

These findings indicate that the definition of parental support is in the nascent stages of development. Some patterns were noted across the articles compiled for this review, however, and Figure 3.1 provides an illustration of the current multi-faceted definition of parent/guardian support, as elucidated from the reviewed literature. Each of these components are discussed further below.
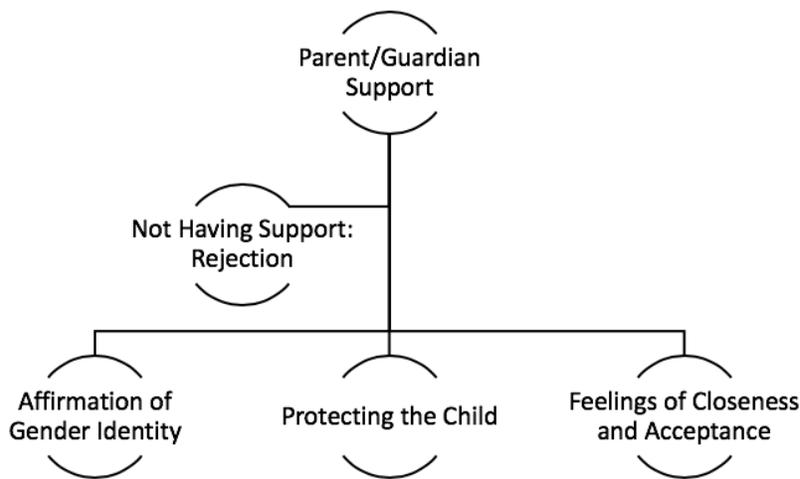
Figure 3.1. Definition of Parent/Guardian Support for Transgender Youth

Not having support: rejection. Several studies explored support from the perspective of the opposite of having support, or what it means to have non-supportive parents, referred to most often as rejection. Platero (2013) described a lack of support as directly resulting from fear and denial about the child's gender identity, especially for parents who struggled with how the child was breaking social norms of gender. One study explored rejection as displayed through microaggressions, which are defined as when family members made offensive comments about transgender people in general (Sterzing et al., 2017). Another study measured rejection as experiences of parental verbal or physical abuse because of gender identity (Grossman & D'Augelli, 2007). Similarly, Nemoto et al. (2012) described physical and emotional abuse from fathers and brothers towards kathoey, transgender women in Thailand, as a form of rejection.

Several studies also described a lack of affirmation from the parent about the youths' gender identity. Birnkrant & Przeworsky (2017) described rejection with specific reference to a lack of acceptance for their specific child's gender identity or gender transition. Hidalgo et al. (2017) found that 7 of the 14 items in the PAGES-Y were validated to a subscale described as "perceived parental non-affirmation." Non-affirmation included questions about whether their

parents were ashamed of them, tried to hide them, or worried about how their being transgender affects the family's image.

Several studies emphasized that transgender youth may simultaneously experience rejection and some form of acceptance or support from their parents. Hidalgo et al. (2017) suggested that parental non-affirmation of gender expansiveness may co-occur with experiences of acceptance. Koken et al. (2009) also found that various types of rejection may occur simultaneously with feelings of acceptance and closeness, and that relationships with PGs were maintained despite ongoing rejection. Similarly, Nemoto et al. (2012) found that among kathoey in Thailand, about one-third of their participants described being rejected at first by their families and then later supported.

Affirmation of gender identity. Le et al. (2016) hypothesized that a parent cannot provide support if they do not affirm the child's gender identity. They defined supportive actions from the parent as talking about gender identity with the child, supporting the child's gender identity or expression, or advocating for the child when mistreatment happened due to gender identity. Riley et al. (2013) asked parents how they supported their children, and the themes included allowing space for the child to talk about feelings, allowing the child to express their gender, as well as valuing the child's gender identity. These studies discussed a component of support whereby the parent not only acknowledged but took seriously their child's gender as a real and valuable component of their identity. Similarly, Platero (2013) discussed parents coming to terms with the permanency of their child's gender identity which allowed them to have agency to act towards seeking professional guidance or help. Finally, Hidalgo et al. (2017) identified "parental support of gender transition" as a sub-construct of the PAGES-Y parental

affirmation subscale. Therefore, the idea that parents identify and validate the gender identity of the child is an important aspect support for transgender youth.

Protecting the child. Grey, Sweeney, Randazzo, & Levitt (2012) used a grounded theory approach to understand the experiences of parents who were seeking gender-affirming clinical services for their children. Parents described their main goal as trying to promote the child's adaptation to their environment, and this could occur via two very different pathways of either protecting the child or advocating for the child (Grey et al., 2012). Parents also discussed feeling good about doing advocacy for their child, which led to a sense of parental self-efficacy (Gray et al., 2016). The authors suggested that themes indicated the parents were either trying to change the child or change the environment, but all with the goal of protecting the child.   Which pathway the parent took depended on the amount of parental self-efficacy and the social context (Grey et al., 2012). In another study, family units comprised of youth and parents described support as providing protection for the child, giving the child skills, and preparing them for the future (Katz-Wise et al., 2017). Similarly, Hidalgo et al. (2017) validated questions for the PAGES-Y measurement tool about youths' perception of their parents advocating for their rights and parents defending them against discrimination. Thus, a major component of support was to protect the child from harm, although the ways this was accomplished, according to the parents in these studies, may vary.

Feelings of closeness and acceptance. Several studies focused on emotional and psychological aspects of the PG-child dynamic, described as closeness or acceptance. The transgender adults reflecting on their childhoods said that when their parents displayed warmth and affection, they felt a sense of improved emotional well-being and closeness (Riley et al., 2011). Wilson et al. (2012) also found themes of parental closeness, defined by transgender

youth as being able to talk with their parents about topics such as sex, asking for financial support, and planning for gender transition. Watson et al. (2016) described family connectedness as exemplified by youth perceiving that their family cared about their feelings. Clark et al. (2014) surveyed high school youth in New Zealand, and asked students if they felt their parent cared about them, considering this to be a protective factor for overall measures of health and well-being.

Acceptance was described as emotional validation and support for a child's gender identity. In one study, acceptance was the next step after coming to a place of understanding the child's gender, whereby parents would take some sort of action to seek help for the child and help other parents of other transgender children (Platero, 2013). Giving care and attention and showing love was also described as acceptance in another study (Birnkrant & Przeworski, 2017). One tool used to measure perceived acceptance asked youth about whether parents talked openly about gender or appreciated clothing that was not typical of gender (Ryan et al., 2010). In the study of chosen family units with house/ball parents, participants described providing a safe environment, love, validation, and recognition of the young transgender people in their houses – noting that these young people did not receive this type of treatment anywhere else in their lives (Kubicek et al., 2013). As defined from the perspective of the transgender adult looking back on childhood, acceptance was described as receiving warmth and affection (Koken et al., 2009); and being valued in their gender variance, with unconditional acceptance and flexibility regarding gender identity and expression (Riley et al., 2013).

Relationship between Parent/Guardian Support and Health/Well-Being

Research to date has identified significant associations between parent/guardian support for their child and three health outcomes among transgender youth: mental health, risk for HIV, and victimization, as illustrated in Figure 3.2 and discussed below.
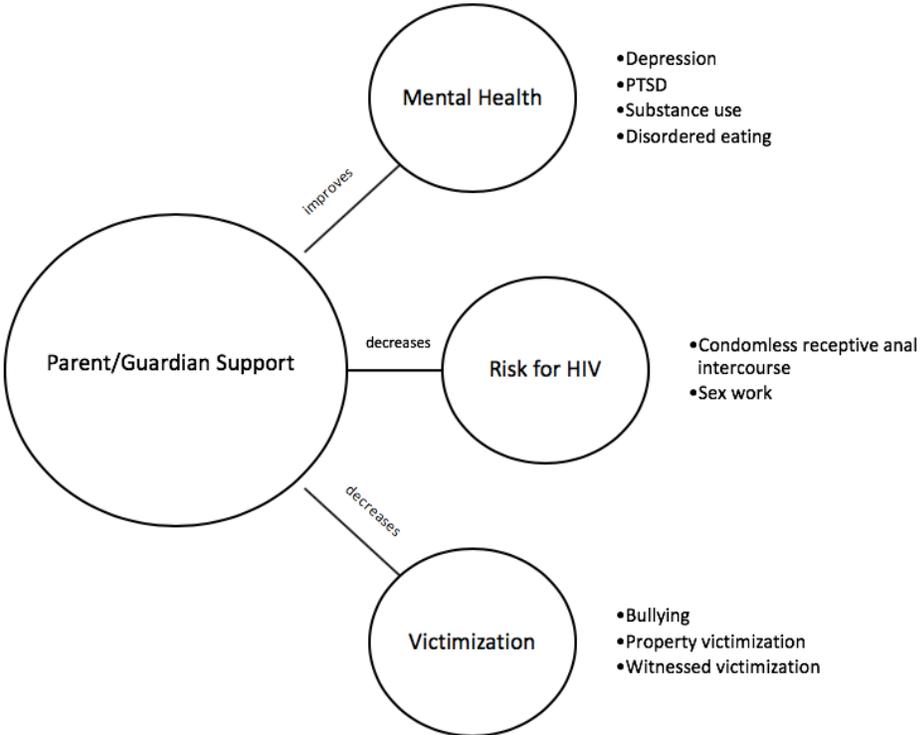
Figure 3.2 Associations Between Parent/Guardian Support and Health Outcomes

Mental health issues. Mental health outcomes were significantly associated with PG support in several studies, with greater support serving as a protective factor while rejection or lower levels of support associated with worse outcomes. Ryan et al. (2010) reported that low levels of family acceptance were significantly associated with higher levels of depression, substance abuse, and suicidal ideation/attempts. Transgender youth reported worse overall general health compared with the non-transgender youth in their sample. Yadegarfard et al. (2014) similarly found that rejection from family was significantly associated with depression among Thai transgender female adolescents. Substance use, described as any illicit drug use

within the year prior to the study, was found to be higher among kathoey in Thailand who also had been rejected by their families (Nemoto et al., 2012).

Conversely, Simons et al (2013) found that higher levels of perceived parental support were associated with fewer depressive symptoms and overall improved quality of life. Family connectedness was an important protective factor against disordered eating behaviors among a large sample of 14-18 year old Canadian transgender youth (Watson et al., 2016). Both studies concluded that it is imperative for health care providers to facilitate supportive relationships between transgender youth and their families.

Wilson et al (2016) conducted a large study (n=216) with transgender young women of color and found that parental closeness and parental acceptance were both protective against poor mental health outcomes in this population. When parental closeness was high, so was resilience, and youth had significantly lower odds of psychological distress, PTSD symptoms, depression, and stress related to thoughts of suicide as compared to those with low parental closeness and low resilience. Parental acceptance was also significantly associated with a lower odds ratio of PTSD symptoms. When examining the specific individual level resiliency promoting protective factors, the authors found that two out of three significant factors for producing resiliency were related to parental relationships. However, almost 70% of the sample overall reported low levels of parental closeness, and 60% of the sample had low levels of resiliency, suggesting that the youth participants were facing significant challenges and risk for mental health issues.

Risk for HIV. Several studies explored the relationship of PG support and risk for HIV. Wilson et al (2012) found that transgender young women of color who reported parental support also reported consistent condom use, while those without parental support reported inconsistent

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condom use. The parents interviewed in Kubicek et al (2013) discussed the challenges of helping young people navigate the "real" world outside of the welcoming environment within the house/ball scene. House parents spoke of the high prevalence of sex work among young transgender people of color as related to the lack of employment opportunities in their community and the stressors of paying for gender transition, compounded by rejection from families of origin and society at large.

Nemoto et al. (2012) found that among kathoey sex workers in Bangkok, Thailand, a history of being abused by the father and/or brother was significantly associated with greater frequency of anal receptive sex without condoms in exchange for money. In a later qualitative study with young kathoey sex workers, Nemoto et al. (2016) found that experiences of abuse during childhood led to a need to leave home and establish financial independence, which was possible through sex work. Once these young transgender women established a source of income, many kathoey felt self-reliant and could reach out to family again to re-establish mutually supportive relationships by sending money home to impoverished rural areas. Both studies suggest that HIV prevention programs for young kathoey in Thailand must recognize and address the importance of economic independence as a key factor for young kathoey who are seeking to re-establish supportive relationships with family.

Victimization. Finally, PG rejection was significantly associated with challenging experiences of victimization outside of the home. Sterzig et al. (2017) found that family level rejection among transgender youth were significantly associated with polyvictimization experiences, defined in their study as an experience of 10 or more forms of victimization such as bullying, property victimization, and witnessed victimizations. In other words, transgender youth who were experiencing a lack of PG support in the home were also likely to experience

multiple challenges and traumas outside of the home. These findings suggest youth who experience PG rejection may also be experiencing higher levels of societal rejection as well. The study was cross-sectional in nature and over 2/3 of participants identified as White so the authors concluded that causal relationships cannot be determined and generalizability may be limited (Sterzig et al., 2017).

Examination of Structural Factors

Finally, this review also specifically asked whether or not studies incorporated an exploration of upstream, structural factors and how they may impact PG support for transgender youth. As conceptualized in the IRTHJ framework (Wesp et al., n.d., Ch 2), structural factors may include ideologies, institutions, or social-structural processes that may have been related to PG support for transgender youth. Each article was examined, with 9 of the 21 articles including some discussion about structural elements as related to PG support, as summarized below.

Structures of domination, namely the ideologies of cisgenderism/transphobia, heteropatriarchy, and racism, were noted in four studies as being influential on parent/guardian support for transgender youth. Kubicek et al. (2013) found that transgender youth of color engaged in the house/ball scene often reported experiences within their families of origin where parents/guardians espoused ideologies fueled by cisgenderism and heteropatriarchy, meaning that they rejected any form of sexuality or gender expression/identity that was not aligned with being cisgender or heterosexual. The house/ball parents alternatively fostered acceptance and validation of any sexuality and gender identity, which facilitated resilience to these experiences of oppression (Kubicek et al., 2013). In their study with adult transgender people recalling experiences of PG support towards them during childhood (Riley et al., 2013), participants felt that heteropatriarchal ideologies fueled the lack of support they had from parents/guardians and

they wished that their PGs had greater support from professionals in helping them navigate and understand these ideologies. Nemoto et al. (2012) found through their qualitative interviews with Thai participants that transphobia often fueled rejection from fathers, but also that Thai culture and the Buddhist concept of karma was used by kathoey sex workers to explain why they sent money to their family in the rural provinces of Thailand, and after doing so, experienced less rejection from their family. Nemoto et al. (2016) similarly discussed transphobia as an ideology that fueled rejection of youth by their parents, and also elucidated the concept of interdependency in the Asian culture, and how it differs from the Western cultural context of independence, to explain findings about the importance of kathoey seeking mutually supportive relationships with family despite experiencing rejection. Yadegarfard et al. (2014), in their discussion section, raised the idea that family rejection of transgender youth may be related to the cultural importance in Thailand placed upon preservation of family lineage through heterosexual marriage and procreation. Platero (2013) discussed how ethnic minority parents of transgender children had challenging experiences of navigating intersecting marginalization to advocate for accessing health care for their child, due to both racism and transphobia related to their social position as minorities and their child's non-normative gender identity.

Riley et al. (2011) explored how institutional systems, especially the educational system, were influenced by some of the above structures of domination (namely cisgenderism and heteropatriarchy). In the study with parents/guardians as participants, PGs stated that they had unmet needs around knowing how to navigate school systems heavily influenced by stigmatizing ideologies about gender (Riley et al., 2011). Similarly, Birnkrant & Przeworski (2017) described how PGs had to navigate stigma within the educational systems, although they did not specifically name the ideologies or structures of domination that were causing this stigma.

Finally, the Katz-Wise et al. (2017) qualitative study with a community-based sample (n=16) of mostly white parents and youth in the U.S. described macro level antecedents of PG acceptance/support for transgender youth. The macro level concepts named the ways that schools, summer camps, employment companies, and colleges were influenced by everyday socio-structural processes about gender (such as binary restrictions on bathrooms or other facilities), which required PGs to advocate in numerous ways to resist these processes and create safe spaces for their child. When PGs were able to facilitate or experience less rigid and restrictive processes within these systems, the easier it was for them to support and advocate for their child (Katz-Wise et al., 2017). Similarly, Gray et al (2016) found in their qualitative grounded theory study that the types of social structural processes around gender binaries was interwoven with how parents were able to support their transgender child, as well as how the parents themselves were able to cope with intolerance and stigma in their communities.

Discussion

The above findings begin to answer several of the questions posed at the outset. The literature thus far has defined parent/guardian support for transgender youth as identifiable actions taken by a diverse group of adults or mentors. Support is also described as emotional care that affirms the child's gender identity, protects the child from harm, and offers closeness or acceptance. Research has identified a positive relationship between having parent/guardian support (as defined in the above ways) and overall improvements in health and well-being, especially improved mental health outcomes and a reduction in risk for HIV as well as forms of victimization. Research that did consider structural factors has begun to identify that structures of domination influence institutional systems and social processes, which influence the ways that parents/guardians support their transgender child.

Parent/guardian support for transgender youth is a complex phenomenon, influenced by multiple structural and interpersonal factors. Another layer of this complexity is the broad definition of "family" in LGBT communities. Families are intricate and fluid, due to structures of chosen family that are often created as a result of stigma and rejection experienced within families of origin. Kubicek et al. (2013) was the only study included here that addressed the crucial role of the house and ball parents for transgender youth of color, adults outside of the family or origin structure who provided significant support. Because some research did not delineate who they meant by "parent" or "family," we are uncertain about who youth were thinking about when answering some of the survey questions. Transgender youth of color must also navigate many layers of social inequality fueled by racism and colonialism, concurrently creating racialized gender norms (Spade & Willse, 2015), thus developing various resilience and resistance processes, including but not limited to building chosen family structures such as these. Some research has documented the value and importance of various chosen family structures in the prevention of HIV among LGBT people (Phillips et al., 2011; Sanchez, Finlayson, Murrill, Guilin, & Dean, 2010). Other studies have begun to explore such resilience strategies among transgender youth of color, and the findings included an evolving self-definition of racial/ethnic and gender identities as well as an awareness of adultism (Singh, 2013; Singh, Meng, & Hansen, 2014). Resilience studies have not focused specifically on the role of PG support, and future research focusing on experiences of resilience with relation to the complex nature of family structures and how dominant ideologies influence PG support will add important knowledge to the ways these concepts are linked to health and well-being.

Several of the original questions require further research and discussion, highlighting several gaps in the literature. First, the literature to date has looked broadly at transgender youth,

considered as a population anywhere from age 12 to 25 years old. However, none of the studies

considered transgender youth from a developmental perspective. We need more information

about the impact of PG support at differing developmental stages in order to understand

differences among youth moving through early or later stages of adolescent psychological and

pubertal development – while also navigating rejection from their parents and legal policy issues

within health care. Specifically, the findings here suggest that literature to date focused

primarily on measuring the impact of emotional types of support (or lack thereof), which was

associated with improved outcomes. Research was lacking as to the impact of instrumental

support, such as the provision of legal consent for the minor child under 18 years to receive

gender affirming medical and mental health care and treatment for dysphoria. A specific

challenge facing pre and early pubertal youth in the U.S. today is that they are generally unable

to access medical care for gender dysphoria treatment without parental consent (Priest, 2019).

Few studies discussed the experiences of youth who were legally unable to consent for

themselves, and how turning 18 years may have impacted access to care. Exploring PG support

in relation to health care access for transgender youth under 18 years was not discussed in any of

the literature published to date. This lack of focus on instrumental support is perhaps because

most studies thus far included samples of youth who were already in clinical care, meaning their

parent or legal guardian has already provided at least some instrumental support in order for

them to engage in medical or mental health services, and thus the research. Further research is

needed to explore the impact of these various types of PG support for minor youth, especially

those in early stages of puberty when dysphoria can be significantly exacerbated (Rosenthal,

2014). Understanding how family nurses can facilitate instrumental support, as well as

emotional support, will be important for future research and intervention development.

Additionally, transgender youth participants were often involved in quantitative survey studies, yet often these studies did not have a clear definition of the constructs being measured (e.g. Le et al., 2016 and Wilson et al., 2016) making it difficult to understand how researchers consistently define support. Without a clear definition of PG support, many of the quantitative survey questions may have missed certain aspects of youths' experiences and the structural level factors that impact their relationships. Qualitative research can provide more complex descriptions, yet most qualitative studies were conducted outside of the U.S. and the one with U.S. participants involved mostly White, middle to upper class, educated youth and parents who were already engaged in support networks (Katz-Wise et al., 2017). These families' experiences may not be transferable to youth or parents in differently situated lives, especially because of ongoing racism experienced by communities of color in the U.S. The other qualitative study that included youth participants used an approach for analysis that presented the results in a quantified fashion (Wilson et al., 2012). The authors analyzed interviews by themes, and grouped youth into categories of those who reported of condom use versus those who did not report condom use, and then compared them among those "with" parental support to those "without" parental support. In-depth qualitative themes may have been underdeveloped with this type of approach (Connelly & Peltzer, 2016). Overall, our understanding about the ways transgender youth are experiencing the role of parents/guardians in their lives is currently limited and would benefit from future qualitative exploration.

One important place for family nurses to begin is to consider cultural safety in our approach to working with transgender youth and their families (Mkandawire-Valhmu, 2018; Mukerjee, 2016), which Kellett and Fitton (2017) explicate for transgender populations as supporting gender diversity and acknowledging the existence of transgender and gender diverse

people throughout history. Creating culturally safe interactions with transgender youth and their parents/guardians is the foundation for facilitating PG support, because nurses can provide safe individualized support that addresses ideologies fueling stigma or rejection. Culturally safe approaches to transgender care require self-reflexivity about biases related to cisgenderism, and the ways that the health care system often perpetuates harm towards transgender people due to gender binary processes within electronic medical records and infrastructures (Kellett & Fitton, 2017). Nurses can look to grass roots community driven educational networks, which provide accessible guidance for all people, as well as specific support for parents/guardians who are seeking to understand how they can support their transgender children. For example, Gender Spectrum (www.genderspectrum.org) is a community non-profit educational network that provides online and in person resources to understand ideologies that produce stigma and facilitate gender affirming support at the individual, interpersonal, and community levels.

Limitations

Limitations of this review include one reviewer completing the initial review that determined inclusion or exclusion of the studies. Many articles were excluded upon full text review because no conclusions were drawn specifically about transgender youth navigating parent/guardian support, although these articles often explored LGBT populations in general. Because they did not disaggregate findings from transgender youth vs. sexual minority youth, they were excluded. These articles may be useful to explore in future reviews, because they may provide ideas or insights about PG support from sexual minority populations that could be

adapted for transgender youth. However, the unique and specific needs of transgender populations, specifically related to gender affirming health care, must always be considered.

Conclusion

In conclusion, research thus far has demonstrated that higher levels of parent/guardian support are associated with improved mental health outcomes, decreased HIV risk, and increased safety among transgender youth. Further research is needed to develop a deeper understanding about the experiences of parent/guardian support, especially considering how structural and social factors shape PG support. Given the health disparities facing transgender youth, and a lack of nursing research in this area so far, the field family nursing can make an important impact on the health of transgender youth via providing culturally safe care that is inclusive of human gender diversity. Ongoing research and intervention development might include exploring brief therapeutic conversations and other relational skills (Bell, 2013) for transgender youth and their parents/guardians, as well as skill building for parents/guardians about how to navigate societal ideologies about gender that fuel stigma within institutions and social processes. The American Nurses Association social policy statement calls for nursing scholarship that emphasizes a reduction in health inequities and facilitation of health among marginalized populations (2010), and nursing has many important contributions to make towards facilitating parent/guardian support for transgender youth and improving their health.

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CHAPTER 4: METHODOLOGY

Chapter four is a manuscript formatted for submission to *Global Qualitative Nursing Research.* This chapter presents best practices for conducting qualitative secondary analysis (QSA), illustrated with a case exemplar of the QSA project conducted for this dissertation. Based on a synthesis of current methodological literature, QSA involves three main steps: 1) describing the QSA project, 2) conducting an epistemological assessment, and 3) conducting an ethical assessment. In sum, this article fills a gap in the qualitative methods nursing literature about best practices for QSA, suggesting that nurses are well poised to conduct and further develop the methodology of QSA for the field of qualitative health research among marginalized populations.

Note: The original semi-structured interview guide from the primary study can be found in Appendix D.

TITLE

Secondary Analysis in Qualitative Nursing Research:

Best Practices and Case Exemplar

Linda M. Wesp

Abstract

Secondary analysis of qualitative data is an important yet underutilized approach for qualitative nursing research. The purpose of this paper is to summarize best practices for conducting secondary analysis of qualitative data, and then illustrate the process with a case exemplar of a secondary qualitative nursing research study. A review of qualitative secondary analysis (QSA) literature summarized the methodological process into three iterative steps: describe the QSA project, conduct an epistemological assessment, and conduct an ethical assessment. As exemplified through a QSA study that sought to describe experiences of parent/guardian support and related health outcomes among transgender youth in the United States, re-use of qualitative data provides an important avenue for conducting research with marginalized populations. The three-step approach provided a roadmap that ensured a sound study design, as well as epistemological and ethical rigor. Nursing researchers are well equipped to develop and refine approaches to secondary analysis of qualitative data for health research in the future.

Keywords: qualitative methodology, re-use of qualitative data, secondary analysis

Introduction

Secondary analysis of qualitative data is an important yet underutilized methodology for nursing research. Secondary analysis provides an efficient and effective use of existing qualitative data, especially because qualitative data collection can be time consuming and expensive (Thorne, 1994). In addition to being a viable modality for nursing research, utilizing existing data can maximize use of information already collected while minimizing burden on participants, especially for sensitive topics or vulnerable populations (Long-Sutehall, Sque, & Addington-Hall, 2011; Szabo & Strang, 1997). Despite an increasing number of studies publishing results from secondary analyses and an initial book summarizing common approaches in social sciences (Heaton, 2004), an updated overview of best practices regarding how to do a qualitative secondary analysis for nursing researchers is currently lacking. Therefore, the purposes of this paper are to present best practices for conducting secondary analysis of qualitative data, illustrate it's use through a case exemplar, and suggest future directions for QSA in qualitative nursing research.

Best Practices for Conducting Secondary Analysis of Qualitative Data

To gain a better understanding of best practices for conducting a qualitative secondary data analysis, a thorough search was conducted in PubMed, Web of Science, and CINAHL using the terms "secondary analysis" and "qualitative." Hand searching of references list of applicable revealed the importance of also searching for the phrase "reuse of qualitative data." Publications in English between 1994-2019 that were focused on methodological issues or best practices for secondary analysis of qualitative data were reviewed. Main ideas were consolidated into a best practices approach to QSA that involves three main steps (see Fig. 4.1): describing the QSA project, Epistemological Assessment, and Ethical Assessment. A summary of literature and which aspect of QSA the article discussed can be found in Table 4.1.

Figure 4.1. Steps for Qualitative Secondary Analysis
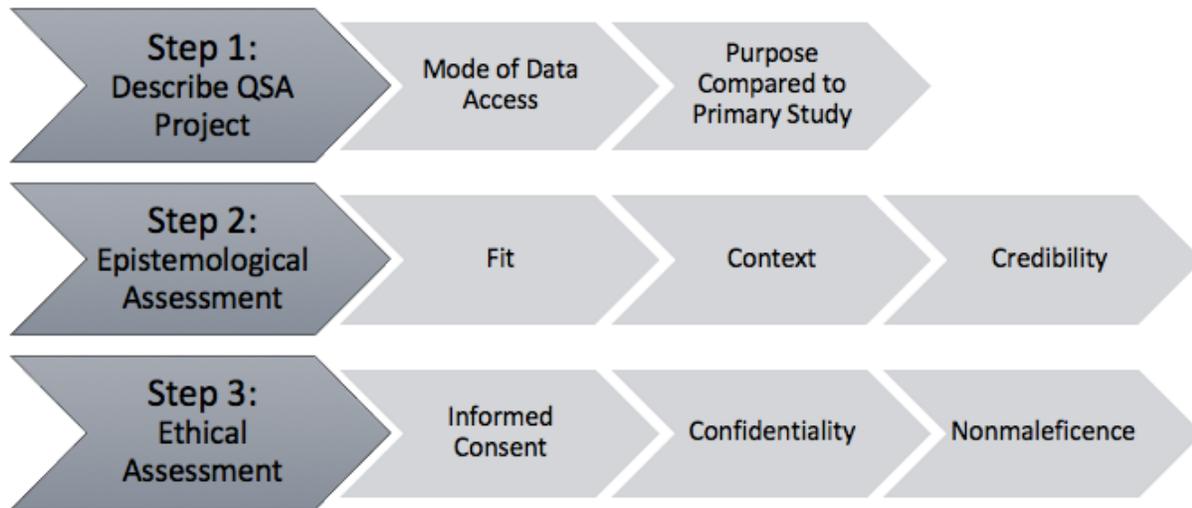
Table 4.1. Overview of QSA Methodological Literature

Author(s)	Aspect of QSA Discussed
Thorne (1994)	Step 1: Describe QSA Project
Hinds (1997)	Step 2: Epistemological Assessment
Szabo & Strang (1997)	Step 2: Epistemological Assessment
Thorne (1998)	Step 3: Ethical Assessment
Heaton (2004)	Step 1: Describe QSA Project; Step 2: Epistemological Assessment; Step 3: Ethical Assessment
van den Berg (2005)	Step 2: Epistemological Assessment
Heaton (2008)	Step 1: Describe QSA Project
Hammersley (2010)	Step 2: Epistemological Assessment
Long-Sutehall (2011)	Step 3: Ethical Assessment
Medjedovic (2011)	Step 2: Epistemological Assessment; Step 3: Ethical Assessment
Irwin & Winterton (2012)	Step 2: Epistemological Assessment
Irwin, Bornat, & Winterton (2012)	Step 1: Describe QSA Project
Coltart, Henwood, Shirani (2013)	Step 1: Describe QSA Project; Step 2: Epistemological Assessment; Step 3: Ethical Assessment
Irwin (2013)	Step 2: Epistemological Assessment
Irwin (2013)	Step 2: Epistemological Assessment; Step 3: Ethical Assessment
Yardley, Watts, Pearson, & Richardson (2013)	Step 3: Ethical Assessment
Redman-MacLaren (2014)	Step 1: Describe QSA Project
Mitchell (2015)	Step 1: Describe QSA Project
Tate & Happ (2017)	Step 1: Describe QSA Project; Step 2: Epistemological Assessment; Step 3: Ethical Assessment

Qualitative secondary analysis (QSA) is generally defined as the return to an existing set of non-naturalistic qualitative research data that were collected in a previous study, but how and why re-use of data occurs can vary widely (Heaton, 2004, 2008). Key aspects of the approach to QSA are described consistently in the literature. As Mitchell states, "secondary analysis should not be considered an easy option as a research strategy" (2015, p. 3). Outlining these steps offers a detailed approach to researchers choosing this strategy. The steps in Figure 4.1 are not considered static or mutually exclusive, rather the secondary researcher returns to these assessments recursively throughout the study to ensure emerging issues are addressed. Each step is discussed in detail below, with an illustration of each from a case exemplar of a QSA project.

Step 1: Describing QSA Project

The first consideration of QSA is to describe the project, by identifying the **mode of data access**, which describes the secondary author's relationship with the primary data set and primary research team (Heaton, 2004). Modes of data access may include 1) Formal data sharing, or the use of archived data that was previously gathered and then made available officially for secondary use; 2) Informal data sharing, which may involve two or more researchers pooling their data or a secondary researcher requesting data from the original study team who must grant them permission. The primary researcher(s) may or may not be involved in the secondary project; or 3) Auto-data which differs from the first two modes because it does not involve sharing data with others, but is strictly when the primary research team returns to their own data to conduct a secondary analysis, involving no one else from outside their original team (Heaton, 2004, 2008). Some questions that the secondary research can ask to help identify the mode of data availability are: Was I originally involved in the design, collection, and analysis of the original data? Is the data archived anonymized data made available through data sharing, that you as the researcher had no role in collecting or producing? Is the primary researcher involved

in any way or available for communication? Will the primary researcher(s) be part of the team

doing the secondary analysis? Is the analysis being conducted because different datasets are

being compared with one another? What type of data will I have access to (transcriptions, audio

recordings, field notes, other information)?

The second component of describing the QSA project is to understand the **purpose**

compared to the primary study. Several authors have described this step as the identifying

what "type" of secondary analysis is being conducted. Thorne (1994, 1998) provided the first

explanations of possible types of QSA describing them analytic expansion, retrospective

interpretation, armchair induction, amplified sampling, and cross-validation. These were later

updated by Heaton (2004, 2008), who redefined and consolidated them based on a systematic

review of 65 completed and published QSA studies. Heaton's five types of QSA are more

commonly used and include supra analysis, supplementary analysis, re-analysis, amplified

analysis, and assorted analysis. These typologies are not exclusive, meaning that it is possible

for the purpose of a QSA project to involve aspects from more than one type (Heaton, 2004).

Supra analysis is when the secondary analysis transcends the focus of the primary study

by taking a different theoretical perspective, exploring a new methodological approach, and/or

asking entirely new empirical questions (Heaton, 2004, 2008).   Supplementary analysis differs

in that it takes a more in-depth approach to an issue that was identified with the primary analysis

that warranted further exploration, but uses similar analytical approach to the original work and

often, but not always, uses the full data set (Heaton, 2004, 2008). Heaton (2004) notes sometime

supplementary analyses are "difficult to distinguish from their parent studies because they re-

used all the primary data and had similar aims to the primary research" (p. 46).

Amplified analysis describes the re-use of more than one data set, to compare or pool

data for a similar population (Heaton, 2004). These data could come from two aspects of a large

project, such as the Timescapes project in the UK (Irwin, Bornat, & Winterton, 2012), or from entirely different studies. Assorted analysis is when a project combines some secondary analysis with primary research and/or analysis of naturalistic qualitative material (Heaton, 2004). Re-analysis is when preexisting data is examined to confirm original interpretations, such as to verify that no important information was missed, and is a less common approach in health and social sciences research (Heaton, 2004). Often this may involve using a different type of coding approach to triangulate and check the original results. Ultimately, the feasibility of a secondary analysis must begin with describing the mode and purpose of the study. Understanding these aspects will then allow researchers understand the next level of considerations: assessing for and mitigating any epistemological and ethical issues of the project.

Case Exemplar Step 1

The mode of data access for the exemplar study was informal data sharing. The primary study was originally conducted in 2015-16 through the Affirming Voices for Action (AVA) study, a mixed-methods research study of the NIH-funded multi-site Adolescent Trials Network for HIV/AIDS Research (ATN). One of the principal investigators for the AVA study agreed to the use of these data for the specific purposes of this project, and was involved in the QSA study, along with two other primary research team members. The lead QSA researcher (LMW) was also closely involved with the primary study as a former research manager at an ATN site. After leaving this position around the time the AVA study began, LMW subsequently returned to work on some of the data management and primary analyses with the primary research team, thus becoming familiar with the content of the interviews. For the QSA study, access to de-identified transcripts of the qualitative interviews, quantitative demographic information for the participants, and any field notes submitted by the interviewers was available. The original audio

recordings were destroyed following quality assurance procedures, as required by IRB protocol, so these were not available.

The purpose compared to the primary study was aligned most closely with a supra analysis, as defined by Heaton (2008). The aims and focus of the secondary project transcended the purpose and findings of the primary research, using a sub-set of the original data to explore an entirely different (but related) phenomenon. The primary study had the following main objectives: 1) to explore from the perspective of transgender youth age 16-24 living with HIV, not living with HIV, or unaware of their HIV status, what socio-ecological facilitators and barriers exist to influence their full participation in the various stages of the HIV continuum of care (prevention and testing, diagnosis, linkage to care, engagement in care, retention in care, initiation of ART, adherence to ART and viral suppression); and 2) to ask participants for their specific recommendations about how health care providers could improve their care for transgender youth. The purpose of the study was to describe how transgender youth of color age 16-18 years in the United States experience parent/guardian support and to explore the role of their parents/guardians in the larger context of their intersecting marginalized identities. This topic was chosen to fill a gap in the literature about this particular population, and because a growing body of research has illustrated the importance of parent/guardian support for transgender youth (see Wesp et al., Ch 3). Thus, only a sub-set of the original sample was used, with these interviews being identified based on the demographics provided by the participant to fit with the QSA study aims.

Step 2: Epistemological Assessment

Heaton (2004, 2008) provides an overview of various debates about secondary analysis related to epistemological underpinnings of qualitative research. Research from a qualitative perspective acknowledges that reality is socially constructed, and thus the researcher is

intricately connected to the process and product of inquiry (Denzin & Lincoln, 2011). However, credibility may be threatened if the secondary project strays too far from the original purpose of the primary study and/or the secondary researcher lacks contextual knowledge (Heaton, 2008; Mitchell, 2015). As with most qualitative inquiry, QSA assumes the researcher is constructing new knowledge through the process of analysis, yet particular steps must be taken to ensure the quality of secondary analysis findings (Coltart, Henwood, & Shirani, 2013; Heaton, 2004). Therefore, assessments of fit, context, and credibility will allow the secondary researcher to maintain epistemological rigor throughout the process of knowledge generation.

Key elements of a successful secondary analysis are a determination of **fit**, or the completeness of the data for the purposes of the study (Hinds, Vogel, & Clarkesteffen, 1997), which involves having enough information about the primary study design, including theoretical underpinnings, methodology, and how the data was collected (Irwin, 2013a; Medjedović, 2011). As with a primary research project, the data collected and the analyses undertaken must align with the research questions (Hammersley, 2010). Certain types of qualitative data may not lend themselves to secondary analysis, based on the methodology through which the data itself was collected. Irwin provides the example of ethnographic inquiry, where data is a product of the researcher embedded within the field, and would thus be difficult to reanalyze by a third party because theoretical understanding is developing as the data is being collected (Irwin, 2013b). Hinds, Vogel, and Clarke-Steffen discuss how grounded theory data collection may not consistently ask all participants the same questions as the study evolves, meaning some participants have answered different questions; whereas semi-structured interviews will ask the same open-ended questions of all participants (Hinds et al., 1997). Methods of data collection that are more consistent and transparent may allow for a secondary analyst to understand why questions are being asked and the context for the conversation (Heaton, 2004). Thus, the

approach to data collection in the primary study, i.e. the study methodology, will influence the nature of the data set and it is important for the secondary analyst to determine if the problems of fit will be too large to surmount and thus impact the study rigor. Without taking the methodology of the primary data collection into consideration, a secondary analyst could come to false conclusions about why some data was incomplete or missing (Hammersley, 2010).

An inadequate fit is often avoided when the ideas for the secondary analysis emerged from members of the primary research team, such as with supplementary or supra types of QSA projects (Heaton, 2004). If someone from the primary research team is not involved in the QSA project, the secondary researcher must become familiar with the data as a first step in determining whether the research question can be answered with the information provided. If it cannot, sometimes additional information can be combined, such as using several qualitative data set in an assorted QSA project (Heaton, 2004).

Significant problems may arise when members of the primary team are not involved in QSA, because secondary researchers may not have access to certain information about the **context** within with the data was collected (Medjedović, 2011; Thorne, 1998; Van den Berg, 2005). Collaboration between secondary researchers and some members of the primary research team is common within secondary work and often mitigates these issues, due to the ability of the primary team to provide information about the study context (Heaton, 2008). Indeed, Heaton (2004) identified that the majority of secondary qualitative analyses prior to 2000 were conducted with involvement of the primary researchers, who were mostly conducting supra or supplementary analyses.

However, regarding the overall constructivist nature of qualitative inquiry, Hammersley (2010) argues that qualitative data are "necessarily constituted, contextualized, and recontextualized within any project" (para 1.2). An adequate understanding of the study may

come from tacit information about the participants that is not available to those outside of the primary interviewer, however "the knowledge of context involved here is a matter of degree, and the problem may be no more serious in some cases of secondary analysis than it is in some forms of primary analysis" (Hammersley, 2010, para. 3.5). To this end, the secondary researcher should make explicit their level of experience and understanding about the population of study, which for nurses may be quite extensive given previous clinical work in the area of scholarship.

Yet, secondary analysis using archived qualitative data creates a very different set of circumstances related to context, as the Timescapes project in the United Kingdom has illustrated (Coltart et al., 2013; Irwin, 2013a, 2013b; Irwin et al., 2012; Irwin & Winterton, 2012). Coltert et al. (2013) discuss the challenges that arise for secondary analysts who are not working within the same established approaches designed for primary study. For example, large qualitative projects involving multiple team members means interviews may be conducted multiple individuals on the primary team (Matteson & Lincoln, 2009), but they would all still have similar approach aligned with the primary study protocol and aims. Therefore, lack of contextual information may be a more serious problem for secondary researchers who are completely uninvolved with the primary study. Irwin has asserted that "distance itself sheds analytic or critical light," but also contends that the secondary researcher must remain "constantly critically reflexive and analytic" about potential issues of context (2013b, p. 298). Ultimately, issues of context will greatly depend on the purpose of the secondary analysis and how relevant contextual information will be to that purpose (Van den Berg, 2005)

The secondary researcher must ensure **credibility** of results. Since member checking is usually not possible, verification of findings may have to occur in another manner. Thorne (1998) describes an obligation for truth telling in qualitative research, and with QSA this may be threatened when the analyst was not available discuss possible misunderstandings with

participants. The secondary researcher should never try to fill in their knowledge gaps about how the data were collected or the situations participants were involved in (Medjedović, 2011). The secondary researcher must instead realize the limitations about certain questions that cannot be answered, rather than trying to fill in the gaps. Although this is not unique to secondary analysis but may be more of a risk than in primary analysis (Hammersley, 2010, para 5.3). Thorne asserts that "the limits of qualitative secondary analysis are increasingly suspect the further the analysis evolves from the data and into the realm of abstraction and theory building" (1998, p. 552).

One way to deal with issues of credibility is to involve the primary research team in the secondary analysis, who may be able to address issues of misrepresentation. Coltart et al found that maintaining close association with team members "have proven to be incredibly valuable in terms of providing checks and balances against misinterpretation" (Coltart et al., 2013) (para. 26). Other secondary researchers have used strategies such as member checking with individuals or informants who were not involved as participants but have similar life experiences (Heaton, 2004) or conducting focus groups in a participatory approach to co-analyze data, which enhanced the trustworthiness of findings (Redman-MacLaren, Mills, & Tommbe, 2014).

Case Exemplar Step 2

Epistemological assessment was recursive throughout the QSA project. Initially, theoretical fit was examined. Bronfenbrenner's bioecological systems theory (Bronfenbrenner, 1995), Gender Minority Stress Theory (Hendricks & Testa, 2012; Testa, Habarth, Peta, Balsam, & Bockting, 2015), and the Gender Affirmation Framework (Sevelius, 2013) informed the primary study design and conceptualization. The original study was also informed by Community-Based Participatory Research (CBPR) principles with participation and representation from community members in study design, recruitment, implementation, and

primary analysis. The secondary analysis study was informed by the Intersectional Research for

Trans Health Justice (IRTHJ) framework (Wesp, Malcoe, Poteat, Elliot, in press), which is based

in feminist intersectionality theory (Crenshaw, 1991; Dhamoon & Hankivsky, 2011) and

Young's theory of structural injustice (Young, 2011). IRTHJ emphasizes the importance of

centering marginalized voices, while examining structures of domination and social-structural

process, to explore health inequities among marginalized populations. Although the theoretical

framings were different, they aligned in their focus on critical approaches to understanding the

contextual as well as personal factors shaping health outcomes.

Second was an examination of study designs and data collection. The primary study was

a mixed-method cross-sectional study that took place across 14 ATN sites in the United States in

2015-2016. Youth participants were recruited using cross-sectional, convenience sampling.

Youth age 16-24 who identified as transgender were identified and asked to participate in the

study through a network of community partners, peer referrals, and/or social media advertising at

each ATN site. The original interviews were collected using a semi-structured interview guide

informed by a phenomenological investigative approach that asked youth about experiences of

individual, community level, and structural level barriers and facilitators to accessing health care,

as well as what health care providers could do better to care for transgender youth. Thus, the

process of data collection was transparent and relatively uniform across each interview. Having

access to the demographic information about the entire data set (n=184 transgender youth) also

meant that we knew 24 participants would meet the criteria for the QSA subsample of youth age

16-18 years (inclusive) and racial/ethnic minorities (which were identified as anyone who

reported a race or ethnicity that was not White or non-Latino).

One challenge that had to be addressed throughout data analysis was whether we would

have enough content related to the secondary research questions, since youth were never directly

asked about experiences with parents/guardians. Some of the interviews would contain more information than others, but due to having familiarity with the data, we knew that many of the participants talked at length about their relationship with their parent/guardian. Based on our clinical knowledge of the community, we also knew that transgender youth age 18 or younger are often on their parent/guardian's health insurance and need parent/guardian consent for accessing certain aspects of their health care (especially gender affirming hormones) and the main study asked questions about access to care (even though it was targeting HIV related care). The contingency plan was to increase the size of the subsample by including 19 year olds. In the end, this was not necessary and data saturation was reached with the originally planned sample.

Assessing our understanding of context was continuous throughout the QSA study. The members of the primary research team and the lead QSA researcher have many years of clinical and research experience working with transgender youth. These experiences, along with involvement in the primary study design, collectively shaped an understanding of the study context and lived experiences of the participants. Due to logistics and loss of funding, the youth advisory board that helped with the primary study was no longer meeting and not available at the time of the secondary analysis. However, collaborations with the primary researchers throughout the analysis process was a valuable tool to enhance trustworthiness, as they were very familiar with the content of the interviews, the interviewers, and issues of context at the research sites.

Furthermore, credibility was successfully addressed through methodological rigor. The qualitative methodology used for analysis, narrative inquiry, supported trustworthiness of the findings. The methodology of narrative inquiry is an approach that understands human experiences as stories (Clandinin & Rosiek, 2007). Riessman asserts that narratives emerge when you least expect them, and that narratives are everywhere (2008). Thus, narrative inquiry lends itself well to secondary analysis. Using a narrative approach meant first identifying the

individual within-case narratives and then using these to inform an across-case analysis. The narrative inquiry process mitigated potential issues of misunderstanding, to the extent that it provided a rigorous deep dive into the content of the interviews (Riessman, 2008). The depth of understanding was enhanced by my use of dramaturgical coding for creating the within case narratives (Saldaña, 2016, pp. 145-146). Saldana (2016) describes dramaturgical coding as identifying six areas within the text: the objectives, conflicts, tactics, attitudes, emotions, and subtexts of each individual's narrative related to the research topic. As Saldana notes, "dramaturgical coding attunes the researcher to the qualities, perspectives, and drives of the participant. It also provides a deep understanding of how humans in social action, reaction, and interaction interpret and manage conflict" (2016, p. 146). Using dramaturgical codes was especially fruitful to identify the youths' relationships with their parent/guardians, which often came up as stories being told in response to interviewer questions about gender affirmation, such as "what sorts of changes have you made so far" or "what changes do you want to make that you haven't made yet." Referencing back to these narratives was useful for developing final themes com to describe lived experiences across the cases. The across case codes and themes were then developed and finalized through consensus with the primary research team. Having the individual participant narratives, constructed through the structured dramaturgical coding mechanism, greatly enhanced our depth of understanding of each person's life and story. These individual narratives along with a collaborative approach to the across case analysis enhanced the dependability and trustworthiness of findings.

Step 3: Ethical Assessment

A great deal of debate has ensued among qualitative scholars around ethical questions surrounding the implementation of a QSA research project (Coltart et al., 2013; Heaton, 2004; Hinds et al., 1997; Irwin, 2013b; Thorne, 1998; Yardley, Watts, Pearson, & Richardson, 2013).

In their article reviewing literature and gathering perspectives from participant sand researchers on the ethical concerns for QSA, Yardley, Watts, Pearson, and Richardson (2013) identified transparency and clarity around **informed consent** as an important consideration. Thorne (1998) also suggests that secondary research requires a judgement about whether the scope of the secondary analysis departs too far from the overall ethos of the original study, as this may cause an unethical use of the interview data without the informed consent of the participants. The issue of consent may also arise if the participants were not aware at the time of consent that their interview transcripts would be archived and available for future use (Yardley et al., 2013). Some primary studies include detailed information in their original consent forms about how future data will be archived and used for secondary analysis (Long-Sutehall et al., 2011), although it is possible participants would need to be re-consented if the researcher feels the scope of the data re-use is significantly different from what was originally consented to (Yardley et al., 2013). Ultimately the secondary researcher must use professional judgement and can consult with their local ethics review board for complex situations (Long-Sutehall et al., 2011).

Thorne (1998) also identified the possibility that secondary analysis of qualitative interviews could raise ethical concerns around **confidentiality**. Issues of confidentiality are often minimized because secondary data is de-identified and anonymized prior to secondary use (Heaton, 2004). However, Thorne (1998) raises a potential ethical issue if the secondary researcher were not as familiar with the community of participants as the primary researcher may have been, especially for marginalized populations or highly sensitive topics. Thorne cautions about the "risk for unwitting violations of confidentiality that the primary research would more easily avoid" (1998, p. 550). Similarly, Yardley et al. (2013) found that research participants entrusted primary researchers to not allow a misrepresentation or misuse of their data if it were to be reused in a secondary analysis. To mitigate these risks, primary researchers allowing

secondary use of their data have a responsibility to "make an ethically appropriate decision about allowing its use" (Yardley et al., 2013, p. 111), while the secondary researcher must pay close attention to any risks to sensitive issues or disclosures that may come about through the dissemination of findings (Thorne, 1998).   Secondary researchers may also have an obligation to spend time immersed in the field, to better apprehend the privacy needs of the population they are studying.

Additional ethical issues may arise regarding **nonmaleficence**, or the obligation to do no harm. Health researchers (more so than researchers in more theoretical disciplines) must remain astutely aware of how findings could impact participants lives through practice and policy (Thorne, 1998). Qualitative researchers have a responsibility to maintain trust, transparency, and clarity of purpose, and this falls upon both the primary and secondary researchers (Yardley et al., 2013). Thorn reminds us, "In articulating the larger social responsibilities underlying academic inquiry, the practice mandate of health researchers may prove an important asset in working out the ethical obligations inherent in secondary analysis." (1998, p. 55). Similar to mitigating issues with confidentiality, secondary researchers who immerse themselves in an understanding of their participants lives, familiarizing themselves through clinical or community work, will have a clearer understanding how findings may have an impact, either positively or negatively. Again, the process of critical self-reflexivity and analysis will provide the avenue for this level of insight that the qualitative researcher is responsible for (Irwin, 2013b).

Case Exemplar Step 3

The exemplar QSA project did not have significant areas of concern regarding informed consent, because when participants were originally consented for the primary study, they were made aware the data could be used in the future for other purposes. Furthermore, because the aims of the secondary analysis were aligned to those of the primary study, namely to improve the

overall health and well-being of transgender youth and understand how we can improve their access to care. Having the ability to consult with the principal investigator, including his participation in the final analysis, also added an extra level of certainty due to the potentially sensitive nature of the topic and vulnerability of this population.

The transcripts used for secondary analysis in this study were de-identified and no links to personal information were available. However, we took care to address confidentiality when selecting quotes and developing themes, due to the sensitive nature of the topics being discussed. We did not display any information that could have been too sensitive or in any way identifiable. We were uncomfortable using any supporting quotes that described personal experiences that felt too specific or unique and did not include specific geographic location or even pseudonyms for participant quotes, to maintain complete anonymity.

Finally, nonmaleficence, or doing no harm, was especially poignant for this study, as transgender people are receiving increased attention, both positive and negative, in the media and social sciences research settings. We took seriously our obligation as researchers to remain attentive to the social and health justice impacts of our findings (Wesp et al., Ch 2). A collaborative team-approach allowed for ongoing conversations about self-reflexivity, which supported culturally safe research practices (Browne et al., 2009).

Discussion

A major challenge of conducting any research with vulnerable and marginalized populations is maintaining confidentiality about sensitive topics as well as addressing any potential implicit biases on the part of the researcher. In our experience of conducting a QSA research study with transgender youth, these challenges were heightened. We had to maintain a careful balance of portraying the depth and truth of participants experiences, while at the same time maintaining their confidentiality about extremely sensitive topics and vulnerable nature of

their lives – especially the detailed stories of sexuality, personal trauma/abuse, and violence. Consultation with one another throughout the analysis process and putting ourselves in the participants shoes helped to maintain both credibility and confidentiality as we re-told their stories. In particular, our clinical knowledge from years of working with transgender adolescents was crucial in addressing these challenges.

Another challenge of this QSA study was understanding contextual information about participants' lives. Not having the audio recordings of the interviews meant that at times it was difficult to understand some of the subtext from the conversation. For a secondary researcher unfamiliar with the population, this may have been even more difficult. However, the lead QSA researcher (LMW) maintains a clinical practice as a nurse practitioner working with transgender youth, which was ongoing throughout the study. The synchronicities between data analysis and experiences in clinical practice became quickly apparent. This was both helpful and important to be attentive to. Detailed analytic note taking allowed for documentation of these observations, and then bracketing the real-life experiences in order to maintain fidelity to the stories of participants. At the same time, when used appropriately, the ongoing clinical work provided an understanding of nuanced language and other contextual information that may have otherwise been unavailable to a secondary researcher without first-hand knowledge of the community.

Future Directions

Qualitative secondary analysis is an established and viable approach to health research, and the specific methodological steps outlined here provide a roadmap forward. Future QSA research can deepen our understanding of this methodology and further develop best practices for health related and nursing research. Some of the main ethical and epistemological issues are related to the secondary researcher not understanding context or causing unintentional harm (Hammersley, 2010; Irwin, 2013b), yet as demonstrated through the case exemplar, these can

successfully mitigated when using a three-step approach offered here, and when the secondary analyst has first-hand experiences in the clinical setting.

The work of qualitative researchers will always involve a certain degree of co-constructing new knowledge, and as "bricoleurs" we are making use of the many tools that are available to complete the task with rigor and discipline (Kincheloe, 2001; Kincheloe, McLaren, & Steinberg, 2011). Nurse researchers bring years of clinical work that shapes our scholarly endeavors, and thus we may be uniquely positioned as secondary analysts of qualitative data. This does not presuppose the need for ongoing self-reflexivity and ongoing critical evaluation of our methods, attending to the contextual aspects surrounding primary data collection that we will never know as secondary researchers. However, we may be uniquely poised to conduct secondary qualitative analyses as bricoleurs, "employing these methodological processes as they are needed in the unfolding context of the research situation" (Kincheloe et al., 2011, p. 168). Future qualitative nursing research should explore and document analytic experiences so as to continue to expand the QSA methodological literature.

Finally, as others have documented, qualitative research can be time consuming for both the researcher and participant (Tate & Happ, 2018). Especially for marginalized populations, like transgender youth, who may be either difficult to recruit or over-burdened as participants due to a rapid increase in research focused on them, secondary analysis can make use of already existing data in an effective and efficient manner. While the secondary researcher must remain vigilant to the potential harms caused by misrepresenting or misunderstanding these populations, when issues of concern are addressed appropriately through a rigorous stepwise approach offered here, the process of secondary analysis can produce useful and important findings for clinical practice and health care policy.

Conclusion

Secondary analysis of qualitative data should proceed through three iterative steps: describing the QSA project, epistemological assessment, and ethical assessment. The case exemplar of a QSA study with transgender youth revealed that this approach was helpful to guide a rigorous secondary analysis. Furthermore, this case illustrates that the front-line clinical experiences many nurses bring to our scholarly work adds important contextual knowledge to the process of secondary qualitative analysis, making qualitative nurse researchers well prepared to continue develop and refine the secondary analysis methodology in the future.

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Chapter 5

Chapter 5 is a data-based manuscript, developed to disseminate the findings from the qualitative analysis that sought to answer the research questions of this dissertation: 1) How do transgender youth of color ages 16 to18 years in the United States experience support from their parents/guardians? 2) How does parent/guardian support relate to the health and well-being of transgender youth of color? 3) How do transgender youth experience parent/guardian support within the context of navigating structural inequalities and intersecting marginalization?

This manuscript is intended for an interdisciplinary audience of nurses and other health professionals who provide care and support for transgender youth and their families, as well as researchers investigating health inequities among transgender youth of color. The paper is formatted for submission to *Qualitative Health Research*.

TITLE

It's A Process: Resistance and Resilience of Transgender Youth of Color

Navigating Parent/Guardian Support and Societal Oppressions

Abstract

Transgender youth who are affirmed in their gender identity have greatly improved mental health and overall quality of life, especially with the support of parents/guardians. However, research has not explored experiences of transgender youth with additional marginalized identities, such as youth from communities of color who are not able to consent for their health care because they are not yet 18 years. This narrative inquiry study sought to describe the experiences of parent/guardian support and intersecting marginalization among transgender youth of color ages 16, 17, and 18 years (n=24), informed by a critical and intersectional framework. Analysis resulted in narratives that described the complex experiences of navigating barriers to health care while seeking to live authentically. Overarching themes included: *It's a Process, We Need Your Help, I'm Lucky to Have Support, Self-Advocacy/Resistance,* and *Having Hope/Resilience.* Findings have important implications for understanding the ways transgender youth of color demonstrate resistance and resilience in the face of challenges, as well as the role of health care professionals in supporting transgender youth and their parents/guardians.

Keywords: transgender youth of color, resistance, resilience, parent/guardian support, narrative research

Background

Transgender[1] youth experience negative mental health outcomes disproportionately, compared to cisgender[2] youth. Transgender youth have two to three-fold greater risk of suicide ideation, suicide attempt, self-harm without lethal intent, anxiety, depression, as well as both inpatient and outpatient mental health treatment (Reisner et al., 2015). A growing body of scientific literature supports the efficacy of gender affirming interventions for improving the health outcomes of transgender youth (Ehrensaft, 2017; Wiepjes et al., 2018). These interventions include use of affirming names and pronouns as well as overall affirmation of youths' authentic gender expression, which lead to significant improvements in mental health and well-being (Olson, Durwood, DeMeules, & McLaughlin, 2016). Interventions such as gender affirming hormone therapy and surgeries also improve psychological functioning as well as social/educational/professional functioning and overall well-being among transgender youth (de Vries et al., 2014). A gender affirming approach is considered the medically necessary standard of care by World Professional Association of Transgender Health, American Medical Association, the American Psychological Association, the American Psychiatric Association, the Endocrine Society, the American Academy of Pediatrics, among others (Lambda Legal).

In the vast majority of the United States (U.S.), transgender youth under the age of 18 must obtain consent from a parent or legal guardian to access medically necessary gender affirming interventions, such as puberty blockers, hormones, surgeries, and legal name changes.

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[1] The term "transgender" is an umbrella term that describes individuals whose gender identity differs from the gender typically associated with the sex they were assigned at birth (American Psychological Association, 2018). Transgender is used throughout this paper to refer to a broad range of identities, including but not limited to gender non-conforming, nonbinary, and genderqueer.

[2] The term "cisgender" refers to individuals who have a gender identity that aligns with sex assigned at birth, i.e. they are not transgender.

Health care professionals are called upon to assess for and facilitate parent/guardian support of their transgender children, due to improved health outcomes among youth with supportive parents/guardians. A recent systematic literature review found that parent/guardian support for transgender youth was associated with improved mental health outcomes, as well as decreased risk for HIV and decreased experiences of victimization, such as bullying (Wesp et al., n.d., Ch 3). A U.S. based survey of transgender people found that 50% reported experiencing lack of support from parents or legal guardians during childhood, and transgender people from communities of color were more likely to report such experiences. Previous research with transgender people of color, mostly among adults, (Singh, 2013; Singh & McKleroy, 2011; Singh, Meng, & Hansen, 2014) described experiences of navigating gender dysphoria along with the intersecting experiences of rejection with in families and racism, transphobia, and ageism. Research describing the experiences of transgender youth of color with their parents/guardians is currently minimal, and literature focusing on youth under age 18 is entirely lacking (Wesp et al., Ch. 3).

Research priorities for transgender youth should focus on examining the social environments of transgender youth, so we can build appropriate interventions that improve long term health outcomes (Olson-Kennedy et al., 2016). Understanding the lives of youth of color who must navigate their relationships with parents/legal guardians in order to gain access to gender affirming interventions, while simultaneously navigating intersecting societal oppressions, is needed to inform person-centered health care and decrease barriers to access. Therefore, this study was conducted to uplift the stories of transgender youth of color, age 16-18 years, in the U.S. and describe how they experience parental support within the larger societal context of intersecting discrimination and victimization. The purpose of this study was to

enhance our understanding of the needs of this population, understand how to better facilitate parent/guardian support, and ultimately improve their overall health and well-being through practice and policy change.

Theoretical Framework

Critical theory provided the broad philosophical underpinning for this study. A critical approach seeks to challenge social inequality by moving beyond the surface and analyzing the roots of injustice through emancipatory knowledge production (Chinn & Kramer, 2015). Critical theory also generates inquiry that is historicized and situated, acknowledging multiple truths and how these truths are shaped by structures of privilege and power (Lincoln, Lynham, & Guba, 2011). Specifically, this study was informed by the Intersectional Research for Trans Health Justice (IRTHJ) conceptual framework, a theory-driven model for conducting transgender health research that considers structural causes of health inequities (Wesp, et al., n.d., Ch. 2). IRTHJ uses the theories of intersectionality (Collins & Bilge, 2016; Crenshaw, 1991; Dhamoon & Hankivsky, 2011) and structural injustice (Young, 2011) to guide research that analyzes the ongoing and historical structures of domination that are the root causes of inequitable health outcomes among transgender people. The IRTHJ framework emphasizes centering the voices and situated knowledge of transgender populations experiencing health disparities, such as transgender youth of color interviewed for this study. Finally, IRTHJ emphasizes the importance of the researcher maintaining a critical perspective throughout the research process, whereby the research is used as a tool for disrupting status quo social structural processes that constrain opportunities and perpetuate inequities (Wesp et al., n.d., Ch 2).

Methods

Study Design

The study was a qualitative secondary analysis (QSA) using narrative inquiry methodology. Secondary analysis of qualitative data offers a viable approach to knowledge generation, using a three step process to ensure rigor in study design, epistemology, and ethics. See Wesp et al., n.d., Ch 4 for details about the secondary analysis approach to this study. The following research questions guided the current study: 1) How do transgender youth of color age 16-18 years (inclusive) in the United States experience support from their parents/guardians? 2) How does parent/guardian support impact the health and well-being of transgender youth of color? 3) How do transgender youth experience parent/guardian support within the context of navigating structural inequalities and intersecting marginalization?

The qualitative interviews used for this study were already collected as part of a national multi-site research study with transgender youth that sought to identify the barriers and facilitators for transgender and gender non-conforming youth in accessing health care services. The original interviews were conducted between 2015-2016 in 14 different cities throughout the U.S. at HIV clinics or adolescent programs serving LGBT adolescents. Interviewers at each site were trained in cultural sensitivity and qualitative interviewing methods. The larger study was designed utilizing community-based research principles, with a youth advisory board (YAB) involved in the design of the original semi-structured interview guide, recruitment, and primary data analyses. For broader discussion of study design and results from the primary study see Harper et al. (2019).

The interviews contained many layers of rich information about the specific experiences with parents and guardians that were as yet unanalyzed. The current analysis was conducted with

a smaller subset of the original uncoded transcripts. The original data set included 186 semi-structured in-depth interviews with youth who identified as transgender or gender non-conforming, and of these, 24 met criteria for the current analysis based on self-reported demographics about their age (16-18 inclusive) and race/ethnicity.

Ethics

The original study was IRB approved by the University of Michigan ethics board. The secondary analysis was conducted with de-identified transcripts, and the ethics boards of University of Michigan and University of Wisconsin-Milwaukee did not require any additional approval due to a lack of identifiable information. Participants signed informed consent for the original study which included their consent for future use of data for additional analyses, and the IRBs at all participating sites recruiting minors granted a waiver of parental consent for youth under age 18.

Data Analysis

Data analysis was conducted using a narrative inquiry approach, chosen because narrative inquiry upholds that human stories reflect important social realities (Clandinin & Rosiek, 2007; Kim, 2016; Riessman, 2008). Although the original interviews were conducted using a phenomenological approach (Harper et al., 2019), narrative inquiry lends itself particularly well to a secondary analysis because humans communicate through narratives, or stories, and narratives are everywhere emerging when you least expect them (Riessman, 2008). Narrative inquiry is also aligned with the theoretical framing of this study, which emphasizes the importance of centering voices and situated knowledge of transgender individuals experiencing multiple forms of marginalization (Wesp et al., n.d., Ch 2). According to Kim, narratives help to

"develop an understanding of the meanings our participants give to themselves, to their surroundings, to their lives, and to their lived experiences through storytelling." (p. 189-190).

The data analyzed for this study included transcribed, de-identified transcripts and demographic data. Analyses were conducted using the software Dedoose version 8.1.1 (2018). A multi-staged analysis process was devised to adequately answer the research questions via narrative inquiry (see Fig 5.1). The first step was to conduct within-case analysis (Riessman, 1993, 2008) and identify the individual stories told by each participant. The within-case analysis was conducted by the first author (LMW) and identified plotlines, thematic structures, and social/cultural referents (Kim, 2012, p. 190). Stories were identified through dramaturgical coding according to Saldana (2016), whereby five main components of stories about parent/guardians were identified: the objectives, conflicts, tactics, emotions, attitudes, and subtexts. A storying process was conducted for each individual participant, summarizing their experiences of PG support. The second step was a second cycle of coding conducted by the first and second authors (LMW and PK), whereby an across-case codes were identified via a process of re-storying that identified commonalities and differences across all participant interviews (Riessman, 1993). The across case codes were then compared to the within-case stories, and the primary research team (GW, LJC, EP) was consulted until consensus was reached on the final organization of themes into an overall narrative.

Figure 5.1. Multi-staged Narrative Inquiry Analysis Process
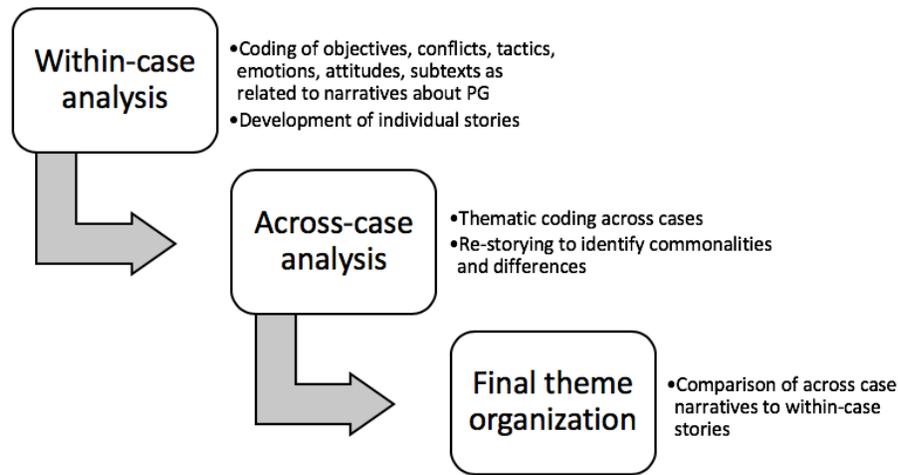
Findings

Description of Sample

A summary of demographic information for the 24 participants is presented in Table 5.1. Geographic location describes the region of the U.S. where the participant lived at the time of the interview. The majority (58.3%) of participants reported being age 18 years at the time of the interview, with the remaining participants age 17 (37.5%) or age 16 (4.2%). Race/ethnicity were not mutually exclusive, and so individuals could name more than one racial or ethnic identity. The majority of participants described themselves as Black (83.3%). Additional race/ethnicity identities included American Indian (20.8%), Asian (8.3%), Pacific Islander (8.3%), and Latinx (20.8%). Overall, half of participants were located in the East Coast, one-third in the South. Only one participant was in the West Coast and three people were in the Midwest.

During the qualitative interview, participants were asked to describe their gender identity using their own words. Based on participant responses, the majority of the sample identified as transgender women (45.8%) and women (20.8%). Additional identities included gender non-conforming (16.6%) and genderqueer (4.2%), along with transgender men (8.3%) and men (8.3%). Participants were also asked to identify their sex assigned at birth, as male, female, or

intersex. The majority of the sample were assigned male at birth (83.4%) and the remaining

assigned as female at birth (16.6%).

Table 5.1. Description of Sample: Participant Demographics

	Total Sample N=24
Age	18 y/o, n=14 (58.3%)
	17 y/o, n=9 (37.5%)
	16 y/o, n=1 (4.2%)
Race/Ethnicity	Black, n=20 (83.3%)
	American Indian, n= 5 (20.8%)
	Asian, n=2 (8.3%)
	Pacific Islander, n=2 (8.3%)
	Latinx, n=5 (20.8%)
Geographic Location	East Coast, n=12 (50%)
	South, n=8 (33.3%)
	Midwest, n=3 (12.5%)
	West Coast, n=1 (4.1%)
Gender Identity	Transgender woman, n=11(45.8%)
	Woman, n=5 (20.8%)
	Gender Non-Conforming, n=4 (16.6%)
	Transgender man, n=2 (8.3%)
	Man, n=2 (8.3%)
	Genderqueer, n=1 (4.2%)
Sex Assigned at Birth	Male, n=20 (83.3%)
	Female, n=4 (16.6%)

A description of the level and nature of parent/guardian support for accessing gender

affirming interventions, to the extent it was described in the participant stories, are summarized

here to provide contextual description of participants' lives (see also Table 5.2). Of the 24

participants, only one participant did not provide enough information to clarify the level and

timing of parent/guardian support for acquiring gender affirming interventions, so data is

provided about the remaining n=23. Of these, almost half (n=11, 47.8%) described having their

parent/legal guardians' consent for gender affirming hormones or legal name change (of these,

n=6 were still under age 18 at the time of the study and n=5 were 18 years but using

parent/guardian's insurance). Three participants (13%) described inconsistent support, where the

parent/legal guardian only consented to partial treatment or had initially consented but then subsequently removed their consent. The remaining 39% (n=9) desired access to gender affirming interventions such as hormones, surgeries, or legal name change but were unable to do so because they did not have a parent/guardian who would consent. Of these participants, n=3 were still under 18 years, n=3 had turned 18 years but their parent/legal guardian was not allowing use of insurance for hormones, and n=3 discussed they had to wait until their 18th birthday to begin because consent had been denied. Of note, two participants who did not have parent/legal guardians consent described their use of hormones without a prescription ("street hormones") prior to turning 18 years.

Table 5.2 Description of Sample: Parent/Guardian Consent[a]

	Overall	Age in years
Had consent for gender affirming interventions	N=11 (47.8%)	16 n=1 (9%) 17 n=5 (45.5%) 18[b] n=5 (45.5%)
Inconsistent consent for gender affirming interventions	N=3 (13%)	17 n=1 (33.3%) 18[b] n=2 (66.7%)
Denied consent for gender affirming interventions	N=9 (39.2%)	17 n=3 (33.3%) 18[b] n=3 (33.3%) 18[c] n=3[*] (33.3%)

[a]Information available for 23 of the 24 participants
[b] Participant still on parent/guardian's insurance, thus parent/guardian's consent was required but denied
[c] Participant had to wait until turning 18 to access medical interventions due to parent/guardian denying consent
[*] Of these, n=2 reported using street hormones prior to turning 18

Overview of Themes

Narratives from transgender youth of color about their experiences of parent/guardian support can be summarized with one overarching phrase: **"IT'S A PROCESS."** Additional themes and subthemes comprise additional narratives about navigating parent/guardian support as well as the multiple issues transgender youth of color face within society at large. As

illustrated in Figure 5.2, four main subthemes that further describe "IT'S A PROCESS" include

We Need Your Help, I'm Lucky to Have Support, Self-Advocacy/ Resistance, and Having

Hope/Resilience. Narratives describing We Need Your Help included subthemes of Living

Authentically, Being Patient/It's Painful, Brush it Off/I Know Who I Am, Crucial Link to Care,

Turning 18, and Never Ending Cycle. Themes are discussed in greater detail below.

Figure 5.2 Themes and Subthemes
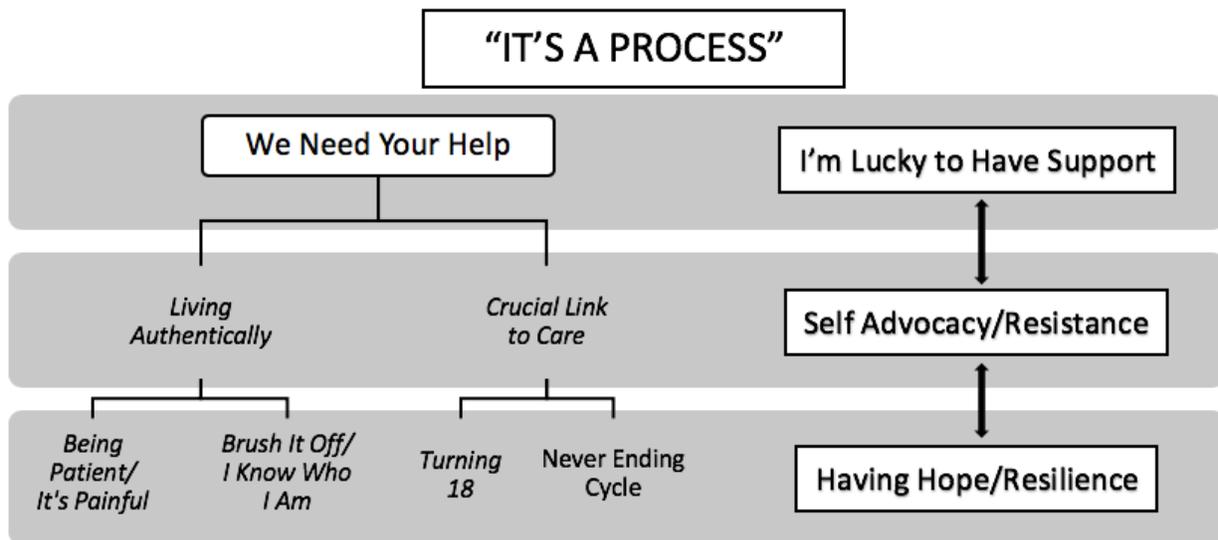
IT'S A PROCESS

The overall narrative "IT'S A PROCESS" describes experiences seeking support from

parents/guardians as a long and sometimes stressful or arduous journey. "IT'S A PROCESS"

also encompasses the strategies that transgender youth of color use for navigating the complex

relationships with their parents/guardians, as well as the challenges of navigating larger

structural barriers, as they also seek to live authentic lives. As one participant says, "its gonna

take a long time for me to - [long pause] get everything that I'm supposed to get. It's a long

process." Youth were acutely aware that living authentically in their gender was not going to be

immediately accessible to them and the steps to accomplish this were not a straightforward or

linear path. They expected to face rejection, ridicule, and discrimination at many points along the way (discussed in greater detail via subthemes below). In general youth told stories about reminding themselves often that it will probably take time and a lot of navigating, but that it was important for them to remain centered in their authentic selves, "because if you're wrestling with your identity there's no way you're gonna branch out unless you're solid in it." Remembering that it is a process, and remaining centered in self-knowledge of their authentic selves, was reassuring, overall:

> "Just knowing that it's a process and I myself um, is comforting and helping um, with those stresses, in a sense that it's not – taken away from me regardless to harassment or an um, or an acceptance, or um, safety concerns and conscious concerns, and safety. That who I am as a person is never taken away from me. Um, I'm my own person."

We Need Your Help

Throughout the interviews, discussion about experiences with parent/guardians was centered around a common request: We Need Your Help. Youth were in need of consent from parents/guardians to access the various services that help them live authentically in their identified gender: namely hormones, surgeries, and/or legal name change. One participant said:

> "We all need, you know, some type of help. We don't really have people. The only person I really needed to, you know, really like help me, was my mother. Cause I knew, like, this right here, she gotta help me with this."

A participant in the foster care system pleaded, "your job is to help me help myself. Help me help myself, you're getting paid to help me help myself. Help me!" Youth under 18 years described stories of their parent/legal guardian refusing to consent to medical treatment, despite

expressing their struggles with gender dysphoria and need for treatment. One person in the foster care system said:

> "I'm a youth. I have youth, you understand? But even with me, like I said, with the foster care agencies, them tryin' to act like a parent, they was neglectful. They have so many cases, but they knew I was transgender and it was a big thing, a part of me and my life and I was neglected, so only imagine a person with a parent. I had a whole agency behind me. [Short pause]. It's a shame. People don't understand. But you knew I was a girl. Every one of this medicals, they have me down as being transgender. I have not gotten no hormones ever since but everything else was made a priority. Everything else was made a priority but that and I knew about this. I knew about this the whole time and I documented everything. Everything. It was never made a priority"

When asking for help, narratives were not only about accessing hormones or gender affirming interventions, but also the complexities they faced when lacking the basic necessities of survival. Homelessness, poverty, violence, and abuse were all experiences that trans youth in this study either experienced themselves or knew friends who were struggling with these issues. Survival sex and interpersonal violence were common experiences. When reflecting on this, one person said,

> "You know, there's a lot of – a lot of girls that still have no place to go. And I think we all need a place to go, we all need a place to, you know, the way I have it, we all need to eat and stuff. So I think that's why some girls be out here doing what they do. Because, like they have nowhere to go."

Woven within the stories about needing help from parent/guardians, professional adults (such as health care providers, therapists, or teachers) were often seen an important source of affirmation:

"When I was around 15 I went to [LGBT counseling center] for therapy and counseling and that's when I really got to have my gender affirmed by an adult, um, who didn't know me and still [pause] you know, never thought a second thing about me saying hey I think I'm trans, and I think that really helped consolidate you know my feeling and you know saying hey I am male."

Health care professionals were an important source of support, especially when parents/guardians were not:

"Now I do got people that supportive, like the health care providers, like they - they've been there for me since day one …so I'm glad they still by my side helping me do what I got to do."

Honest and consistent support from professional adults was especially important throughout the process of coming out as trans to parents/guardians or waiting for them to take certain actions, such as consenting for hormone therapy:

"That's why I was so happy to find you guys [referring to clinical site]. And I was bringing it out to my mother, you know, at the time, so it was like, I didn't really have any parent to, you know, sign or do this and do that. So I had to bring it out to her first. So, you know, she can, you know, get with the program. I just – I'm like – my doctor, like, he's a very supportive person. Very supportive. And he tells me the real, like he tells me the real."

Multiple subthemes under We Need Your Help further describe the experience of needing help from parents/guardians, including why it was needed and how it felt. These subthemes are:

Living Authentically. Youth requested support from parents/guardians primarily because they needed help Living Authentically. When not able to live authentically, youth described feeling distressed, sad, anxious, and at times used substances to cope with the experiences of dysphoria. Several participants described experiences of abuse and rejection from their parent/guardian upon coming out, and the abuse along with dysphoria, resulted in depression and low self-esteem: "I hate myself sometimes, but then I don't, but then like it gets to me…" Another participant who had some support but was still in the process of transition and thus still experiencing distress also says about the dysphoria: "those physical characteristics had been a major factor to my depression, and I was diagnosed with major depressive disorder because of all of those factors."   Ultimately, youth who had begun the process of transitioning, whether with the support of a parent/guardian, because of accessing street hormones, or because they were able to consent to their own treatment upon turning 18 years, felt a great sense of relief upon receiving interventions that would help them live in the gender that was true to themselves. As one participant said,

> "I guess now that like I'm on hormones and everything it's, um, it's made me more comfortable with myself and that like I used to be so inclined to have to dress a certain way and do things a certain way but now I'm just like being myself and its allowed me to be more positive about life."

And another person said,

"I've begun to think more clearly. I've begun to deal with my issues in a much more intelligent way. Um, eh, it's just often times we don't expect to be capable of doing something, but when you feel that you are yourself, your confidence boosts and you are able to accomplish things more than you can -- more than you think you know."

Being Patient/It's Painful. Youth understood that their parents/guardians needed time to come to terms with their child's gender identity, but at times waiting for parent/guardian acceptance was also very difficult for them emotionally, as described in Being Patient/It's Painful. While youth understood it would be challenging for their parent/guardian to begin using a different name or pronoun, or consent to hormones, this was simultaneously a time of hurtful exchanges and exhausting conversations that took a toll on everyone emotionally. Some participants also talked about being patient with the process the parent/guardian was going through in adjusting to a new name and pronoun, "So I mean they were open to the idea, they were just not used to the change you know…They have more difficulty switching from female to male pronouns, but they have good intentions." While youth observed that their parents/guardians often needed more time to adjust, they also described struggling with their dysphoria both internally and externally while they waited. Youth described the relationships between structural factors, such as religious ideology, and parent/guardian support for their gender identity, describing the emotional toll it took: "My family wouldn't let me go get hormones. I was raised in a Catholic household so it's typically frowned, it's frowned upon to be trans so that's a barrier and it just causes emotional distress."

Yet, they also described feeling respectful about their parent's beliefs, because their parents were also going through their own process:

"So it's like, my mom, when I told her that I need a – I need – that this is what I want to do, it was kinda hard for her to even, you know, go through it. It still is. But I respect it because, she, you know, she's a mother. And my mom is the type too, always being that parent that's like, you know, the mothers that's always like, there, like she's there, like she be in the interviews in school. Like, she be in the – like she's there so when I told her, she was like 'Okay, we'll see about it. We'll see.'"

Other youth describe the pain when an otherwise accepting parent/guardian would not support them accessing gender affirming hormones:

"I feel like my mom and I have such, we do have such a connection um, that I think that, um I think it's just very hurtful and - and, saddening. And I try to remember everyone's and where everyone is coming from and I try to meet to everyone where they are at, and have understanding."

Finally, participants described stories about how both they and their parent/guardians are existing within a society driven by ideologies of strict binary gender norms and expectations, especially for people of color.

"Putting my makeup on and doing my hair. My eyelashes. Like, when I used to go out with my hells and dresses. Before I step food out that house, just know I Had to look, you know, at least decent, for me, today. You know, look like at least something."

Youth described stories about how important it was for family members to stick together, describing the value of extended family and kin networks and their understanding about why parent/guardian support may need time to navigate rejection from extended family. As one person described,

"She is coming around. She, I just think it's, she just don't want to go against the whole family with me. So I mean, that's fine as well too. But I think, she's just, she's not ready to go against the whole family and blood, you know, pain, like go against them with me and tell them."

Brush It Off/I Know Who I Am. As transgender youth were navigating experiences with parents/guardians, they were also describing multiple experiences of rejection and discrimination in the health care setting. Facing these barriers, youth also talked about their resilience in the face of rejection from others in their lives as well, including extended family members, peers, or teachers. The overarching response to these difficult experiences was a guarded determination to not let hateful words or experiences deter them, as described by the theme Brush It Off/I Know Who I Am. Youth who did have parent/guardian support and were linked to the health care services they needed often then faced ridicule or lack of understanding in the health care setting. For example, when health care providers would refuse to accept their gender or refuse to use their name/pronouns in the health care setting, youth just brushed it off as one person said,

"I know what I am -- I know what I was born -- I know what I have between my legs, but that's not what -- I don't -- I feel a different way but it's not up to you, you can say-- you can call me whatever you want to call me, that's not going to change who I am. I'm not going to let you start; I'm not going to let the little words you say hurt me from getting my healthcare."

Another participant said, "It's like, I mean, you get your few stares and your whispers underneath. The nurses actually laugh at me. But it just don't it really don't phase me like that anymore." When discussing stares in the waiting room another youth said,

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"Cause like people they - they would look at me and laugh or they would say something,

but I won't really pay no mind, but now I see people doing that and I just -- I just -- it

don't bother me no more, I just laugh at them like, okay (laughs). What am I supposed to

do this is me."

Even if a parent/guardian was supportive, rejection or lack of acceptance was sometimes

experienced from extended family members, and youth described similar resilience of trying not

to pay attention to this, but it was more challenging emotionally to do so: "My grandma, said

one thing to me, one day, and she was like, she just like, as much lipstick you put on and as

much breasts you going to grow, you always be a boy. And I was just like, oh, okay. Okay.

But, I really don't pay attention to any of it anymore. But the majority of the time, it still like,

you still feel that, but I just try not to show it in front of people."

Crucial Link to Care. Parallel with the experiences youth described around living

authentically, were the narratives about parents/guardians as a Crucial Link to Care, not only as

providing consent for treatment but as valued advocates to help them navigate complicated

structures, especially legal, insurance, and health care systems. For example, when asked a

question about what facilitates their access to health care services, many participants responded

by talking about what seemed obvious to them: having consent from their parent or guardian. As

one person said, "parents for sure!" and went on to highlight the situation for youth who may not

have had parent/guardian consent:

"Although I was young, I had parental approval and with that I mean it was fair game like

they allowed me to get the services that I needed, um, however if there is a younger you

know 18 and younger um trans or gender diverse youth who is trying to get into that, um,

and they don't have the support of their parents then you know what options do they

have? It's more limited without parental consent."

Youth in the foster care system were often interfacing with multiple adults as well as their

parents/guardians, to access gender affirming interventions. One story was told that illustrates

the many people involved in a legal name change process:

"Although I was young, I had parental approval and with that I mean it was fair game like

they allowed me to get the services that I needed, um, however if there is a younger you

know 18 and younger um trans or gender diverse youth who is trying to get into that, um,

and they don't have the support of their parents then you know what options do they

have? It's more limited without parental consent."

Youth also shared how their parents/guardians helped navigate insurance coverage or facilitated

finding providers who would prescribe hormone therapy, even when they were over 18 years,

because the parent was the insurance beneficiary:

"Um my mom she handled like all my insurance and stuff so she um switched my doctor

that gave me the information and um…and gave my primary care doctor to them to get

my hormones. And um since she has my information I was kind of dependent on her to

give me my hormones basically."

Many participants discussed the challenges of being on their parents insurance, even after their

18th birthday, because being on parent/guardian's insurance meant the parent who was the

beneficiary had to be involved in the logistics of approvals for various treatments and would

receive statements of care received. At times this meant navigating complex family dynamics,

especially if parents were divorced or estranged. One participant expressed, "that was a process,

to deal with my father recently um, because I stated that I don't ever speak to my father, I don't."

Turning 18. A monumental event for transgender youth under who did not have their parent/guardians consent for hormones was their 18th birthday. Most of the participants in the study lived in a jurisdiction where they could not consent to hormones or gender affirming surgeries for themselves while still minors, and thus a common theme was Turning 18: "When I was first trying to get hormones, I don't think I was eligible for that at the moment either by me being under the age of 18 and my mom didn't want to consent with it." Becoming their own legal guardian for access to health care services was a pivotal moment. Many people were very focused on their upcoming 18th birthday: "I would like to do it at 18. Like the second I turn 18, I'm like I want hormones. Put me on hormones." Others who were already 18 years presented for care on or shortly after their 18th birthday, "I had to wait until I tuned 18 and then on that day I went to the [clinic]." Another participant did live in a state where being an emancipated minor allowed for them to consent to hormone therapy prior to turning 18 years:

"I'm learning just recently now that I live independently and I'm not under her [the mother's] household and I have my own source of income and I'm living by myself, I can consent to medical care for myself, which I think is an important step and I think that um, that should expand to all youth."

Never Ending Cycle. Juxtaposed with the stories of reaching the 18th birthday and becoming legal adults, additional barriers still existed as described with the theme, Never Ending Cycle, which includes experiences of what seemed like unending challenges. As one person said,

"Um, so a lot of youth particularly speaking from my own experience grow up feeling they are lonely. And um, that it -- in the sense that am I the only person that feels this way and then the inner shame that comes with that and trying to express who you are and

then being suppressed at home and then being harassed at school. And it just feeling like

a never ending cycle."

As another person says, "all of these barriers just keep popping up and popping up and popping

up and it just becomes this dome, which is very hard to breathe through, and that's - that's the

best way I can put it."

Four major components of the never ending cycle were commonly discussed. The first

included the complexities that continue with navigating parent/guardian support even when a

young person turns 18 years, because they are often still on the parents insurance until age 26.

Due to the ways that insurance companies inform the primary beneficiary (i.e. the

parent/guardian) of the services rendered via explanation of benefits statements, youth who did

not have supportive parent/guardians could not use their insurance to access hormones because

the parent/guardian would be told in the statement about diagnoses and prescriptions billed to the

insurance. While some youth were still able to access care via sliding scale clinics that did not

bill insurance, others could not access gender affirming health care interventions even after

turning 18 years because they were unable to use insurance and unable access sliding scale

clinics: "um, my family was not like helping me in any way, like its separate, like I'm under their

insurance but I don't really have insurance or money."

Navigating school and employment was another narrative within the never ending cycle,

and these were places where youth described intersecting oppressions on multiple levels. Being

kicked out of school, or fired from jobs because of being trans and a person of color were some

of the experiences youth in this study described. One person described being fired from a job

they traveled over an hour to every day, and when asked why they thought they were fired, they

responded "I think because I was the only black person there, no shade no tea - because I was the

only black person there." Another person who had not finished high school yet said: "My identity kept me from graduating. They kicked me out of school cause I was transgender," and further explained that they had moved to a different state where the laws were more protective against discrimination, in order to finish school.

The third component of the never ending cycle included how it felt to be expected to live up to specific gender expectations, being both transgender and people of color. Participants described the experiences of navigating racialized gender norms, and this often created internal and external challenges that felt like a lose-lose situation. One person explains the struggles of receiving messages as a woman that it is important to be natural and that natural is beautiful, but at the same time receiving messages that transgender and gender nonconforming people of color have to look a certain way to be "passable." Many transgender women talked about the amount of time and money it cost for them to present in a way that made them feel safe to move throughout the world as female. As one person said,

> "For me it's very difficult um, to take off my make up, and it's also very challenging emotionally to present without make up on as I am today just for the record. Um, but I also conflict with being resilient and being natural and it's like feeling beautiful um, externally but also working within."

For people who identify as non-binary, navigating binary gender expectations about how to act and present was also extremely difficult, especially being young:

> "Patriarchy, um, machismo, you know, all that stuff, it's very much like enforcing the gender binary. This is this and this and that is that. So everyone like, non-binary, agender, all those people get kinda like pushed aside and told they don't exist. Uh, so there's a bunch of different barriers depending on where you identify on a spectrum. It's definitely

nerve-wracking considering the fact that I might not only – do I have that, of like a strike against me for that, but then I also have the fact that I'm 18. So there's also age-ism that comes like that. Um, you know, the whole, oh, listen to your elders, and they have experience, and whatnot."

As this participant also described, being young meant that any transgressions of gendered expectations were often met with ridicule for being immature or too young to know better.

The fourth and final component of the never ending cycle were challenges of presenting to health care settings for services and facing discrimination because of their age, race/ethnicity, country of origin/nationality, and/or gender identity combined. At times people would try to just temporarily present as if they were not transgender (i.e. being "stealth"), to avoid some of the mistreatment, but they might still face discrimination because of the other factors. As one person said of a health care encounter,

"It's like, I know what's going on with my body, and you're not listening to me. So if I choose to not be stealth, I get barriers. If I choose to be stealth, I still get barriers because I still have certain strikes against me, it's just less."

Another common scenario described was withholding information to health care providers about their gender identity, out of fear that the provider would disclose this information to the parent/guardian resulting in stressful or dangerous situations for them at home:

"I didn't want to come out to them because I was afraid they were going to tell my mom. Um, And they probably would've like talked about it and I probably would've had to go on like some medication to make me happier but, and because I was like probably like 15, 16 then. Um, They wouldn't – they would probably also need my parent's consent for

me to go on hormones. So that just wouldn't happen , it would just cause more stress, so I didn't tell them."

Other people described seeking emergency services but then lying about their symptoms or leaving the encounter without being treated, because the mistreatment they received made them feel worse than their original problem. This was the case for one person who presented with suicidal ideation and was hospitalized:

"When I went to a private hospital, uh, because I was in danger to myself. Um, uh, they didn't they just did not respect the identity that I you know perceived myself as and they just automatically put me with what I was like the assigned birth sex group. And that alone created uh… questioning within the group. And made me just want to get out of there as soon as possible. Because I didn't feel comfortable being there. I didn't feel accepted. I just wanted to get out of there as soon as possible."

Others would avoid seeking care all together, unless absolutely necessary, or described experiences where they felt unable to stand up for themselves because an unsupportive parent was in the room using the wrong pronouns, or because of their age. As one person said,

"I've – I have felt unsafe um, regarding healthcare and like the anxiety that – that creates visiting like your physician and um, especially like as a child um, pronouns and just how that feels and like a suppressed girl with my identity being suppressed and maneuvering through that."

Another person said, "I think some of them--or at least one of them--didn't take me seriously because I was still young. I was still like 15 years old, um, and all -- it felt like on a personal level they weren't taking me seriously." An extra layer was described by several participants who were not born in the U.S., facing fears about deportation and the dangers of returning to

their country of origin. Describing the environment in their home country, participants described a hostile environment for transgender people: "You will literally get attacked." Their lives in the U.S. centered around navigating an increasingly hostile environment due to immigration practices in their towns: "By me not having a permanent residency to be here, it's a lot difficult. I was scared if I go to the hospital would they call immigration for me."

I'm Lucky to Have Support

Alongside the stories about needing help, transgender youth also shared the common sentiment of I'm Lucky to Have Support. Variations on this theme included stories of feeling surprised, blessed, privileged, or fortunate that they had support from parents/guardians. These narratives allude to an underlying sense that parent/guardian support felt untenable or perhaps even not deserved by transgender youth. The experience of feeling lucky to have support was also true for any support received from other adults in professional roles, such as health care providers, teachers, or mental health providers, and felt like a fortunate occurrence that would not be guaranteed in the future.

When sharing their story about their parents who consented to hormones and a legal name change, one participant said, "I've personally have been very, very lucky, um, to have like the, uh, the cards that I have that, uh, I've been like - I've been almost as I say, uh, blessed or lucky that I have this support." Youth often discussed their experiences of parent/guardian support in comparison to stories they knew about other transgender youth, saying it was "not so good as me," as one participant described it. As one person explains: "Cuz like some of them be like homeless, some of them don't got families to support them, so like some of them are not as fortunate as us." Rejection from parent/guardians resulting in potentially unstable housing was an experience that was well-known within their social circles:

"I know there are other transgender people out there and I have actually met transgender

people out there who are not so lucky, who have to worry about um if they're gonna be

kicked out of the house."

When parent/guardian support was received, participants felt privileged because it was

experienced as uncommon or unexpected based on what they knew about others:

"I have familial support and never had to think you know these people are not going to

support me. I've always had, um, friends and peers and even teachers who would back me

up, um, and I have access to the medical care, um, and the social services if I needed to

and you know I realize that not everybody has that, um, and it's just because I'm so --I

grew up so privileged in that sense."

Youth were acutely aware of the potential for rejection not only from parents/guardians

but also from strangers or peers, in the form of discrimination, bullying, or violent victimization

they expected could happen as they move through the world:

"I haven't had as like many bad experiences like the worst that I have gotten was that

medical experience and maybe sometimes uh teasing. But that happened last school year.

It - it hasn't uh has yet to happen this year for me."

Others spoke about the likelihood of facing discrimination in health care:

"Um I feel like with healthcare when they examine your bodies they just don't

understand. So I feel like that is something that I would have to face in the future if I do

have to go to the emergency room for certain things. Um…that's definitely something

that would come up I'm not even going to put it past you, like that's the type of world we

live in, so…"

Youth also described the feeling that parent/guardian support was tentative at times, as well as inconsistent. When asked general questions about what a barrier to health care might be, youth described stories of when their parent/guardian withdrew consent or did not follow through on renewing health insurance, leading to a lapse in their gender affirming hormone treatments. As one person said, "if my mom would decide not to sign my papers for me to finish my hormone therapy…that's a barrier" and another youth said, "My mother can be very vindictive, and um, she has canceled my hormone blocker implant three times."

Self-Advocacy/Resistance

Despite often lacking support and acceptance from those around them, transgender youth were able to push against structures that were trying to constrict their identities and creating barriers to the care they needed. Self-Advocacy/Resistance was described as making one's self creative and powerful in the face of oppressive ideologies:

> "I feel like we're all creative but I think trans um, and gender nonconforming people have a special creativity around um, around their beings and like their personalities and um, the oppression and the suppression that is like forced upon us - I think like that creates, a special vibe."

Another participant describes a common experience of resisting rigid gender standards about masculinity and femininity, taught and enforced by their parent/guardians and society. This resistance occurs simply by being who they are:

> "I feel like, well, my existence just proves that none of that really works out, um, and so being a transgender person I feel like I -- I -- it allows me to look at structures, laws, policies and say you know it doesn't have to be that way. And knowing that I do have

the power to change it or influence it so I think that -- that comes with me being a transgender person."

Youth would also often self-advocate with their parent/guardian, resisting any indifference or rejection of their authentic gender. Youth discussed these experiences of knowing and expressing their gender identity from very young ages: "I've always questioned my gender identity since I was little and it wasn't really like questioning it, it was like I didn't really feel like I felt like I was what I was told I was supposed to be." When gender did not align with what was expected, the parent/guardian often critiqued this, and youth had to assert themselves even further. A common scenario was around pronoun use: "I would put my foot in the door sometimes like I mean - like she would say like 'she' and I'd be like 'him or he, Mom.'" And another was around hair and clothing:

"I think it was like my birthday when I turned, when I turned 18, my mom was like "How the hell are you wearing hair and then you have, you still have your, like, your stats all lined up and stuff?" and "You're like, you dress like, I don't get it" she was like. And I was like, because it's just how I want to dress today. She was like "So what are you a girl or you're not a man?" I was like "I'm a girl today if I wanted to be." She was like "Oh, okay, well that's fine."

Young people described finding their own resources and support, whether it was looking for information online, advocating for themselves, or taking hormones from acquaintances until they could get a prescription. As one person said,

"Um, so it was very different for me because it wasn't like oh mom and dad I want to get on hormones. It was like I had to look online for places that would help me out so that was different because I was very like self-sustaining."

When describing experiences seeking help in foster care, one person said,

> "It's an institution. I have resources available to me because I advocated for them. They weren't given to me, um, and the knowledge I have today is because of my advocacy and being articulate about the services that I need and that I needed them."

Some youth found access to hormones outside of a medical provider until turning 18 years, although this was not something they wanted to do:

> "Um, I've had, I've taken hor-, I have bought hormones from a lady before, like before, like, when I was like 17 ... I went and bought hormones from this lady and they lasted me like, I want to say like 6 months and then I ran out and I was like I don't want to go get hormones off the street."

Self-advocacy and resistance also came up when youth discussed their greater risk of facing ridicule, discrimination, violence, and even murder because they are transgender, especially for young transgender women of color participants. As one person said,

> "I know there's girls like me that go outside, and you know, there's stupid people outside that act dumb, and you know, a lot of girls that are losing their lives and stuff like that, so... I think that me hearing stuff and me seeing stuff, I'll always have my guard up."

Participants expressed outrage that they had to navigate these threats, especially when they faced such violence within their families or neighborhoods. As one person talks about a recent murder, they express both outrage and opposition, saying,

> "That's makes no absolute sense to see transwomen die for nothing, like a girl got shot by her father cause she's trans or cause he like, what?! [pause] A person my age, 17 or 18, just got killed. It's okay to want to be safe. [pause] At times, I get worried, like I tell

people, if I know the history about that neighborhood, I'm not walking up in there and damn sure not by myself because I refuse."

Having Hope/Resilience

The internal process of transgender youth emerging from these ongoing struggles culminated in the common experience and strategy of Having Hope/Resilience. Having hope was a common topic when discussing the multiple struggles and barriers. Participants had the general sense that, in the end, their own internal sense of themselves and hope for the future was the most powerful healing force that would propel them onwards through difficult times:

> "Mm, I think being resilient and in the sense of um, being oppressed for so long and my individuality being suppressed and I came to a point in my life where um, as I mentioned I took control. And um, I feel without that I – I wouldn't have been stable, I probably would not be here present today. Um, so I think that being articulate and resilient in the sense of everything that I enjoyed um, and always having a sense of hope. I've always had a sense of hope even in the darkest and loneliest hour I've always had a sense of hope and yeah I always goes back to hope."

And when asked to define what hope means, the participant said: "the first thing that popped in my mind was the future. And I think hope for me means my future of living authentically in my full self and my full truth and happy."

As youth face of multiple challenges both in the interpersonal relationships with their parents/guardians and within larger society, they also described multiple strategies for building this resilience. For youth who did not have parent/guardian support or acceptance, they often found support from outside adults, whether teachers, mental health providers, or health care providers. These adults helped them through difficult times. As one participant said, "One of

the teachers, she was like you just need to be you and don't care about what nobody else say, and I just kept that throughout the whole school year and I never got in trouble." Still other participants found this support through mental health providers, who often helped them to navigate challenging relationships with parents/guardians at home: "well, she will do art therapy. That helped me and then we will literally talk about better choices that I could make regarding like how to come out to my mom and all this stuff." Others who experienced abuse at home found help from agencies that helped them access trans-friendly services:

> "I feared that my dad would do something to me and so I could never really access these resources by myself, I needed someone to pave the entire road for me and that's exactly what [Latino/a-focused LGBTQI Nonprofit] did for me. The advocate there called and ever since then I haven't had as much trouble doing things for myself."

Other participants discussed their chosen family, or gay family, describing individuals who are committed to filing the role of parents, providing support and nurturing throughout their adolescence. "I have a gay mother, then I have a grandma. So I have a, some, a really big support system." These people were an important source of support, even if they did not provide legal guardianship, they provided love and acceptance, allowing the young person to continue on and recover from periods of depression and low self-esteem.

Discussion

The narratives of transgender youth of color in this study described common experiences of asking for help to live authentically in their gender identity, and the many facets of the process related to receiving support from their parents/guardians. Transgender youth participants in this study are similar to other teens their age, moving through the various stages of adolescent identity development and navigating independence from their parents, while also having the

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unique experience of having to navigate and advocate with their parents/guardians for access to health care interventions that will drastically improve their psychological health and well-being. Worldwide standards of care emphasize the medical necessity of gender affirming interventions to alleviate gender stress and improve mental health (Ehrensaft, 2017; Rafferty & Committee on Psychosocial Aspects of Child Family Health, 2018; World Professional Association for Transgender Health, 2011), yet participants in our study were not always sure if support for these interventions would come consistently from their parents/guardians. The inconsistent nature of support described in our study resonates with other qualitative studies with transgender youth that described the changing nature of parent/guardian support (Weinhardt et al., 2019).

Transgender youth in our study experienced several aspects of parent/guardian support as crucial to their ability to access gender affirming interventions, namely parent/guardian consent for medical care and hormones. To our knowledge, this was the first description of the experiences of community-based transgender youth who were under 18 years or who just turned 18. A review of literature about parent/support for transgender youth found that most research was conducted with older adolescents or from clinical samples that recruited within gender-based clinics or online support groups, where parents/guardians were more likely to be involved (see Wesp et al., n.d., Ch 3). The narratives from this study describe the pivotal moment of one's 18th birthday, while also indicating that youth over age 18 may still need to contend with parent/guardian consent for use of health insurance. Another important finding was that several minor transgender youth who did *not* have parent/guardian consent to treatment were seeking hormones from friends or from the street. Future research can expand upon these findings, to understand further the needs of youth and their parents/guardians as they move through various stages of adolescence, including the pivotal moment of turning 18 years and becoming legal

adults while still very much connected to their parents/guardians and needing support as they continue to develop psychologically through young adulthood.

Informed by the IRTHJ framework, which theorizes that health inequities among transgender people are driven by intersecting structures of domination and oppressive ideologies that influence institutional systems and every day social processes, we sought to describe narratives from transgender youth of color about their experiences of parent/guardian support with a consideration of these structural factors. Understanding experiences of transgender youth within the larger structural context is important, and the experiences our participants shared about navigating the never ending cycle further illustrates the matrix of barriers and challenges they face in order to access health care. Previous research about parent/guardian support for transgender youth identified that structures of domination (in particular, the ideologies of racism, heteropatriarchy, and cisgenderism) influenced parent/guardian support for their children, as well as shaped the institutions and everyday social processes that both parents and youth must navigate (Wesp et al., n.d., Ch 3). Findings from this study further add to our understanding about how structures of domination work to create societal norms and a status quo of limited opportunities. Narratives describe how transgender youth of color resist and push back with the truth about themselves, despite facing ongoing cycles of stigma fueled by racism and transphobia. Transgender youth of color also describe a sense of empathy and patience regarding their parents, describing how they cope with waiting while parents/guardians struggle with adjusting their views on gender and coming to various levels of support, a process which has also been shaped by structures of domination that influence societal norms and standards about gender. Thus, our study reinforces the importance of naming structural level factors that shape antecedents (such as parent/guardian support) of improved health for transgender youth,

especially for transgender youth of color living at the intersection of ideologies that marginalize because of race, ethnicity, age, gender and nationality.

Describing experiences of resilience were not an aim of our research, but instead emerged as a theme describing what it was like to navigate the relationship with one's parent/guardian, as well as navigating larger societal intersecting oppressions. Resilience is a concept often studied in adolescent health disparities as a response to a stressor that helps an individual cope with the detrimental effects (Aburn, Gott, & Hoare, 2016). Resilience in psychology-based research among LGBT populations has been critiqued for lacking a structural analysis of the prevailing systems that create structures of power, and thus causes of the stress, in the first place (Chown & Malcoe, 2017). Two previous studies that were specifically exploring resilience among transgender people of color described similar experiences to the youth in our study around adultism (Singh, 2013) and cultivating hope for the future when navigating relationships with family of origin (Singh & McKleroy, 2011).

Finally, transgender youth of color described seeking help from health care professionals or non-profit organizations, especially when lacking support from parents/guardians, an important finding which illustrates the importance of expanding training and education of health care providers on culturally safe care for transgender youth of color. Although some youth described supportive encounters with health care providers, other transgender youth of color in our study described troubling experiences within the health care system. Social norms have influenced everyday systems, such as electronic medical records, which are often unable to capture accurate gender identities, pronouns, or preferred names for transgender people within our electronic medical records (Deutsch, Keatley, Sevelius, & Shade, 2014). Previous research has also identified a glaring lack of training for health care providers about gender diversity and

transgender people (Carabez et al., 2015), which fuels uncertainty within the provider-patient relationship and leads to stigmatizing interactions (Carabez, Eliason, & Martinson, 2016; Poteat, German, & Kerrigan, 2013). Understanding the ways that structural factors shape a complex and fluid process of parent/guardian support, as well as the everyday challenges transgender youth of color face, will be crucial to include in educational curricula for health professionals.

Limitations

Due to the nature of the study being a secondary analysis, we may have missed certain aspects of the parent/guardian relationship, because participants were not being asked about this relationship directly. Although this study generated valuable information about parent/guardian support for transgender youth of color, filling a gap in the literature, primary research with this population and with their parents/guardians would perhaps more accurately and comprehensively describe nuanced experiences of navigating the intersections of race and gender in the U.S. Additionally, the nature of qualitative secondary analysis makes member checking difficult. The intention was to review themes with the primary study's youth advisory board, however due to a loss of funding, the original youth advisory board had disbanded by the time of the current analysis, and thus we were unable to complete member checking of the themes. However, three of this study's authors (LJC, EP, GW) were primary team members and had significant involvement in the data collection process and with the youth advisors throughout the time the parent study was conducted. Additionally, the study's primary author (LMW) worked as a researcher and clinician with participants at one of the study sites. Our familiarization with the participants allowed for adequate depth of analysis and maintained trustworthiness of our findings.

Implications and Conclusion

Overall, the findings from this study illustrate several important ways that health care providers and researchers can improve our work with transgender youth of color and facilitate the help they are requesting. As the first study to describe the experiences of transgender youth of color under 18, these findings provide a stepping stone for future work towards understanding the relationship between unmet needs for gender affirmation, in the face of multiple barriers to accessing gender affirming interventions, building upon Sevelius' gender affirmation framework developed with adult populations (2013). Furthermore, these findings highlight the value of situated knowledge generated from centering voices of marginalized populations to highlight the matrix of oppression created from structures of domination influencing institutional systems and socio structural processes (Wesp et al., n.d., Ch 2). The complex nature of parent/guardian support described here calls for a reconsideration about how we measure parent/guardian support via quantitative surveys. Future research that is community-based and participatory, where transgender youth of color and other marginalized transgender youth, such as transgender youth with disabilities or those from under-resourced countries, would allow transgender youth to work together with researchers to advocate for interventions that would improve parent/guardian acceptance and support, as well as reduce other structural barriers.

Important policy implications include examining the legal age of consent for gender affirming hormones, currently set at age 18 for most of the United States, however this varies globally. These findings do illuminate the various confidentiality issues with United States insurance, whereby youth who are legally able to consent for their own care are unable to use their insurance without disclosing medical information to the policy holder (their parent/guardian). Health insurance landscapes in the U.S. are complex and ever-changing,

however exploring policy interventions that added a layer of privacy for services rendered could provide youth over 18 years with some levels of increased access to care.

Health care providers are in the position to expand our understanding about the importance of gender affirming interventions and then provide non-stigmatizing, evidence-based information to families. Multiple educational resources exist, including a recently-launched international campaign called Advancing Acceptance (www.advancingacceptance.org) provides education and support for parents/guardians and youth (Gender Spectrum, 2019). Additionally, the World Health Organization has removed any classification of gender non-conformity as a mental disorder in the latest version of the global manual of diagnoses (2018) and leads a global effort of destigmatization of transgender people (2016). Support from health care professionals was pivotal as participants navigated the sometimes changing and inconsistent support from their parent/guardians, thus these findings suggest the responsibility of health professionals to build our knowledge base in order to advocate for and support transgender youth. Nursing and other health professions will benefit from incorporating foundational and mandatory content about transgender health into their curricula and continuing education materials, especially to ensure culturally safe care for transgender youth of color.

In conclusion, the rich and complex findings of this study are a call to health care providers in clinical settings to improve their knowledge and support for both transgender youth and their parent/guardians, which will improve access and quality. As future research continues to elucidate the specific needs and interventions for this population, health care practitioners will be important advocates for transgender youth and key players in facilitating acceptance and support from parents/guardians, as well as leaders in policy changes that can improve access to care.

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CHAPTER 6: SYNTHESIS

Overview

The opening line of this dissertation was the following quote: "Stories are about human plights, personally experienced. Stories of those who experience human plights every day tend to get buried. The role of narrative inquiry then is to excavate those stories and use them as seeds for social justice" (Kim, 2016, p. 238). This study aimed at centering the stories of transgender youth of color about their experiences navigating parent/guardian support within a larger context of societal oppressions in the United States – stories that tend to get buried because of social marginalization. Due to ongoing disparities in health and the importance of parent/guardian support for transgender youth, this study sought to answer the following specific questions: 1) How do transgender youth of color age 16-18 (inclusive) in the United States experience support from their parents/guardians? 2) How does parent/guardian support relate to the health and well-being of transgender youth of color? and 3) How do transgender youth experience parent/guardian support within the context of navigating structural inequalities and intersecting marginalization? The previous chapters demonstrate a critical approach to qualitative inquiry that excavates the stories of transgender youth of color, bringing their situated knowledge about parent/guardian support and intersecting oppressions to the forefront. In this final chapter, I will begin with an overview of the important contributions from each chapter, share some of my own story about the process of conducting this qualitative narrative inquiry, and outline the ways we can further utilize the work presented here as seeds for social justice in our nursing research, practice, and health care policy.

As introduced in Chapter 1, critical theory provided the broad philosophical underpinning for the study, which sought to maintain a structurally competent focus throughout (Metzl &

Hansen, 2014). A critical approach to research seeks to move beyond the surface and generate

emancipatory knowledge that acknowledges how every day experiences are shaped by structures

of privilege and power (Chinn, 2013). The critical framing of the study was expanded further in

Chapter 2, with a manuscript introducing a theory driven conceptual framework for

Intersectional Research for Trans Health Justice (IRTHJ). The IRTHJ framework theorizes that

downstream factors, such as parent/guardian support for transgender youth, are inevitably

influenced by a number of upstream factors. These upstream factors are identified in the IRTHJ

framework as structures of domination, institutional systems, and social-structural processes that

interlock to shape and constrain opportunities for transgender people. Examples were provided

about how to think about health inequities research using an intersectional and structural

approach, via action steps that include: naming intersecting power relations, disrupting the status

quo, and centering embodied knowledge. The IRTHJ conceptual framework and IRTHJ action

steps guided the remainder of this study, particularly the review of literature and data

analysis/presentation of findings.

Ch. 3 presented a systematic review of literature targeted for submission to a family

nursing journal. The systematic review sought to examine the current research about

parent/guardian support for transgender youth using a structurally competent approach. Studies

meeting inclusion criteria were examined to answer the following questions: How is

"parent/guardian support" currently defined in the literature and what do we know about the

relationship between parent/guardian support and the health and well-being of transgender

youth? To what extent do studies about parent/guardian support for transgender youth include

discussions of structural level factors (as named in the IRTHJ framework) including historical

and structural systems of domination, institutional systems, or social processes? The review of

literature led to a working definition of PG support, which was an affirmation of gender identity, protecting the child, and feelings of closeness and acceptance. Not having support was conceptualized in the literature as rejection. Parent/guardian support for transgender youth was associated with improved mental health outcomes and decreased risk for HIV and victimization. The review also found that PG support was influenced by structural factors, specifically the ideologies of cisgenderism, heteropatriarchy, and racism that shape ideologies about gender and create layers of stigma that both parents/guardians and transgender youth have to navigate. The discussion section of this manuscript suggests several important gaps and areas of focus for future research, as well as nursing practice that uses a culturally safe approach to caring for transgender youth and their parents/guardians. Several gaps identified in this review of literature included a lack of research with transgender youth of color under age 18 and the need for more information about the different aspects of support, such as the instrumental support needed from parents/guardians to provide consent and insurance access to gender affirming care. The qualitative study findings shared in Chapter 5 (discussed below) began to fill several of these gaps.

Since secondary qualitative data was used for this research, Chapter 4 presented a qualitative research methods manuscript outlining a three-step iterative approach to conducting secondary qualitative analysis (QSA) research, an important yet underutilized process that allows for re-use of qualitative data to answer different research questions than what were originally asked. The re-use of qualitative data in this study provided a case exemplar that illustrated each of the three QSA steps: describing the QSA project, conducting an epistemological assessment, and conducting an ethical assessment. Overall, this chapter demonstrated that QSA offers a sound study design that ensures trustworthiness of qualitative findings. The experience of

conducting this study as a secondary analysis provided insights into the ways that nurses who have first-hand clinical experience with marginalized populations are equipped to handle any potential pitfalls of secondary analysis, such as concerns about confidentiality or context that may occur if the researcher was not familiar with the population from conducting the original interviews. This chapter concluded that nurse researchers are in an important position to further develop and utilize the secondary analysis approach in qualitative research and expand the use of already collected data, an approach that is both time-efficient and cost-effective.

Finally, Chapter 5 provided a rich and complex description of the lives of transgender youth of color (n=24), providing answers to the study questions about how youth age 16, 17 and 18 experience support from their parents/guardians and how it relates to their health and well-being, within the context of structural inequalities and intersecting oppression. Participant narratives about navigating parent/guardian support described a never ending cycle of structural barriers and a need for help from their parents/guardians, and also from health professionals who care for them. Transgender youth of color in this study demonstrated various resilience processes as they navigated lack of support, stigma, and other barriers to care. They also described fierce self-advocacy that served as a way to resist oppression, help them get connected to the care they needed, and live authentically. Findings also suggested that youth experienced PG support inconsistently, particularly the instrumental support in the way of consent to medically necessary gender affirming interventions. A young person's 18th birthday was a pivotal moment, but did not always mean access to hormones was guaranteed nor that health care providers were supportive. This chapter also demonstrated the naming of structural level factors that shape the larger context for transgender youth of color, as illustrated through narratives describing discrimination fueled by a never ending cycle of ageism, racism, and transphobia.

Reflection and Discussion

Narrative inquiry researchers are encouraged to "stay attentive to experience with no clear outcome beyond a deeper understanding of experience. It is in this relational deep attending to experience that we see hope for personal, social, cultural, and institutional change" (Clandinin et al., 2015, p. 25). As I remain attentive to the experiences of the participants in this study, I also reflect on my own experience as both a researcher and nurse practitioner. I realize that my clinical work has essentially involved a collecting of and re-telling of stories of the hundreds of transgender youth I've worked with over the years, and the hundreds of health care providers I have educated about transgender health care. My own narratives about my work experiences have shaped my relational approach to the experiences of the participants in this study. Indeed, the original inspiration for this research comes from my own passion for improving access to care for transgender youth of color, who often feel like the hardest group to reach in the clinical setting, due to multiple barriers that many participants so astutely describe in Chapter 5. One story I remember vividly was when I sat at a health fair table, where we were promoting the health services of our LGBT youth program, and a young homeless trans woman of color came up to ask if she could get an appointment for hormones. She told me right away that she was under 18 and had been turned away at other places because all of the other clinics told her she would need a parent to consent. This was the same policy at our clinic, and I felt completely helpless as I told her we required a parent to consent. She walked away frustrated. I often wonder what happened to this young woman. Indeed she may have a story that remains untold in the narratives here.

Despite the dent this research had made in highlighting experiences of our participants, we still need research that describes the experiences of the parents/guardians in communities of

color, the experiences of immigrant and refugee transgender youth, and the stories of people living in rural settings. Research needs to expand on the global scale, exploring structural factors across various cultures and societies that have very different systems of care. We also need stories from health care providers, like myself, who must navigate a health care system steeped with oppressive ideologies about gender and race, and fueled by for-profit capitalism. These groups all have important perspectives that remain missing pieces of this experiential puzzle. While this project remained steadfast in presenting trustworthy findings that accurately portray the stories and narratives of the participants, we are left with much more work to be done.

What follows are specific implications of this study for nursing research, clinical practice, and health care policy. As Riessman says, "a good narrative analysis prompts the reader to think beyond the surface of the text, and there is a move toward a broader commentary" (2008, p. 13). Attending to these implications will begin to do just that.

Implications for Nursing Research

Research centering experiences of marginalized populations, such as transgender youth of color in this study, disrupts systems of power and domination by centering voices that have been long silenced. Findings from Ch 5 provide a more comprehensive description of the experiences of transgender youth of color, and future research can continue to utilize community-based participatory methods in order to delve further into an understanding about how to work with youth and parents/guardians to disrupt structural processes that hinder support. Nursing research with marginalized populations must seek to decolonize our research methodologies (McGibbon, Mulaudzi, Didham, Barton, & Sochan, 2014) and challenge historical structures of domination that shape academic research and health care systems (Varcoe, Browne, & Center Laurie, 2014). Participatory action research principles would

provide an opportunity for the active participation of researchers and participants in the co-creation of knowledge that leads to collective social change (McIntyre, 2008). Nurse researchers can continue to explore utilization of the IRTHJ framework to inform study designs that name intersecting power relations, disrupt the status quo, and center embodied knowledge (Wesp et al., Ch 2). Specific research projects might include participatory action research with parents/guardians, or community based mentoring programs between older and younger transgender people.

Another more general contribution to future nursing research is the comprehensive approach outlined in Chapter 4 for conducting a secondary qualitative analysis. The experience of re-using qualitative data for this study was both cost and time efficient. These are important considerations for work with marginalized populations or early career researchers that may experience a lack of funding streams. Furthermore, nursing researchers often come to their research questions from their clinical experiences, as was the case for this project. The case exemplar this study provided suggests that nursing researchers bring personal and historical experiences to our scholarly endeavors that can enhance trustworthiness of our findings, especially for qualitative secondary analysis.

Implications for Nursing Practice

Nurses report feeling underprepared to care for transgender populations (Carabez, Eliason, & Martinson, 2016) and need to embrace gender diversity in order to address the lack of safe and supportive nursing care for transgender populations (Kellett & Fitton, 2017). Some nurses report feeling that transgender youth are a specialty population, and would rather refer transgender youth to those who specialize in transgender health issues (Carabez et al., 2015). However, as Tusaie states in an editorial for *Archives of Psychiatric Nursing*: "We must reflect

upon our own beliefs, be willing to listen to stories, be open to lived experiences that may be different from our own, and embrace gender diversity" (2015, p. 256).

Transgender youth in this study expressed a need for help to live authentically and affirmed in their gender. These narratives are a call to action for *all* nurses. Nursing professional ethics call upon us as advocates, especially for socially marginalized populations (American Nurses Association Center for Ethics and Human Rights, 2016). Transgender youth are seeking care throughout our health care system, as rough estimates suggest 1 out of every 137 youth under age 18 in the U.S. identify as transgender (Herman, Flores, Brown, Wilson, & Conron, 2017). Transgender youth in this study described a need for help from their parents/guardians, yet they also turned to health care professionals as their advocates and as nurses we can be leading the way by translating the findings from this research, about how to help and advocate for transgender youth, into action.

Translating critically oriented knowledge to practice can be filled with complexities, ambiguities and tensions (Browne et al., 2009; Reimer-Kirkham et al., 2009). The primary way that nurses can translate these findings to practice advocate is to adopt a framework of cultural safety and inclusivity in our educational programs and clinical practice (Browne et al., 2009; Kellett & Fitton, 2017; Mukerjee, 2016). Cultural safety in health care is based on a foundation of self-reflexivity and an awareness of the ways that structures and ideologies permeating health care institutions create unsafe spaces for marginalized populations (Mkandawire-Valhmu, 2018; Ramsden, 1990). Nurses can advocate for changes within the health care system, such as creating policies that support use of patients' preferred names and pronouns, facilities that are inclusive of non-binary people, and patient-centered approaches to medical and mental health care. Educational curricula and continuing education for nurses can include information about

the ideologies of cisgenderism, binary gender norms, and the pathologization of gender identity. These steps must begin with nurses learning how to recognize oppressive ideologies and address internal bias about gender, building an understanding about how that creates uncertainty and thus stigmatizing interactions with transgender patients (Poteat, German, & Kerrigan, 2013). Only through ongoing critical self-examination can we work towards a disruption of the status quo, and ensure transgender youth of the future will no longer feel simply lucky to have support in the health care setting, but can instead rest assured it is guaranteed.

Implications for Health Policy

This research has several important policy implications, the first of which is a greater understanding about the implications of having health insurance coverage for transgender youth on a parent/guardian's plan, even after reaching the age of majority for medical consent. Youth in this study identified this as a barrier when the parent/guardian was not supportive of their need for gender affirming interventions. This lack of support leaves some young people, who are legal adults, without the capacity to use their health insurance for medically necessary procedures due to potential backlash from their parent/guardian. Further research is needed to understand these implications more fully. For example, an exploration into potential policy changes about confidentiality protections for youth on their parents insurance that address how health services rendered must be reported to the insurance policy holder. The issue of access to insurance will be an important area of policy focus as we seek to increase access to medically necessary care for this population to improve health outcomes.

The sociopolitical climate for transgender youth in the United States has also shifted dramatically since the conceptualization of this study and data collection, and continues to shift even now (Flaskerud & Lesser, 2018). Increased awareness about transgender populations has

led to an increase in support, and unfortunately, at times this attention has decreased protections against discrimination in health care and schools (Dowshen et al., 2016). In addition to this ever-changing climate, multiple federal legal cases continue to complicate health insurance coverage for gender affirming interventions overall, with significant variation by state (Baker, 2017). As of the writing of this chapter, ongoing litigation may even impact the overall health care insurance marketplace if the Affordable Care Act is repealed, which will have unknown effects on the entire insurance system for all people in the U.S. Tackling this policy issue will be complex, but nevertheless the considerations raised from our findings here point to important areas of concern for transgender youth that must not be overlooked.

Another policy implication will be raising awareness of the experiences of transgender minor youth's inability to consent for gender affirming medical interventions, which youth in this study have identified as a major area of concern and cause of emotional distress, due to untreated gender dysphoria. Turning 18 years was a milestone for participants in this study because it opened the door to an ability to consent for their own medical treatment, which some youth in our study had been denied up to that point. With regards to other medical interventions, such as reproductive health care and family planning medications, youth under 18 years are considered emancipated, although the stipulations for this vary significantly by state (Lane & Kohlenberg, 2012). At this time, the United States is lacking jurisprudence or legislation to protect the minor transgender adolescent's ability to consent for gender affirming interventions (Romero & Reingold, 2013), and previous arguments have been made that restricting transgender youths' ability to consent limits their autonomy and some youth have successfully invoked the mature minor doctrine in order to access care (Carroll, 2009). Little has been published about the complex decisions that clinicians face when working with parents/guardians

who are not in agreement about a treatment plan for their child, although anecdotally this is a significant area of concern for pediatric and adolescent transgender health providers (Tishelman et al., 2015). As the final edits to this chapter were being made, a prominent bioethics journal published an issue focused entirely on the ethical arguments about parent/guardian consent for transgender youth minors accessing gender affirming hormone care (American Journal of Bioethics, 2019). The primary article argued that it is an ethical responsibility of the state to ensure access to medically necessary treatment if it is being denied by a parent or legal guardian (Priest, 2019). Other commentaries suggested this should be bolstered by state funding for the support and counseling of parents of trans youth, to promote parent acceptance and emotional support (Ashley, 2019). The timeliness of the research presented here and its implications for policy are ongoing, as debates around these issues continue. The stories of transgender youth from this study will bring an important perspective to the table, and future research (as discussed above) is needed even more imminently to address aspects of how policy changes stemming from these debates might impact the health and well-being of this population.

Conclusion

As one of the participants stated, "I've always had a sense of hope - even in the darkest loneliest hour I've always had a sense of hope." This dissertation study has provided important contributions to the field of transgender health research and qualitative nursing research. Many questions are yet unanswered and structural barriers remain, amidst a quickly changing social and political landscape. Transgender youth of color continue to struggle every day with navigating access to care, victimization, and at times even rejection from their parents/guardians. Yet they have demonstrated through their stories here that they will continue to resist and push forward, with hope for their futures, as they seek to live with dignity and authenticity. As nurses

and scholars, we can hear these stories and use them to advocate for a better future where gender diversity is celebrated and all youth are supported in their ability to reach their fullest potential. Advocacy towards transgender health justice is also a process, and will continue to build upon the foundations set forth here, to make changes in the clinical setting, in policy work, and in future research.

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Appendix A. Systematic Literature Review Search Terms According to Database

PUBMED:
 (((((((((((("transgender persons"[MeSH Terms] OR ("transgender"[All Fields] AND "persons"[All Fields]) OR "transgender persons"[All Fields] OR "transgender"[All Fields]) AND ("adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "youth"[All Fields])) AND (("family"[MeSH Terms] OR "family"[All Fields]) AND support[All Fields])) OR (((("transgender persons"[MeSH Terms] OR ("transgender"[All Fields] AND "persons"[All Fields]) OR "transgender persons"[All Fields] OR "transgender"[All Fields]) AND ("adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "youth"[All Fields])) AND (("family"[MeSH Terms] OR "family"[All Fields]) AND acceptance[All Fields]))) OR (((("transgender persons"[MeSH Terms] OR ("transgender"[All Fields] AND "persons"[All Fields]) OR "transgender persons"[All Fields] OR "transgender"[All Fields]) AND ("adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "youth"[All Fields])) AND (("family"[MeSH Terms] OR "family"[All Fields]) AND ("rejection (psychology)"[MeSH Terms] OR ("rejection"[All Fields] AND "(psychology)"[All Fields]) OR "rejection (psychology)"[All Fields] OR "rejection"[All Fields])))) OR (((("transgender persons"[MeSH Terms] OR ("transgender"[All Fields] AND "persons"[All Fields]) OR "transgender persons"[All Fields] OR "transgender"[All Fields]) AND ("adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "youth"[All Fields])) AND (("caregivers"[MeSH Terms] OR "caregivers"[All Fields] OR "caregiver"[All Fields]) AND support[All Fields]))) OR (((("transgender persons"[MeSH Terms] OR ("transgender"[All Fields] AND "persons"[All Fields]) OR "transgender persons"[All Fields] OR "transgender"[All Fields]) AND ("adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "youth"[All Fields])) AND (("caregivers"[MeSH Terms] OR "caregivers"[All Fields] OR "caregiver"[All Fields]) AND ("rejection (psychology)"[MeSH Terms] OR ("rejection"[All Fields] AND "(psychology)"[All Fields]) OR "rejection (psychology)"[All Fields] OR "rejection"[All Fields])))) OR (((("transgender persons"[MeSH Terms] OR ("transgender"[All Fields] AND "persons"[All Fields]) OR "transgender persons"[All Fields] OR "transgender"[All Fields]) AND ("adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "youth"[All Fields])) AND (("caregivers"[MeSH Terms] OR "caregivers"[All Fields] OR "caregiver"[All Fields]) AND acceptance[All Fields]))) OR (((("transgender persons"[MeSH Terms] OR ("transgender"[All Fields] AND "persons"[All Fields]) OR "transgender persons"[All Fields] OR "transgender"[All Fields]) AND ("adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "youth"[All Fields])) AND (("parents"[MeSH Terms] OR "parents"[All Fields] OR "parental"[All Fields]) AND ("rejection (psychology)"[MeSH Terms] OR ("rejection"[All Fields] AND "(psychology)"[All Fields]) OR "rejection (psychology)"[All Fields] OR "rejection"[All Fields])))) OR (((("transgender persons"[MeSH Terms] OR ("transgender"[All Fields] AND "persons"[All Fields]) OR "transgender persons"[All Fields] OR "transgender"[All Fields]) AND ("adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "youth"[All Fields])) AND (("parents"[MeSH Terms] OR "parents"[All Fields] OR "parental"[All Fields]) AND acceptance[All Fields]))) OR (((("transgender persons"[MeSH Terms] OR ("transgender"[All Fields] AND "persons"[All Fields]) OR "transgender persons"[All Fields] OR "transgender"[All Fields]) AND ("adolescent"[MeSH Terms] OR "adolescent"[All Fields] OR "youth"[All Fields])) AND (("parents"[MeSH Terms] OR "parents"[All Fields] OR "parental"[All Fields]) AND support[All Fields]

CINAHL and Medline:
((MH "Transgender Persons") OR (MH "Transsexuals") OR (MH "Transvestites") OR (MH "Gender Dysphoria") OR TI (Transgender OR Transgendered OR "Trans men" OR Transmen OR transman OR"trans man" OR"trans male" OR transmale OR "trans masculine" OR transexual OR Intersex* OR Transsexual OR transvest* OR "Sex Reassignment" OR "Gender Minority" OR "Gender Minorities" OR Transsexualisms OR "Gender Reassignment" OR "Sex Reassignment" OR "Sex Change" OR "Gender Change" OR "Trans women" OR Transwomen OR Transwoman OR "Trans woman" OR "Trans female" OR Transfemale OR "Trans feminine" OR "Trans person" OR "Trans people" OR Transsexualism OR "Gender dysphoria" OR "gender dysphoric" OR "gender incongruence" OR "gender incongruent" OR "gender non-conforming" OR "gender affirming" OR "gender variant" OR "gender nonconforming") OR AB(Transgender OR Transgendered OR "Trans men" OR Transmen OR transman OR"trans man" OR"trans male" OR transmale OR "trans masculine" OR transexual OR Intersex* OR Transsexual OR transvest* OR "Sex Reassignment" OR "Gender Minority" OR "Gender Minorities" OR Transsexualisms OR "Gender Reassignment" OR "Sex Reassignment" OR "Sex Change" OR "Gender Change" OR "Trans women" OR Transwomen OR Transwoman OR "Trans woman" OR "Trans female" OR Transfemale OR "Trans feminine" OR "Trans person" OR "Trans people" OR Transsexualism OR "Gender dysphoria" OR "gender dysphoric" OR "gender incongruence" OR "gender incongruent" OR "gender non-conforming" OR "gender affirming" OR "gender variant" OR "gender nonconforming")) AND ((MH "Child+") OR (MH "Adolescence+") OR (MH "Young Adult") OR (MH "Minors (Legal)")OR TI(child OR children OR youth OR adolescence OR adolescent OR teen OR teenager OR teens) OR AB(child OR children OR youth OR adolescence OR adolescent OR teen OR teenager OR teens)) AND ("family" OR "caregiver" OR "parent") AND ("support" OR "rejection" OR "acceptance")

PsycInfo:
Transgender AND youth AND family OR caregiver AND acceptance
Transgender AND youth AND family OR caregiver AND rejection
Transgender AND youth AND family OR caregiver AND support

Appendix B. PRISMA Diagram of Systematic Literature Search
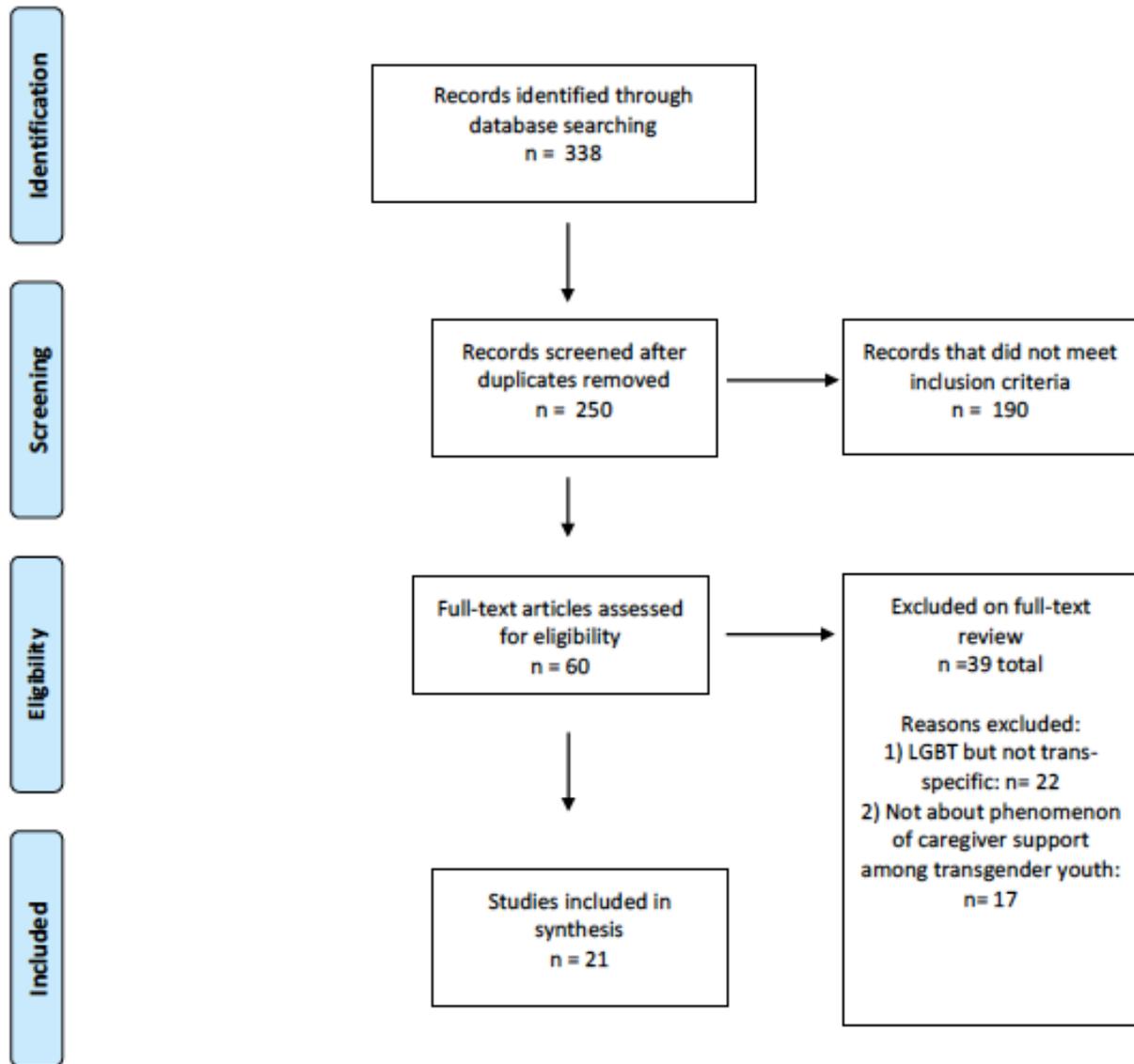
(Diagram adapted from Moher, Liberati, Tetzlaff, & Altman, 2009)

Author/Year	Aims	Design	Sample/ Demographics	How Support Measured/ Defined	How Parent/ Guardian Defined	Findings & Structural Factors (SF) related to PG Support
Birnkrant & Przeworski, 2017	Describe disclosure and communication processes within families of transgender youth	Online; Mixed methods	n= 56 parents connected to support groups or online forums in U.S. 92.8% White; no income data available	Measures: CRPBI-30 acceptance/rejection subscale (parent version) Defined as acceptance, giving care and attention, showing love, discussing identity, doing advocacy	"Parent"	Parental advocacy was associated with increased outside support (school and extended family) SF: Stigma within educational system
Clark et al., 2014	To describe health and well-being of transgender high school students in New Zealand	Quantitative, descriptive	National, cross-sectional, randomized, population-based sample of New Zealand high school students n= 96 transgender (from larger sample of n=8166 youth) 60.4% under age 15 39.6 over age 16 49.2% New Zealand European 19.6% Maori 13.1% Pacific 12% Asian 6% Other	Measure: "How much do you feel your mum/dad (or someone who acts as your mum/dad) cares about you?" Defined as whether youth perceived being cared for by parent	"Parent – Mum/Dad or Someone who acts as Mum/Dad"	Transgender students were significantly less likely to perceive that they had a parent who cared about them OR= .3; (95% CI, .2-.4) SF: None

Author/Year	Aims	Design	Sample/ Demographics	How Support Measured/ Defined	How Parent/ Guardian Defined	Findings & Structural Factors (SF) related to PG Support
Gray, Sweeney, Randazzo, Levitt, 2016	Describe the experience of parenting a gender-variant or transgender child	Qualitative grounded theory	n= 11 parents connected to gender affirming clinic in U.S. 100% White; avg income >$65,000	Measures: NA Defined as support and acceptance, creating long-term safety and happiness for child, through rescuing and/or advocacy	"Parent – biologic or adoptive"	Social context is interwoven with how parents support youth, as well as how parents cope with social intolerance and stigma SF: Social structural process and stigma related to gender
Grossman & D'Augelli, 2007	Describe correlates of life-threatening behaviors among transgender youth	Quantitative, descriptive	n=55 transgender youth age 15 – 21 in U.S. 75% White, 13% Black/African American, 7% more than one race, 4% American Indian, 1% Asian; no income data available	Measures: Child and Adolescent Psychological Abuse Measure (questions about abuse asked in relation to gender expression) Defined as rejection, lack of support in form of physical and/or verbal abuse	"Parent"	50% of participants had thought seriously of suicide; 25% had attempted suicide; youth who attempted suicide experienced significantly more verbal and physical abuse from PG SF: None
Hidalgo, Chen, Garafalo, Forbes, 2017	To test a measurement tool for perceived parental support among gender expansive youth	Quantitative factor analysis	N=341 transgender youth age 12-24 (mean 15.6 years) 65.7% White 4.4% Black/African American 11% Latinx 3% Asian/Pacific Islander 10% Mixed race/other	Measure: 17 items developed through two content experts Defined based on ideas of general parental support and nonaffirmation of gender identity	"Parent"	Final 14-item scale measures two constructs: perceived parental nonaffirmation of gender expansiveness; perceived parental acceptance of gender expansiveness SF: None

Author/Year	Aims	Design	Sample/ Demographics	How Support Measured/ Defined	How Parent/ Guardian Defined	Findings & Structural Factors (SF) related to PG Support
Katz-Wise et al., 2017	Explore parent and transgender youth perceptions of the future, to inform counseling interventions	Qualitative grounded theory	n= 16 family units in U.S. (16 transgender youth age 7-18 & 29 caregivers); 80% White, 20% Multiracial/other; avg income >$60,000	Measures: NA Defined as acceptance, being a good caregiver, wanting to protect child, give child skills, prepare them for future, provide support	"Caregiver" - defined as mother, father, or grandmother	Social factors impacted all constructs of conceptual model; Acceptance/Support was directly associated with participants' mental health/emotions and relationships SF: Educational institutions, public facilities, religious institutions; Socio-structural processes including gender norms
Koken, Bimbi, Parsons, 2009	Explore transwomen's experiences with parents regarding transgender identity (retrospective)	Qualitative thematic analysis using Parental Acceptance Rejection (PAR) Theory (Rohner, 2004)	n=20 transgender women of color in U.S.; age 18-55 50% Latina 50% African American	Measures: NA Defined as acceptance and rejection (from PAR theory): warmth-affection, hostility-aggression, indifference-neglect, undifferentiated rejection	"Any significant caregiver who bears substantial responsibility for raising children"	Rejection and indifference impacted mental health, self-esteem, housing, poverty; Rejection and acceptance occur at same time and may improve over time; Relationships often maintained despite ongoing rejection SF: None

Author/Year	Aims	Design	Sample/ Demographics	How Support Measured/ Defined	How Parent/ Guardian Defined	Findings & Structural Factors (SF) related to PG Support
Kubicek et al., 2013	Explore how house/ball scene parents can support HIV-prevention intervention.	Community-engaged project; Qualitative ethnography	n= 26 house parents in U.S. 90% African American/Black 10% Latino/a	Measures: NA Defined as creating a safe environment, creates a structure to provide family love, support, acceptance, validation, and recognition	"House parents"	Youth who engage with house/ball scene were rejected by family of origin/society due to racism and homophobia; family is broadly defined SF: Racism and homophobia
Le, Arayasirikul, Yea-Hung, Jin, Wilson, 2016	Assess relationship between parental primary social support and parental acceptance.	Secondary analysis; Quantitative	n=301 transgender female youth of color in U.S.; 22.6% age 16-19 77.4% age 20-24 36.5% White 21.9% Latina 13% African American 6.3% Asian 7% Other race 15.3% Mixed race	Measures: "From whom do you get the most social support?" – either parents or friends "Did any of your parents or caregivers talk about your trans identity or express affection when you first talked about it?" – yes/no (Cronbach's alpha 0.775) Defined as social support and as family acceptance from Ryan et al (2009)	"Parents"	Greater family acceptance associated with receiving primary social support from parents; Receiving primary social support from non-parents associated with greater psychological distress SF: none
Nemoto, Iwamoto, Perngparn, Areesantichai, Kamitani, & Sakata, 2012	To investigate substance use and HIV risk among kathoey sex workers in Bangkok, Thailand	Descriptive; Mixed method	n=25 kathoey (transgender women) sex workers in Thailand Age 18-31 (mean age 25)	Measures: NA Open-ended questions about family attitudes toward gender identity and transition, support from family members	"Mother/Father"	43.8% abused by father and/or brother, which was risk factor for less likely to use condoms with customers for anal sex;

Author/Year	Aims	Design	Sample/ Demographics	How Support Measured/ Defined	How Parent/ Guardian Defined	Findings & Structural Factors (SF) related to PG Support
						34% were first rejected but then later supported SF: Transphobia from fathers; Cultural beliefs about karma
Nemoto et al., 2016	To understand the sociocultural context of engaging in HIV risk behaviors.	Descriptive; Qualitative grounded theory	n=24 kathoey (transgender women) sex workers in Thailand age 18-43 (mean age 25.3)	Measures: NA Main theme was family support, which involved meaningful relationships as well as financial support (both receiving money from the parents and sending money to the family)	"Parents"	Many kathoey left home because of not being accepted; sex work enabled economic independence, which enabled re-connection with family SF: Transphobia, religion and belief systems
Platero (2013)	To explore how families in Spain talk, behave, and feel about transgender children and themselves	Descriptive; Qualitative	n= 12 parents of transgender children in Spain (9 mothers; 3 fathers with children ages 4-19 years)	Measures: NA Support was showing agency and action; Acceptance was next level of support; Some parents could not be supportive due to denial and fear of child's gender breaking with social norms	"Parents"	Parents often could not find support from professionals; One Roma parent (ethnic minority in Spain) experienced intersectional discrimination from professional b/c of ethnicity and child's gender SF: Racism and intersectional marginalization

Author/Year	Aims	Design	Sample/ Demographics	How Support Measured/ Defined	How Parent/ Guardian Defined	Findings & Structural Factors (SF) related to PG Support
Riley, Sitharthan, Clemson, Diamond, 2011	To explore parent's needs, in order to identify what is necessary for promotion of well-being of gender variant child.	Online: Qualitative content analysis of open ended questions	n=31 parents (87% Mothers, 10% Fathers, 3% Guardian)	Measure: NA Defined as meeting needs of the child, defined as promoting child's emotional and behavioral health.	"Parent/ Guardian"	In order to meet needs of child, PG had needs which were not being met; desired more guidance and societal support on how to raise transgender child SF: Cisgenderism and societal bias; Educational and political/legal institutions
Riley, Clemson, Sitharthan, Diamond, 2013	To understand difficulties and needs of transgender children and their parents (retrospective)	Online; Qualitative content analysis of open ended questions	n= 110 transgender adults 54% with income >$50,000 Race/ethnicity not reported.	Measures: NA Defined as loving and valuing child, being inclusive of gender identity, providing space to talk about feelings and express gender	"Parent"	Even with caregiver acceptance and support as children, bullying and societal pressures around gender expectations were a struggle. SF: Support from educational institution would have helped facilitate PG support; Heteropatriarchal ideologies fueled lack of PG support

Author/Year	Aims	Design	Sample/ Demographics	How Support Measured/ Defined	How Parent/ Guardian Defined	Findings & Structural Factors (SF) related to PG Support
Ryan, Russell, Huebner, Diaz, Sanchez, 2010	To assess family accepting behaviors and relationship to mental health, substance abuse, and sexual risk	Participatory research; Quantitative	n=22 transgender youth (from larger sample of n=245 total LGBT youth) 50% Latino/a 50% White	Measures: Ryan et al (2009) Family Acceptance Measure (Cronbach alpha = .88) Defined as gender affirmation and acceptance	"Family"	Low levels of family acceptance associated with depression, substance abuse, suicidal ideation/attempts; Transgender youth worse general health overall SF: None
Simons, Schrager, Clark, Belzer, Olson, 2013	Investigate relationship among parental support, quality of life, and depression	Descriptive; Quantitative cohort (baseline)	n=66 transgender youth age 12-24 51.5% White 28.8% Latino/a 10.6% African American/Black 9.1% Other	Measures: Multidimensional Scale of Perceived Social Support (family subscale, Cronbach alpha 0.93) Defined as getting emotional help and support from parent(s)	"Parent"	Parental support associated with higher life satisfaction, lower perceived burden, fewer depressive symptoms SF: None
Sterzing, Ratliff, Gartner, McGeough, Johnson, 2017	To understand poly-victimization among sexual and gender minority youth	Online; quantitative	n=307 transgender youth (overall sample n=1,177) age 14-19 62% White 6% Black 6% Latino/a 21% Multiracial 5% Other	Measures: Juvenile Victimization Questionnaire; 13-item microaggression/ affirmation scale Defined as microaffirmations vs microaggressions & maltreatment	"Family"	Higher levels of family-level microaggressions were associated with greater odds of polyvictimization; More than half of transgender participants reported child maltreatment SF: None

Author/Year	Aims	Design	Sample/ Demographics	How Support Measured/ Defined	How Parent/ Guardian Defined	Findings & Structural Factors (SF) related to PG Support
Watson, Veale, Saewyc (2016)	To explore relationship between disordered eating and risk or protective factors for transgender youth	Quantitative; Survey	N= 923 transgender Canadian youth Age 14-25 (35% under age 18) 75% White 10% Aboriginal (First Nations, Inuit, or Metis)	Measures: 7 questions about family connectedness (Cronbach alpha 0.92) Defined as being connected with family members	"Family"	For 14-18 year olds, family connectedness was associated with lowest likelihood of disordered eating. SF: None
Wilson, Yea-Hung, Arayasirikul, Raymond, McFarland, 2016	Examine discrimination, relationship to mental health, and protective factors	Quantitative	n=216 transgender female youth of color	Measures: MSPSS (may not have been parent); Ryan et al (2009) Family Acceptance Measure; Parental closeness (5-item) Defined as family acceptance and parental closeness	"Parent"	High parental closeness (30% of sample) associated with lower odds of psychological distress, PTSD, depression, and stress related to suicidal thoughts SF: None
Wilson, Iverson, Garofalo, Belzer, 2012	Explore perceived parental support and association with reported condom use among transgender female youth	Secondary analysis; Qualitative	n= 21 transgender female youth (from larger sample of n=43) age 16-24 19% Latina 33% Black/AA 14% Asian/PI 14% Multiracial 14% White 5% Native American	Measures: NA Defined as feeling supported (i.e. receive protection from discrimination, financial assistance) or rejected (estranged due to disapproval of gender)	"Biologic Parent"	Support was defined broadly by participants; youth could cope when parents provided limited social support but had a more difficult time when parents were outright rejecting. PG support may influence HIV risk behaviors. SF: None

Author/Year	Aims	Design	Sample/ Demographics	How Support Measured/ Defined	How Parent/ Guardian Defined	Findings & Structural Factors (SF) related to PG Support
Yadegarfard, Meinhold-Bergmann, Ho (2014)	To examine influence of family rejection, social isolation, and loneliness on negative health outcomes among Thai male-to-female adolescents compared to Thai cisgender male adolescents	Quantitative, descriptive	n=129 transgender women and n=131 cisgender men in Thailand age 15-25 (mean age 20)	Measure: Six items about family rejection due to gender identity such as physical punishment, financial deprivation, exclusion from family activities, ejection from house (Cronbach alpha .91) Defined as rejection by family	"Parent/ Caregiver"	Transgender women experience more family rejection compared with cisgender men SF: Heteropatriarchy as possible antecedent for rejection

ATN130
QUALITATIVE INTERVIEW GUIDE – YOUTH LIVING WITH HIV

Font Key

Section Titles	**SECTION TITLES**
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	*Note: things that aren't necessarily said out loud, but ought to be covered or considered.* *If: text that guides to skip certain questions or to read certain questions, depending upon participant answers.* *Instructions for interviewer are italicized.*
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.

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?

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- 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.

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.
   - 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.

ATN130

QUALITATIVE INTERVIEW GUIDE – YOUTH NOT LIVING WITH HIV OR YOUTH OF UNKNOWN HIV STATUS

Font Key

Section Titles	**SECTION TITLES**
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	*Note: things that aren't necessarily said out loud, but ought to be covered or considered.* *If: text that guides to skip certain questions or to read certain questions, depending upon participant answers.* *Instructions for interviewer are italicized.*
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 NOT LIVING WITH HIV OR OF UNKNOWN HIV STATUS

I. INTRODUCTION

This section is designed to:

Let the individual know why they are here and how the discussion will be structured.

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.

4. **Do you have any questions?**

If yes, answer participant's questions.

5. **Do you give me permission to audio-record today's interview?**

6. **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.

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

Please note name: _____   _

10. 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.

11. 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?

12. *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.

13. 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]: _____

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

15. 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:

16. 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.

4. **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?**

5. **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?

6. **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.

4. **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.

5. **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?

6. **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.

2. **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.

5. **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.

6. **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.

7. **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?

7. **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?**

8. **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 could help someone not get HIV or that could help someone living with HIV 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.

Today we are only going to be talking about your experiences with the first few stages of the continuum of care, that is, HIV prevention, testing, and receiving test results. We'll also ask you about the experiences of other transgender and gender nonconforming young people that you know.

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

Note: Answer participant's questions before beginning next subsection.

> 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.

3. **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.

4. **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.

6. **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?

7. **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?**

8. **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. **Have you ever been tested for HIV, or tried to get tested for HIV?**

Note: If Yes, continue with questions below. If No, skip to Q3.

2.   **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.
3. **What things make it harder or have 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 - makes it harder for you to get tested for HIV?
*   What, if anything, related to your interactions with different people makes it harder to get tested? (Could be family, friends, partners, providers, employers, etc.)
*   What things in the communities you're a part of make it harder to get tested?
*   What things about the places where HIV testing is offered make it harder to get tested?
*   What sort of big picture things like policies, politics, religion, or common beliefs make it harder to get tested?

4. *[If participant has been tested for HIV]* **What things helped you or made it easier to get tested?**
    [If participant has never been tested for HIV] **What things would make it easier for you 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?

5. **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?**

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

If participant has never been tested for HIV, skip to Section VII. Program Recommendations.

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.**
   - In what ways did these experiences make you feel supported? In what ways did they not?
   - Tell me about a time that you were tested for HIV but did not return to receive your results.
   - How comfortable were you with this service? What made you comfortable/uncomfortable?
   - How, if at all, did your gender identity affect these experiences?

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2. **What things made it more difficult to receive your results?**
   - Tell me about a time, if ever, that you got tested but did not receive your results.
   - What, if anything, has happened when receiving your results that makes you not want to get tested there again?

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?

5. **What things make it easier to receive your HIV test results?**
   a. What, if anything, has happened when received your results that makes you want to get tested there again?

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?

8. **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?**

9. **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?**

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 you think health care professionals (e.g., doctors, nurses, psychologists, social workers, or case managers) could develop to promote the health of transgender and gender nonconforming youth.

2. **What kinds of programs, activities, or events would you like to see for transgender and gender nonconforming youth, or specifically for young people with 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"?

6. **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"?

7. **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?

8. **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.

4. **Is there anything else that you would like to share with me?**

5. **Is there anything that you thought I should have asked about that I didn't?**

6. **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 X. 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 we 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:

7. **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.

8. **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

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:

9. **At one point in the interview, you mentioned doing some things that might be putting yourself at risk for HIV and other STIs (sexually transmitted infections), 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:

10. **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 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.

11. **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.

PREVENTION

HIV prevention services & programs
Risk reduction counseling
Info on how to properly use condoms
PrEP

HIV TESTING

Traditional or rapid test

Does not include receiving test results

HIV DIAGNOSIS

Learing your HIV status or receiving the results of an HIV test, whether positive, negative, or indeterminate.

LINKAGE TO CARE

ONE HIV-SPECIFIC VISIT
AFTER A POSITIVE TEST

ENGAGEMENT IN CARE

TWO HIV-SPECIFIC VISITS
AFTER A POSITIVE TEST

RETENTION IN CARE

ONE HIV-SPECIFIC VISIT EVERY 6 MONTHS

INITIATION OF ART

Being prescribed ART
&
taking it for the first time

ADHERENCE TO ART

Regularly taking your ART as prescribed.

VIRAL SUPPRESSION

Viral load less than
200 copies/ml for the most
recent value reported.

SOCIOECOLOGICAL MODEL

INDIVIDUAL

INTERPERSONAL
FAMILY
FRIENDS
SOCIAL NETWORK

COMMUNITY
SCHOOLS
COMMUNITY CENTERS

CULTURE/POLICY
RELIGION
CULTURE
LAWS

226
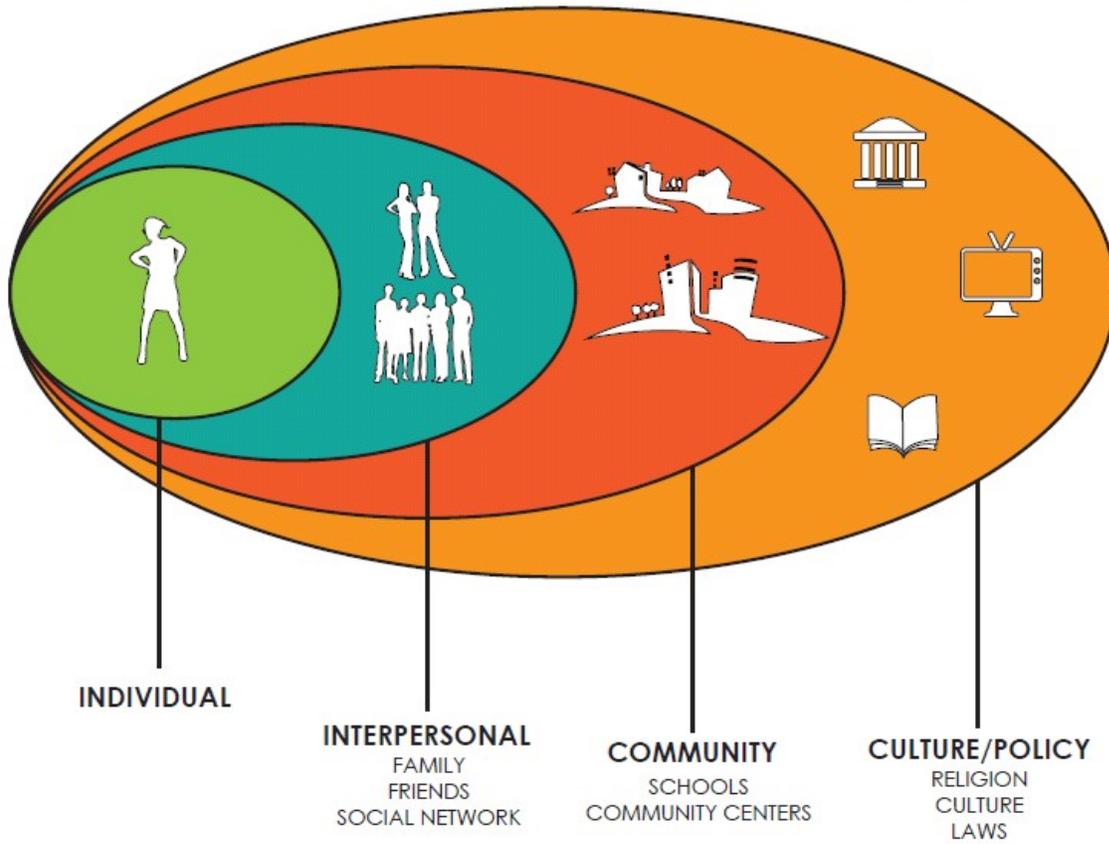
Linda Wesp
Curriculum Vitae
2019

EDUCATION
University of Milwaukee Wisconsin, College of Nursing
PhD in Nursing (expected graduation date May 2019)
Dissertation: It's A Process: A Qualitative Study About The Resistance And Resilience Of Transgender Youth Of Color Navigating Parent/Guardian Support And Societal Oppressions
Major Professor Dr. P. Kako

University of Illinois at Chicago, College of Nursing
Master's of Science in Nursing, 2006
Family Nurse Practitioner
Thesis: Impact of Exercise on HIV-Related Lipodystrophy

Loyola University Chicago Niehoff School of Nursing
Bachelor's of Science in Nursing, Summa Cum Laude, 2000
Minor in Theology

LICENSURE/BOARD CERTIFICATIONS
State of Wisconsin Advanced Practice Nurse Prescriber #6596-33
State of Wisconsin Registered Nurse #223928-30
Board Certified Family Nurse Practitioner – AANP #F0706072
Certified HIV Specialist – American Academy of HIV Medicine

PUBLICATIONS
PEER REVIEWED JOURNALS
Weinhardt, L. S., Xie, H., **Wesp, L. M.,** Murray, J. A., Apchemengich, I., Kioko, D., Weinhardt, C. B., Cook-Daniels, L. (2019). The Role of Family, Friend, and Significant Other Support in Well-Being Among Transgender and Gender Non-Binary Youth. *Journal of GLBT Family Studies.* doi:10.1080/1550428X.2018.1522606

Harper, G. W., Jadwin-Cakmak, L. A., Popoff, E., Campbell, B. A., Granderson, R., **Wesp, L. M.,** & Adolescent Medicine Trials Network for HIV/AIDS Interventions. (2019). Transgender and Other Gender-Diverse Youth's Progression Through the HIV Continuum of Care: Socioecological System Barriers. *AIDS Patient Care and STDS, 33*(1), pp. 32-43.

Wesp, L. M., Scheer, V., Ruiz, A., Walker, K., Weitzel, J., Shaw, L., . . . Mkandawire-Valhmu, L. (2018). An Emancipatory Approach to Cultural Competency: The Application of Critical Race, Postcolonial, and Intersectionality Theories. *Advances in Nursing Science.* 41(4), 316-326. doi:10.1097/ans.0000000000000230

Olukotun, O., Mkandawire-Vahlmu, L., Kreuziger, S., Dressel, A., **Wesp, L.M.,** Sima, C., Scheer, V., Weitzel, J., Washington, R., Hess, A., Kako, P., Stevens, P. (2017). Preparing culturally safe student nurses: An analysis of undergraduate cultural diversity course reflections. *Journal of Professional Nursing.* 34(4), 245-252. Doi: 10.1016/j.profnurs.2017.11.011.

Weinhardt, L.S., Stevens, P., Xie, H., **Wesp, L.M,** Chavez-Korell, S., John, S.A., Apchemengich, I., Kioko, D., Cochrane, K., Watjen, J., Lambrou, N. (2017). Transgender and gender non-conforming youth's public facilities use and psychological well-being: A mixed method Study. *Transgender Health*, 2(1), 140-150. doi: 10.1089/trgh.2017.0020.

Deutsch, M.B., Radix, A., **Wesp, L.M** (2017). Breast cancer screening, management, and a review of case study literature in transgender populations. *Seminars in Reproductive Medicine*, 35(5), 435-441. doi: 10.1055/s-0037-1606103.

Cicero, E. & **Wesp, L. M.** (2017). Supporting the Health and Well-Being of Transgender Students. The *Journal of School Nursing,* 33(2), 95-108. doi: 10.1177/1059840516689705.

Wesp, L. M., & Deutsch, M. B. (2016). Hormonal and surgical treatment options for transgender women and transfeminine spectrum persons. *Psychiatric Clinics of North America,* 40(1), 99-111. doi: 10.1016/j.psc.2016.10.006.

Wesp, L. M., Dimant, O., Cook, T. (2016). Excellence in the Care of Trans Patients: Expanding the Base of Gender-Affirming Healthcare Professionals. *HIV Specialist,* 8(2),11-15.

INVITED BOOK CHAPTERS
Wesp, L.M. and Demidont, A.C. (in press) "Transgender and Gender Non-Conforming Patients" in *Sexual and Reproductive Health - A Practical Guide to Primary Care Clinicians.* Springer Science & Business Media.

Kako, P.M. and **Wesp, L.M.** (in press) "Women and HIV" in *Women's Health: A Primary Care Clinical Guide*, 5th Ed. Pearson Education.

CLINICAL PRACTICE GUIDELINES
Wesp, L.M. Diabetes Mellitus. (2016) In M. B. Deutsch (Ed.), *Guidelines for the Primary and Gender-affirming Care of Transgender and Gender Nonbinary People (2nd ed.).* Center of Excellence for Transgender Health, Department of Family and Community Medicine, University of California San Francisco. Available at: http://www.transhealth.ucsf.edu/trans?page=guidelines-diabetes

Olson-Kennedy, J., Rosenthal, S., Hastings, J., & **Wesp, L.M.** (2016). Health considerations for gender non-conforming children and transgender adolescents. In M. B. Deutsch (Ed.), *Guidelines for the Primary and Gender-affirming Care of Transgender and Gender Nonbinary People (2nd ed.).* Center of Excellence for Transgender Health, Department of Family and Community Medicine, University of California San Francisco. Available at: http://www.transhealth.ucsf.edu/trans?page=guidelines-youth

Wesp, L.M. Ovarian and Endometrial Cancer Considerations in Transgender Men. (2016) In M. B. Deutsch (Ed.), *Guidelines for the Primary and Gender-affirming Care of Transgender and Gender*

Nonbinary People (2nd ed.). Center of Excellence for Transgender Health, Department of Family and Community Medicine, University of California San Francisco. Available at: http://www.transhealth.ucsf.edu/trans?page=guidelines-ovarian-cancer

Wesp, L.M. Prostate and Testicular Cancer Considerations in Transgender Women. (2016) In M. B. Deutsch (Ed.), *Guidelines for the Primary and Gender-affirming Care of Transgender and Gender Nonbinary People (2nd ed.).* Center of Excellence for Transgender Health, Department of Family and Community Medicine, University of California San Francisco. Available at: http://www.transhealth.ucsf.edu/trans?page=guidelines-prostate-testicular-cancer

Wesp, L.M. Transgender Patients and the Physical Examination. (2016) In M. B. Deutsch (Ed.), *Guidelines for the Primary and Gender-affirming Care of Transgender and Gender Nonbinary People (2nd ed.).* Center of Excellence for Transgender Health, Department of Family and Community Medicine, University of California San Francisco. Available at: http://www.transhealth.ucsf.edu/trans?page=guidelines-physical-examination

PAPERS PRESENTED AT CONFERENCES
ORAL PRESENTATION
Wesp, L.M., Mustich, I., Popoff, E., Jadwin-Cakmak, L., Sarin, A., Harper, G.W., Kako, P. (2018). Don't Dehumanize Me: Recommendations from Transgender Youth for Healthcare Providers. International Congress for Qualitative Inquiry, Champaign, IL.

Wesp, L.M., Mustich, I., Popoff, E., Jadwin-Cakmak, L., Sarin, A., Harper, G.W., Kako, P. (2017). Don't Dehumanize Me: Recommendations from Transgender Youth for Healthcare Providers. UWM College of Health Sciences Research Symposium, Milwaukee, WI.

Wesp, L.M., Popoff, E., Mustich, I., Sarin, A., Jadwin-Cakmak, L., Harper, G. (2017). Hearing the Voices of Transgender Youth: Recommendations for Programs and Providers. USPATH Scientific Conference, Los Angeles, CA.

Cicero, E., **Wesp, L.M.,** Eliason, M., DiSantis, J., Bolt, L., Goodrum, B. (2017). Nursing's Role in the Continuum of Transgender Health Care: A Panel Discussion with Nurse Leaders. USPATH Scientific Conference, Los Angeles, CA.

Deutsch, M., Radix, A., **Wesp, L.M.** (2017). Cancer Screening in Transgender People: An Evidence-Based Approach. USPATH Scientific Conference, Los Angeles, CA.

Wesp, L.M. (2016). Clinical Guidelines for Providing Primary Care for Transgender People. Midwest LGBT Health Summit. Chicago, IL.

Wesp, L.M. (2016). Update for Nurses on the Guidelines for Primary Care of Transgender and Gender Non-binary People. 4th Annual GLMA Nursing Summit. St. Louis, MO.

Deutsch, M.B., Radix, A., **Wesp, L.M.** (2016). Cancer Screening in Transgender People: Updates from UCSF Protocol Revisions. WPATH Biennial Symposium, Amsterdam, The Netherlands.

Deutsch, M.B., Radix, A., **Wesp L.M.** (2014). Mini-Symposia on Preventative Screening and Health Maintenance for Transgender Patients: A Rational and Evidence-Based Approach. WPATH Biennial Symposium, Bangkok, Thailand.

Ducheny, K, **Wesp, L.M.,** Emerick, M., Katona, L. (2014). Engaging and Retaining Transgender Patients in Primary/HIV Care Through An Informed Consent Hormone Protocol. WPATH Biennial Symposium, Bangkok, Thailand.

Ducheny, K., **Wesp, L.M.,** Emerick, M., Katona, L. (2014). Informed Consent Hormone Prescription in a Community Health Center – "THInC"– Reviewing the implementation of Howard Brown Health Center's Informed Consent Hormone Protocol and Transgender Community Response. WPATH Biennial Symposium, Bangkok, Thailand.

Wesp L.M. (2013). Caring for Transgender Youth. LGBT Health Workforce Conference, New York, NY.

POSTER PRESENTATION
Weinhardt, L.S., Xie, H., **Wesp, L.M.,** Murray, J.R., Apchemengich, I., Kioko, D., Weinhardt, C., Cook-Daniels, L. (2017) American Public Health Association Annual Meeting

Wesp, L.M., Mustich, I.A., Popoff, E., Sarin, A., Jadwin-Cakmak, L., Harper, G., Kako, P. (2018). Recommendations from Transgender Youth for Health Care Providers. Poster #166 at Midwest Nursing Research Society Annual Conference, Cleveland, OH.

Wesp, L.M., Mustich, I., Popoff, E., Jadwin-Cakmak, L., Sarin, A., Harper, G.W., Kako, P. (2017). Don't Dehumanize Me: Recommendations from Transgender Youth for Healthcare Providers. Michigan Primary Care Association LGBTQ Health Summit, Lansing, MI.

Wesp, L.M., Mustich, I., Popoff, E., Jadwin-Cakmak, L., Sarin, A., Harper, G.W., Kako, P. (2017). Don't Dehumanize Me: Recommendations from Transgender Youth for Healthcare Providers. Abstract #36. UWM College of Health Sciences Research Symposium, Milwaukee, WI.

Wesp, L.M., Malcoe, L.H., Loyd, J. (2016). Conceptualizing a Health Inequity: HIV Among African-American Transgender Women. Abstract #120. World Professional Association for Transgender Health Biennial Symposium. Amsterdam, The Netherlands.

Akchurin, OM, Fernandez, AD, **Wesp, L.M,** Schwartz, D, Pullman, JM, Kaskel, FJ, Skversky, AL. (2013). Syphilis in a Patient with Recently Acquired HIV-infection: A Reversible Cause of Nephrotic Syndrome. Abstract #1343 for poster presentation accepted at American Society of Nephrology Annual Meeting. Toronto, Canada.

FELLOWSHIPS
2017-18   Distinguished Dissertator Fellowship - UW Milwaukee ($16,500)
2016-17   Distinguished Graduate Student Fellowship – UW Milwaukee ($15,000)

AWARDS/HONORS

2017-18	University of Wisconsin-Milwaukee Chancellor's Award ($10,000)
2017	First Place Award for Student Podium Presentation at UWM College of Health Sciences Research Symposium ($350)
2017	Sigma Theta Tau Eta Nu Chapter Clinical Nursing Excellence Award
2017	Sigma Theta Tau Eta Nu Student Poster Award ($25)
2016-18	Jonas Nurse Leaders Scholar Award ($20,000)
2016-17	University of Wisconsin-Milwaukee Chancellor's Award ($8000)
2015-16	University of Wisconsin-Milwaukee Chancellor's Award ($8000)
2006	Howard Brown Staff Spirit Award
2000	Inductee Sigma Theta Tau Honors Nursing Society
	Presidential Scholar Loyola University Chicago
	Niehoff School of Nursing Service Award
1999	Helene Fuld Nursing Fellowship
	Mary Menze Thomas Award Loyola University Chicago
	Inductee Alpha Sigma Nu National Jesuit Honors Society
	Kathy Klauseger Scholarship
	Spirit of Nursing Award – US Army & National Student Nurses Association
1998	Vice President's Student Leadership Award Loyola University Chicago
	Community Service Student Leader Award Loyola University Chicago
	Niehoff School of Nursing Service Award
1996 – 2000	Niehoff School of Nursing Full Undergraduate 4-year Scholarship Award

TEACHING EXPERIENCE

Spring 2019 **University of Wisconsin Milwaukee,** Zilber School of Public Health, Milwaukee, WI
Course Instructor for PH 763 Epidemiology for Equity in Action (taught graduate level course on participatory action research methods for final semester epidemiology MPH students)

Fall 2018 **University of Wisconsin Milwaukee,** Zilber School of Public Health, Milwaukee, WI
Course instructor for PH700 Structures of Inequality and Population Health *(taught graduate level course on critical theory and health inequities for first semester epidemiology and policy MPH students)*

Spring 2018 **University of Wisconsin Milwaukee,** College of Nursing, Milwaukee, WI
Clinical Site Supervisor for NURS 433 BSN students community health rotation *(clinical site: Greater Milwaukee Center for Health and Wellness)*;
Guest Lecture "LGBT Health" NURS767 Family Nurse Practitioner Theory I

Fall 2017 **University of Wisconsin Milwaukee,** Zilber School of Public Health, Milwaukee WI
Grader for PH700 Structures of Inequality in Population Health *(graded written assignments, course instructor was Dr. Lorraine Halinka-Malcoe)*

Fall 2017 **University of Wisconsin Milwaukee,** College of Nursing, Milwaukee, WI
Guest Lecture "LGBT Communities" for NUR101 Cultural Diversity in Health Care

2017-2018 **Aurora Family Medicine Residency,** Milwaukee WI
Clinical instructor for resident completing special populations continuity clinic with transgender populations *(clinical site: Greater Milwaukee Center for Health and Wellness)*

Spring 2017 **University of Wisconsin Milwaukee,** College of Nursing, Milwaukee, WI
Guest Lecture "Transgender Health"NURS 767 Family Nurse Practitioner Theory I
Fall 2016 **University of Michigan,** College of Nursing, Grand Rapids, MI
Guest Lecture "Caring for Transgender Patients" NU356 Senior Nursing Seminar
Spring 2016 **University of Wisconsin Milwaukee,** College of Nursing, Milwaukee, WI
Guest Lecture "Transgender Health" NURS 769 Family Nurse Practitioner Theory III
Fall 2016 **Briggs & Stratton College**, Associate Nursing Program, Milwaukee, WI
Guest Lecturer "LGBT Populations" Associate Degree Nursing Students
Spring 2016   **University of Wisconsin Milwaukee,** Zilber School of Public Health,
Milwaukee, WI Guest Lecture "Transgender Populations and Violence" PH710 Health
and Violence
2012-2015 **Albert Einstein College of Medicine**, Montefiore Medical Center, Bronx, NY
HIV Mini-Residency Instructor and Youth Specialty Site Faculty – NY/NJ AIDS
Education Training Center (*clinical site: Adolescent AIDS Program)*
2007 - 2011 **Loyola University Chicago,** Niehoff School of Nursing, Chicago, IL
Clinical Instructor - Family Nurse Practitioner Students (*clinical site: Howard Brown
Health Center)*
2007 - 2011 **Northwestern University,** Feinberg School of Medicine, Chicago, IL
Clinical Instructor for Medical Students Adolescent Medicine rotation (*clinical site:
Broadway Youth Center)*
2007 - 2011 **Lurie Children's Hospital of Chicago,** Medical Residency Program, Chicago, IL
Clinical Instructor for Pediatric Residents completing adolescent medicine rotation
(*clinical site: Broadway Youth Center*

RESEARCH EXPERIENCE

2017-2018 Project Coordinator Oral History of HIV/AIDS in Wisconsin - UWM Library
Archives - Milwaukee, WI. Organize and conduct audio/video taped oral history
interviews with individuals who have been involved in the fight against HIV/AIDS in
Wisconsin from 1980's to today

2017-current Trans Youth Health Study: Mixed Methods Study of Trans Youth Health and Well-Being
(Prinicipal Investigator: Lance Weinhardt, PhD, Zilber School of Public Health,
University of Wisconsin - Milwaukee)

2015-current ATN 130 Affirmative Voices for Action: Assessing the Engagement of Transgender and
Other Gender Minority Youth Across the HIV Continuum of Care (Principle Investigator
Dr. Gary Harper, PhD, MPH, University of Michigan)

2015-2016 Protocol Team Member, ATN 132: EPIC ALLIES: A Gaming Mobile Phone
Application to Improve Engagement in Care, Antiretroviral Uptake, and Adherence
Among Young Men Who Have Sex With Men (YMSM) and Trans Women, A Multi-
Center Study of the Adolescent Medicine Trials Network for HIV/AIDS Interventions
(Protocol Chair: Lisa Hightow-Weidman, MD, University of North Carolina, Chapel
Hill)

2013-2015 Study Coordinator and Clinician, MTN 023 Phase 2a Safety Study of Dapivirine Vaginal
Ring in Adolescent Females (Principal Investigator: Donna Futterman, MD, Montefiore
Medical Center, Bronx, NY)

2013-2015 Study Coordinator and Clinician, ATN 109, A Randomized, Double-Blind, Placebo-
Controlled Trial of the Safety and Effectiveness of Vitamin D3 50,000 IU Every 4 weeks

to Increase Bone Mineral Density and Decrease Tenofovir-Induced Hyperparathyroidism in Youth with HIV Infection Being Treated with Tenofovir-Containing Combination Antiretroviral Therapy (Principal Investigator: Donna Futterman, MD, Montefiore Medical Center, Bronx, NY)

2013-2015   Clinical Supervisor, ATN 116, A Strategic Multi-Site Initiative for Identification, Linkage- and Engagement-to-Care (SMILE) Program (Principal Investigator: Donna Futterman, MD, Montefiore Medical Center, Bronx, NY)

2013-2014   Study Coordinator, ATN 104, Testing a Secondary Prevention Intervention for HIV-Positive Young Black Men who Have Sex with Men (Principal Investigator: Donna Futterman, MD, Montefiore Medical Center, Bronx, NY)

2012-2015   Study Coordinator and Clinician, AMC 072 A Study of the Protective Effects of Quadrivalent HPV Vaccine in HIV+ Young Men Who Have Sex with Men (Principal Investigator: Donna Futterman, MD, Montefiore Medical Center, Bronx, NY)

CLINICAL EXPERIENCE

2016-present   Family Nurse Practitioner – Health Connections, Inc., Glendale, WI. (Formerly Greater Milwaukee Center for Health and Wellness) (*Prescribe gender affirming hormones and provide general primary care to a panel of ~ 175 transgender, gender non-conforming, and non-binary individuals age 17 and up; prescribe HIV prevention [PrEP] and HIV treatment*)

2015-present   Clinical Consultant Transgender Health - Chicago Women's Health Center – Chicago, IL.

(*Provide trainings, monthly consulting calls, and on call clinician consultation for development of transgender health program including provision of gender affirming hormones*)

2013-2015   Research Manager/Site Coordinator for Adolescent Trials Network – Adolescent AIDS Program, Children's Hospital at Montefiore – Bronx, NY. (*Oversee multiple NIH funded research trials, supervise research nurses and staff, conduct all IRB and regulatory requirements, plan and manage research budgets*).

2012-2015   Family Nurse Practitioner - Umbrella Program & Adolescent AIDS Program, Children's Hospital at Montefiore – Bronx, NY. (*Developed program policies and protocols to launch program providing gender affirming hormones, primary care, and psychosocial services to transgender, gender non-conforming, and non-binary youth age 13-25; provide HIV prevention (PrEP) and HIV management for ~100 youth*)

2010-2012   Director of Adolescent Health Services/Ryan White Part D Project Manager - Howard Brown Health Center/Broadway Youth Center - Chicago IL. (*Managed health care services for youth ages 13-24 at Broadway Youth Center, implemented nurse led clinical services including STI/HIV testing, treatment, and linkage to care; Managed Ryan White Part D grant that provided HIV linkage to care and engagement in care services for ~100 youth age 13-25 living with HIV – provided clinical care, supervised RW project staff, completed reports, planned and managed budget*)

2006-2012   Family Nurse Practitioner and lead transgender health clinician - Howard Brown Health Center - Chicago IL. (*Provided primary care clinical services to a panel of patients including hormone care for >400 transgender/gender non-conforming/non-binary individuals; implemented agency-wide informed consent model for hormone access*)

2004-2006   Clinic Manager - Howard Brown Health Center - Chicago IL.
(*Supervised nursing staff and medical assistants; oversaw clinic operations for two primary care locations*)
2002-2006   Registered Nurse - Howard Brown Health Center - Chicago IL.
(*Provided community health nursing interventions including medication administration, STI walk in clinic assessments, telephone triage, patient education*)
2000-2002   Registered Nurse - Labor & Delivery - Advocate Illinois Masonic Hospital - Chicago IL.
(*Provided labor and delivery nursing interventions to individuals during intrapartum and postpartum, including scrub and circulating nurse duties for operating room*)

SELECTED PROFESSIONAL PRESENTATIONS
INVITED SPEAKER

2019   "Hormone Basics" and "HIV Prevention for Transgender Youth" National Transgender Health Summit, Oakland, CA April 2019

2019   "ELEVATE- Gender Affirming Healthcare Environment for Optimal HIV Care" - National Speakers Bureau, Annenberg Center for Health Sciences – Academy of Family Physicians Chapter meetings Charleston, WV and Deadwood, SD

2018   "Gender Affirming Care for Transgender People" Aurora Hospital's Clinical Pastoral Education Group, Milwaukee, WI

2017   "Basics of Gender Affirming Care and Hormone Therapy" at National Transgender Health Summit, Medical Training Track, Oakland CA, November 10, 2017.

2016   "Supportive Care for Transgender Children" sponsored by Eta Nu Chapter, Sigma Theta Tau, International Greater Wisconsin Chapter, Society of Pediatric Nurses, at University of Wisconsin-Milwaukee, WI

2016   "Gender Affirming Care for Transgender Youth" University of Michigan, College of Nursing, Ann Arbor, MI

2016   "HIV and Transgender Health" for UW Health HIV/AIDS Comprehensive Care Program, Madison, WI.

2015   Recorded webinar "Basics of Masculinizing and Feminizing Hormone Therapy" on Adolescent Trials Network Transgender Youth Resources page:
https://www.atnonline.org/public/TransYouthRes.asp

2015   "Caring for Trans Patients: Building Skills for Effective Communication and Patient-Centered Care" presented at Howard Brown Health Center, Chicago, IL

2015   "Trans Populations and the Criminal Justice System" presented at National Transgender Health Summit, Oakland, CA

2015   "Soft Tissue Fillers and Silicone Injections: Examining the Epidemic" presented at National Transgender Health Summit, Oakland, CA

2014   "Medical Management of Cross Sex Hormones and Puberty Blockers for Youth" Pediatric Endocrinology Fellows Lecture, Children's Hospital at Montefiore, Bronx, NY

2014   "Plenary Panel: Transgender Youth - Puberty Blockers and Cross Sex Hormones" presented at the Fourth Annual New York Transgender Health Conference, Pace University, New York, NY

2014   "Trans Health 101" presented at the Bronx LGBTQ Health Forum for Health Equity: Drafting a Blueprint for Success, New Settlement Community Center, Bronx, NY

2014   "Transgender Health and HIV" presented for the Cornell Medical Center HIV Program, New York, NY

2014   "Transgender Health 101" for Woodhull Medical Center HIV Center staff inservice, Brooklyn, NY
2013   "Primary Care for Transgender and Gender Non-Conforming Patients" presented at the 9th annual Philadelphia Trans Health Conference, Philadelphia, PA
2013   "Transgender Health and HIV" for Grand Rounds at Center for AIDS Research, Montefiore Medical Center/Albert Einstein College of Medicine, Bronx, NY
2013   "Comprehensive and Evidence Based Transgender Health Care" half day training for HIV clinical staff at the State University of New York - Downstate, Brooklyn, NY
2013   "Health Care for LGBTQ Youth" presented for HIV Grand Rounds, Roosevelt University Hospital, New York, NY
2013   "Sexual Health Care for LGBTQ Youth" presented at professional development day for Nursing and Allied Staff at Middlesex County Health Department, Sayreville, NJ
2012   "Transgender Youth" presented for Adolescent Medicine Fellows lecture, Children's Hospital at Montefiore, Bronx, NY
2012   "Trans Health 101" presented at Rush University Medical School LGBT Medical Student Forum, Chicago, IL
2012   "Evidence Based Primary Care for Trans Masculine Spectrum Patients" presented at Trans Medicine Education Initiative - Philadelphia Trans Health Conference, Philadelphia, PA
2011   "Trans 101" presented at Rosalind Franklin University of Medicine and Science, Student Lecture Series, North Chicago, IL
2011   "Providing Comprehensive Health Care to Transgender Populations" presented at Philadelphia Trans Health Conference, Philadelphia, PA
2011   "Gender Transitions" presented at LGBT Behavioral Health Consortium, Center on Halstead Chicago, IL
2011   "Health Disparities – Transgender Youth" presented at Chicago Kent School of Law LGBT Civil Rights Conference, Chicago, IL
2010   "Introducing the Transgender Informed Consent (THInC) Model" presented at Philadelphia Trans Health Conference, Philadelphia, PA
2010   "Medicine, Health and Gender" lecture for Gender Studies Class at Roosevelt University, Chicago, IL
2009   "Gender Transitions" presented at LGBTQ Behavioral Health Consortium, Chicago, IL
2007   "Women Who Have Sex with Women and STIs" presented at Illinois Department of Health Annual STD Conference, Springfield, IL

PROFESSIONAL ORGANIZATION MEMBERSHIPS
Sigma Theta Tau Nursing Honors Society - Eta Nu Chapter (since 2015)
GLMA Health Professionals Advancing LGBTQ Equity (since 2015)
Midwest Nursing Research Society (since 2015)
World Professional Association for Transgender Health (since 2011)
American Association of Nurse Practitioners (since 2006)

COMMUNITY ENGAGEMENT/VOLUNTEER SERVICE
2016-Present   Vice President UWM College of Nursing Doctoral Student Nursing Organization
2016-2018   UWM graduate student representative on Chancellor's Advisory Committee for LGBTQ+
Advocacy

2009-2012   Health advisor – Young Women's Empowerment Project, Chicago, IL

PEER REVIEW/ADVISORY BOARDS

2018-Present   WPATH Standards of Care 8 Chapter Workgroup Member for "The Role of Primary Care in Gender Health"

2016-Present   Peer reviewer for Transgender Health journal

2016-Present   Peer reviewer for LGBT Health journal

2015-Present   Member Medical Advisory Board, UCSF Center of Excellence for Transgender Health, San Francisco, CA

2017   Nat'l Transgender Health Summit Medical Track Planning Committee/Reviewer

2013-2016   Member, Transgender Advisory Group to the Adolescent Trials Network for HIV/AIDS Interventions

2015   Curriculum Planning team, Gender Conference East, Baltimore, MD

2014   Curriculum Planning team, Gender Conference East, Baltimore, MD

2014   Medical liaison – Gender and Family Project, Ackerman Institute for the Family, New York, NY

2013   Curriculum Lead for the Basic Medical Track at the National Transgender Health Summit, Oakland, CA

2013   Medical Editor – Trans Bodies Trans Selves, Ed. Laura Erickson-Schroth, 2014, Oxford Press

2012   Inaugural Planning Committee - Trans Medicine Education Initiative, Philadelphia Trans Health Conference, Philadelphia, PA

2010   Transgender Youth and Adolescents Medical Curriculum Development Committee – Physicians for Reproductive Choice and Health, Chicago, IL