CHARACTERIZING THE SOCIAL NETWORKS & ART ADHERENCE BEHAVIORS OF TRANS WOMEN LIVING WITH HIV

by

MIRANDA HILL

(Under the Direction of Nathan Hansen)

ABSTRACT

The increasing visibility of transgender people within the American landscape necessitates increased knowledge concerning their personal networks. The goal of this crosssectional study was to 1) describe the characteristics of the personal, health, and gender-focused networks of transgender women living with HIV (TWLH) and 2) explore the association between network support (emotional, appraisal, informational, and instrumental) and ART adherence. Mixed-venue-based convenience sampling was used to recruit (N=231) TWLH in the U.S. Participants took a 20-30-minute online survey assessing their individual characteristics and network characteristics. Means and frequencies were calculated to describe the sample and their networks. Hierarchical logistic regression models were used to predict antiretroviral therapy adherence from demographic characteristics, depression, social support, network size and density. On average participants were about 32 years old and had been diagnosed for about 4.5 years. Most identified as white (62%); nearly 27% were black. Most were employed (67.8%), stably housed (70.9%), insured (73%) and optimally adherent to ART (69%). On average, they had 4-5 confidants with whom they discussed at least one issue - they confided in nearly half of alters about multiple issues. Their networks were moderately dense (.51) and they perceived

multiple forms of support from a high proportion of their network (\geq 75%). Bivariate analyses showed that participants with suboptimal adherence had higher odds of depression (r = -.21, p < .05), larger networks (r = -.26, p < .01), and lower perceived emotional (r = .20, p < .01) and appraisal support (r = .19, p < .01) from a smaller proportion of their network. Depression (aOR = .91, p = .016) and network size (aOR = .85, p = .018) significantly and strongly predicted ART adherence in the full hierarchical model, while emotional support was marginally significant (aOR = 1.03, p = .046). Additional research is needed to understand the psychosocial dynamics of depression, ART adherence, and perceived support among TWLH. Given the pervasive use of social technology in this sample, multilevel online interventions which deliver trans-affirmative CBT while also promoting relationship management skills may minimize adherence disparities among TWLH.

INDEX WORDS: transgender, trans women, HIV, treatment, antiretroviral therapy,
medication adherence, social networks, network analysis, network episode
model, egocentric network analysis, HIV disparities

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by

MIRANDA HILL

BS, Spelman College, 2007

MPH, University of Georgia, 2012

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MIRANDA HILL

Major Professor: Committee: Nathan Hansen Dawn Robinson Eric Wright Tamora Callands

Electronic Version Approved:

Ron Walcott Interim Dean of the Graduate School The University of Georgia December 2019

DEDICATION

To my grandmother, Florine (deceased), my mother, Deanna, and my daughter, Eden.

Your unconditional love has made me better in every way. I love you beyond life.

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No amount of scholarly discourse could make me an authority on something that I've never experienced. Foremost, I would like to express immense gratitude to the trans women who assisted with and participated in this research. None of this would be possible without you. I am astounded by your resilience. It is because of you that I have transitioned from a person who does research *on* trans communities to a person who does research *with* trans communities.

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CHAPTER 1

CHARACTERIZING THE SOCIAL NETWORKS & ART ADHERENCE BEHAVIORS OF

TRANS WOMEN LIVING WITH HIV

INTRODUCTION

General Overview

After decades of an escalating epidemic, progress towards eradicating the global HIV/AIDS crisis is ever more evident. While nearly 37 million people are living with HIV infection worldwide, HIV infection rates have been steadily declining over the past 18 years (UNAIDS, 2017a). Moreover, HIV resources in poverty-stricken regions have nearly quadrupled (from \$4.8 to \$19.1 billion dollars). The HIV infection trends in the United States resemble those found globally. Nearly 1.2 million people living with HIV are in the United States (Centers for Disease Control and Prevention, 2017) and it is estimated that the rate of annual HIV infections decreased by nearly 10% from 2011 to 2015 (CDC, 2017). Declining trends in AIDS diagnoses and related death rates are promising -- indicating earlier detection and improvements in treatment access for people living with HIV (PLWH) (CDC, 2017). Yet, progress towards national HIV objectives is uneven with persistent disparities between different racial, sexual orientation, and gender identities. Socially marginalized populations have carried a higher burden of HIV since the inception of the US epidemic. Consequently, social inequality has materialized into diverging trends where infection is decreasing among some groups while they are stabilizing and/or increasing among others (CDC, 2017). HIV transmission is considerably

higher among lesbian, gay, bisexual, and transgender (LGBT) people (CDC, 2017b). For many years, gay and bisexual men have led other populations in HIV incidence and prevalence. (CDC, 2017b). This enduring disparity has spurred a public health agenda heavily focused on monitoring, researching, and developing programs for MSM above all other LGBT groups. However, relatively less is known and about the burgeoning HIV crisis within the transgender community and there are relatively fewer resources to assist with it. "Transgender" is a broad term used to describe a diverse group of people who identify or express their gender differently from their assigned sex at birth (GLAAD, 2017). Nearly one to one and a half million adults identify as transgender in the U.S. (Centers for Disease Control and Prevention, 2019; Flores, 2016; Meerwijk & Sevelius, 2017). Within the transgender population, the burden of HIV infection, illness, and death is most severe among transgender women (referred to as "trans women" from here on out), or people who identify as women or some other feminine identity and were assigned male sex at birth.

Background

To date, there is some dispute over the validity of the estimated HIV prevalence among trans women (Baral et al., 2013; Bauer & Scheim, 2013). Gender misclassification and incomplete surveillance across local, state, and national agencies has diminished efforts towards obtaining an accurate census of HIV within this population (Centers for Disease Control and Prevention, 2017, 2019). Nevertheless, the disturbingly high burden of HIV in trans women is unrefuted by researchers and health authorities alike (Centers for Disease Control and Prevention, 2019; World Health Organization, 2015). Past studies predict that between a quarter to a half of trans women in the U.S. are living with HIV (Baral et al., 2013; Herbst et al., 2008; Santos et al., 2014) and meta-analyses suggest sizeable disparities, with trans women having 49

times higher odds of HIV infection than all other adults (Baral et al., 2013). Their increased vulnerability for HIV infection and disease progression signify an urgent need for research exploring facilitators and barriers to antiretroviral therapy (ART) adherence (Mizuno, Frazier, Huang, & Skarbinski, 2015).

Antiretroviral therapy is the name for the medication regimen prescribed to individuals diagnosed with HIV. The widespread distribution ART over the past 40 years has effectively slowed the HIV epidemic (UNAIDS, 2017b). In contrast to the earlier stages of the ART implementation, it is now more accessible than ever with the scale-up of global treatment programs. However, accessing ART is only the first step to treating HIV. People living with HIV must adhere to ART by taking their doses as originally prescribed to sustain optimal levels of protection against disease progression and transmission (UNAIDS, 2017b). Despite the importance of ART, optimal adherence is rarely sustained among most people living with HIV and marked treatment disparities exist between trans women and other populations (Beer & Skarbinski, 2014; World Health Organization, 2003). Multiple studies have found that a higher percentage of trans women are accessing ART when compared to the general population (Kay, Batey, & Mugavero, 2016; Santos et al., 2014), however, data consistently show significantly lower adherence in trans women when compared to non-transgender populations (Baguso, Gay, & Lee, 2016; Kalichman, Hernandez, Finneran, Price, & Driver, 2017; Mizuno, Frazier, Huang, & Skarbinski, 2015; Sevelius, Carrico, & Johnson, 2010). Though new research has begun to explore macrosocial and individual correlates of ART adherence in transgender populations (Kalichman et al., 2017; Sevelius, Saberi, & Johnson, 2014), little is known about the role of social networks.

Social networks describe the web of relationships and interactions surrounding individuals. The evidence demonstrating social networks to be important determinants of health is extensive and robust (Berkman, Glass, Brissette, & Seeman, 2000; Valente, 2010). Previous studies have linked the structure and characteristics of social networks to numerous health behaviors, ranging from smoking (Christakis & Fowler 2008) to cervical cancer screening (Luque, Opoku, Ferris, Condorhuaman, & Guevara Condorhuaman, 2016). To date, research on social networks and HIV has primarily explored network characteristics in relation to transmission risk. Studies in the above area have found relationships to be powerful predictors of condom use, injection drug use, substance use and sexual partner concurrency (Latkin, Forman, Knowlton, & Sherman, 2003; Latkin & Knowlton, 2015; Murphy, Gordon, Sherrod, Dancy, & Kershaw, 2013; Rothberg et al., 2000). Yet, knowledge of how social networks might impact HIV treatment is scarce and the lack of interventions using social network approaches to address barriers to ART adherence is concerning. A recent meta-analysis (Ghosh et al., 2017) found that only 3% of the interventions included in the analyses were applying social network strategies to improve ART adherence as opposed to the 83% which focused on HIV prevention outcomes (Figure 1.1).

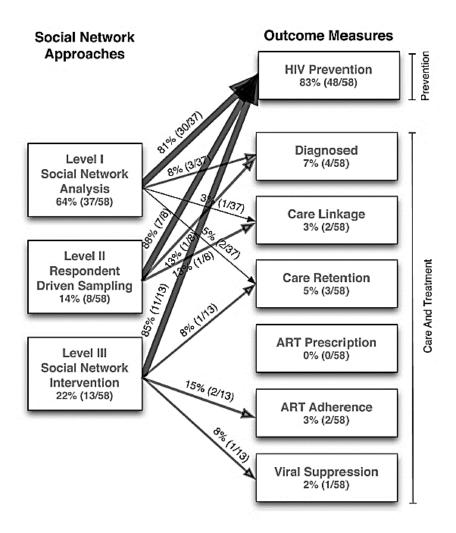


Figure 1.1 Cross tabulation of studies categorized by social network approaches and study outcomes representing the stages of the HIV care continuum

Source: Ghosh et al., 2017

The development of effective social network strategies for facilitating ART adherence is predicated upon knowledge of how the networks of various populations are structured and operate. A few researchers have investigated the connections between networks and ART adherence among cisgender people living with HIV, though the current knowledge does not extend to understanding the role of social networks in the ART adherence behaviors of trans women living with HIV (Bogart et al., 2015; Bogart et al., 2016). Literature suggests that transgender networks are unique from non-transgender persons' networks and may play an important role in behavioral health due to their relatively large size, strong ties, and substantial support systems for a variety of behaviors and personal needs, ranging from sex work to housing (Barrington, Wejnert, Guardado, Nieto, & Bailey, 2012; Fredriksen-Goldsen et al., 2013; Lombardi, 1999). However, more remains to be known about the personal networks of trans women living with HIV, the perceived availability of support from the people around them, and importantly, how these characteristics might shape HIV treatment.

Statement of Purpose

The purpose of this study is to characterize the social networks of trans women living with HIV and fill knowledge gaps concerning the relationships between trans women's network characteristics and ART adherence outcomes. The Network Episode Model (NEM) (Pescosolido, 1991) will be applied to exploring the association between social network structure, support, and ART adherence. The NEM is a theoretical framework which explains the socially derived health care utilization patterns among chronically ill populations. It has previously been used to explore health care utilization and compliance among several stigmatized and marginalized groups, (Lindsey et al., 2006; Pescosolido, Wright, Alegría, & Vera, 1998; Pullen, 2013). The results of these studies, along with others, support the NEM's theoretical premise that the health care usage

and compliance behaviors of individuals are shaped by the structure, content, and type of networks in which they are embedded. To that end, the proposed research seeks to achieve the following aims:

- 1. Describe the structure, composition, and relationship (tie) characteristics of TWLH egocentric networks.
- 2. Evaluate the associations between different forms of social network support (appraisal, instrumental, emotional, informational) and ART adhere

CHAPTER 2

LITERATURE REVIEW

Language

Language is immensely powerful in placing boundaries between wellness and pathology. As terminology evolves with culture, it is important to use language that is culturally sensitive and appropriate. While describing the study population in the first chapter, the terms transgender and trans woman were introduced. Table 2.1 briefly summarizes gender identity terms that will be used throughout the following sections.

It is important to note that the vocabulary used to describe gender is constantly changing and can vary across individual and social contexts. Various cultures have different understandings and interpretations of gender identity, just as individuals do. The terms presented here reflect present-day terminology promoted by LGBT education & advocacy organizations in mainland US (GLAAD, 2019; Transgender Student Educational Resources; 2019). Though not all people ascribe to these terms, the intention is to focus on those relevant to this study population and others who may also be referenced throughout

Gender Expression Fransition Fransgender/Trans	One's internal sense of being male, female, neither of these, both, or other gender(s). The physical manifestation of one's gender identity through clothing, hairstyle, voice, body shape, etc. A person's process of developing and assuming a gender expression to match their gender identity. An umbrella term for people whose gender identity and/or gender expression differs from what is typically associated with the sex they were assigned at birth. Trans is a prefix or adjective used as an abbreviation of transgender, derived from the Latin word meaning "across from" or "on the other side of." Trans woman generally describes someone assigned male at birth who identifies as a woman. This individual may or
Gender Expression Fransition Fransgender/Trans	The physical manifestation of one's gender identity through clothing, hairstyle, voice, body shape, etc. A person's process of developing and assuming a gender expression to match their gender identity. An umbrella term for people whose gender identity and/or gender expression differs from what is typically associated with the sex they were assigned at birth. Trans is a prefix or adjective used as an abbreviation of transgender, derived from the Latin word meaning "across from" or "on the other side of." Trans woman generally describes someone assigned male
Fransition Fransgender/Trans	through clothing, hairstyle, voice, body shape, etc. A person's process of developing and assuming a gender expression to match their gender identity. An umbrella term for people whose gender identity and/or gender expression differs from what is typically associated with the sex they were assigned at birth. Trans is a prefix or adjective used as an abbreviation of transgender, derived from the Latin word meaning "across from" or "on the other side of." Trans woman generally describes someone assigned male
Transition Fransgender/Trans	A person's process of developing and assuming a gender expression to match their gender identity. An umbrella term for people whose gender identity and/or gender expression differs from what is typically associated with the sex they were assigned at birth. Trans is a prefix or adjective used as an abbreviation of transgender, derived from the Latin word meaning "across from" or "on the other side of." Trans woman generally describes someone assigned male
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	other side of." Trans woman generally describes someone assigned male
	Trans woman generally describes someone assigned male
Trans Woman / Trans	
	at birth who identifies as a woman. This individual may or
	•
	may not actively identify as trans. It is grammatically and
	definitionally correct to include a space between trans and
	woman. The same concept applies to trans men.
	Sometimes trans women identify as male-to-female (also
	MTF, M2F, or trans feminine) or women and sometimes
	trans men identify as female-to-male (also FTM, F2M, or
	trans masculine) or men
	Preferred umbrella term for all genders other than
	female/male or woman/man, used as an adjective. Not all
	nonbinary people identify as trans and not all trans people
	identify as nonbinary.
	A term used to describe some people whose gender
	expression is different from conventional expectations of
	masculinity and femininity.
	Adjective that means "identifies as their sex assigned at
	birth" derived from the Latin word meaning "on the same
	side." A cisgender/cis person is not transgender. "Cisgender" does not indicate hislagy, conder expression
	"Cisgender" does not indicate biology, gender expression,
	or sexuality/sexual orientation.
Sources: GLAAD, 2019; T	Frans Student Educational Resources [TSER] 2019

The Importance of ART Adherence

Early and continuous HIV treatment is imperative to reducing transmission risk and improving the livelihood of persons living with HIV infection (PLWH). The HIV care continuum (also known as the HIV treatment cascade) was developed to monitor the progression of PLWH though different treatment stages (Gardner et al., 2011), which can widely range from

diagnosis to viral suppression. Figure 2.1 shows the most recent diagnosis-based continuum detailing the percentage of people diagnosed with HIV who received care, were retained in care, and virally suppressed.

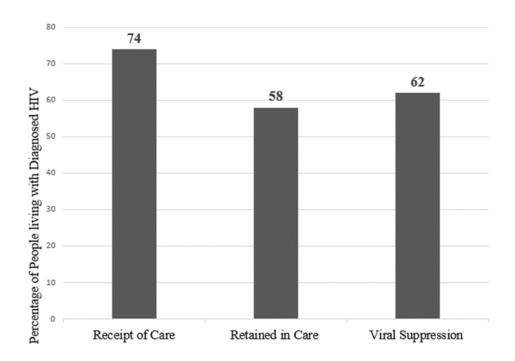


Figure 2.1. CDC (2019) Diagnosis-Based Continuum, 2016

As the figure shows, most people who are diagnosed with HIV are virally suppressed (62%). Viral suppression describes the clinical point at which the amount of virus in the body is so low that it cannot be detected on an HIV viral load test (CDC, 2019). It is a critical status because once reached and maintained, HIV mortality risk for the affected person is significantly reduced (Palella Jr et al., 2006), as well as the likelihood of transmitting the virus to uninfected people (Attia, Egger, Müller, Zwahlen, & Low, 2009; Cooper et al., 2002; Donnell et al., 2010; Guay et al., 1999). Optimal ART adherence is essential to achieving and sustaining viral suppression while realizing the aforementioned personal and public health benefits (Montaner et al., 2006). Alternatively, the implications of suboptimal adherence can be incredibly detrimental. When doses are not taken as prescribed, the likelihood of viral rebound and opportunistic infection multiplies (Paterson, Swindells, Mohr, & et al., 2000). Poor adherence can also lead to the development and transmission of ART-resistant strains of HIV which are harder to treat (Wainberg & Friedland, 1998; World Health Organization, 2003).

In 2012, Beer & Skarbinski identified three aspects of adherence integral to HIV management. Dose adherence is defined by taking the prescribed quantity of medications (e.g. one vs. two pills), schedule adherence refers to the prescribed frequency (e.g. daily), and instruction adherence refers to taking medication as instructed (e.g. with a meal). Many other studies have adopted simplified measures. This research often classifies optimal versus suboptimal adherence according to clinical cut-off points for sustaining viral suppression, designating \geq 90-95% of doses over a specified time period as optimal (Chesney, Morin, & Sherr, 2000; Kalichman et al., 2016).

ART Adherence Disparities among Trans Women

Adherence to long-term therapies is universally difficult (World Health Organization, 2003). From diabetics to PLWH, many people find it hard to integrate daily medication regimens into their lives. Collectively, studies have found adherence to antiretroviral therapy to vary widely across different samples of PLWH. For example, a study with a diverse group of PLWH found that 33% of their study participants had poor adherence (Simoni et al. 2012) while another study with high risk PLWH reported markedly higher poor adherence (53%) (Holstad, Spangler, Higgins, Dalmida, & Sharma, 2016). Studies comparing adherence across different gender groups have consistently found poorer ART adherence and viral suppression among trans women (Baguso et al., 2016; Jalil et al., 2017; Kalichman et al., 2017; Sevelius et al., 2010; Weiss Wiewel, Torian, Merchant, Braunstein, & Shepard, 2016). In 2016 Baguso et al. found that trans female participants were significantly more likely to have poor adherence scores than trans male participants. Similarly, a recent cohort study found that only 42% of trans women were optimally adherent to ART compared to 68% of cisgender women and 72% of cisgender men (Kalichman et al., 2017). Research showing the persistence of treatment disparities between trans women and non-transgender people after known barriers are eliminated (such as lack of access to HIV care or ART) are especially concerning given the lack of health interventions designed for them (Melendez et al., 2006; Mizuno et al., 2015). The alarming burden of HIV infection coupled with treatment disparities among TWLH signify an urgent need for increased understanding and intervention on the social determinants of medication adherence among this group.

Social Determinants of ART Adherence

The social determinants of health are the biological, environmental, behavioral, and/or social factors which shape health outcomes (US Department of Health and Human Services, 2010). There are a variety of determinants which shape people's ability to access and properly adhere to ART, ranging from health insurance to HIV medication beliefs. Among trans women, factors such as social marginalization and gender affirmation may play a larger role in impacting their ability to adhere to medications while being less relevant to non-transgender groups. The following sections explore the determinants which will be examined in this study.

Social Marginalization

The social marginalization of trans women has serious implications for their adherence to ART and overall health. Hetero-cisnormativity and transphobia form the basis of societal discrimination against trans women (White Hughto, Reisner, & Pachankis, 2015; World Health Organization, 2015; Yep, 2003). Hetero-cisnormativity is a cultural phenomenon by which society has hegemonized heterosexuality and a male/female gender binary (Yep, 2003). Similarly, transphobia is a type of stigma specifically targeted against transgender people, based upon their gender identity or expression (Mink, Lindley, & Weinstein, 2014). Heterocisnormativity and transphobia are systemic forces used to justify exclusion and hatred against those who identify or express themselves outside of predominant standards. Most US Transgender Survey (USTS) participants reported high exposure to discrimination and mistreatment in multiple sectors of society, including, schools, homeless shelters, the criminal justice system, and their own homes (James et al., 2016). The literature illustrates the substantial effect that these marginalization factors have on several factors related to ART adherence (World Health Organization, 2015). In this study, demographic and gender-related indicators of social marginalization will be assessed. These include income, housing, employment, and gender affirmation.

Discrimination against transgender people in housing and job sectors produces high rates of unemployment and housing instability. In a statewide survey in Massachusetts, researchers found that transgender participants had three times higher odds of being unemployed and living at or below poverty (Conron, Scott, Stowell, & Landers, 2012). Similarly, national survey data indicate that transgender people are 2.5 times more likely to live in poverty and experience homelessness than the general US population (James et al., 2016) The disparate poverty rates

among trans women living with HIV translate into an urgency for ancillary and support services. Economic stability is critically important to ART adherence because it provides people with the resources, security, and privacy needed to access medications and take them as prescribed (Aidala et al., 2016; Kidder, Wolitski, Campsmith, & Nakamura, 2007; Leaver, Bargh, Dunn, & Hwang, 2007). In one systematic review of studies examining the effect of housing on health-related outcomes among PLWH, authors found that those with unstable housing had 2.76 times higher odds of poor ART adherence (Leaver et al., 2007).

Gender Affirmation

In their development of the gender affirmation framework for conceptualizing HIV risk among transgender women of color, Sevelius (2014) defined affirmation as "an interpersonal, interactive process whereby a person receives social recognition and support for their gender identity and expression (p. 2)." Examples of gender affirmation include addressing an individual by their preferred pronoun or chosen name (as opposed to their assigned birth sex or name), using gender-inclusive language, or reflecting the language that they use to describe themselves. Qualitative research has found that definitions and interpretations of affirmation can vary on an individual basis (Bircher, 2016). Despite these differences, affirmation is important because it communicates acceptance, respect, and value (Bircher, 2016). Though this concept is widely applicable to most people, recent studies have found affirmation to have multifaceted implications for the health and relationships of trans and non-binary individuals (Nuttbrock, Rosenblum, & Blumenstein, 2002). The quest for affirmation can lead trans women to seek and remain in unhealthy relationships in which they may compromise their health in exchange for social acceptance (Melendez & Pinto, 2007). For example, while testing her gender affirmation framework, Sevelius (2013) found that when trans women of color needed affirmation from

others, yet lacked access to it, they were more likely to engage in HIV risk behaviors which would help fulfill that need. In a different study, Sevelius et al. (2014) also identified gender affirmation as a barrier or facilitator to HIV care linkage and engagement among trans women living with HIV. If participants felt affirmed in their clinical encounters, they were more likely to continue HIV care. Conversely, non-affirming experiences (e.g. being misgendered) contributed to care lapse and dropout (Sevelius et al., 2014). Outside of health providers, it is also important for family and friends to affirm gender through their words and actions (Larry Nuttbrock et al., 2012; Larry Nuttbrock, Rosenblum, & Blumenstein, 2002b). Though the importance and impact of gender affirmation on mental health, HIV risk, and care engagement has been well-established, little attention has also been afforded to examining the impact of gender affirmation on adherence to an HIV treatment regimen.

Depression

Social marginalization factors (e.g. transphobia, economic instability) contribute to minority stress, which in turn increases trans women's vulnerability to chronic stress, anxiety, and depression. (Hoffman, 2014; Logie, James, Tharao, & Loutfy, 2011; Sayles, Ryan, Silver, Sarkisian, & Cunningham, 2007; Sevelius et al., 2014; Sugano, Nemoto, & Operario, 2005). Results from the most recent United States Transgender Survey [USTS] (2016) show that nearly 40% of participants had severe psychological distress over the previous 30 days versus that found in only five percent of the US population. Additional research has found elevated depression, and suicidal ideation and attempts among trans women, with one study finding nearly 54% of trans women having experienced suicidal thoughts (Herbst et al., 2008). People living with HIV are also disproportionately impacted by mental health disparities, with research estimating people living with HIV to have nearly 2.5 times higher prevalence of any depression

than the general population (Do et al., 2014). Using data from a national survey, the same study also found trans women to have the highest prevalence of depression (17.5%) among all other groups of PLWH (Do et al., 2014). The mental health disparities experienced by trans women living with HIV are concerning given evidence demonstrating depression as a key determinant of ART adherence (Gonzalez, Batchelder, Psaros, & Safren, 2011; Langebeek et al., 2014; Sayles et al., 2007). Though one study (Sevelius et al., 2014) found an insignificant correlation between depression and ART adherence among trans women living with HIV, many others have found depression to be common reason for suboptimal adherence in diverse populations with a variety of chronic illnesses, including PLWH (DiMatteo, Lepper, & Croghan, 2000; Langebeek et al., 2014; Lima et al., 2007). These studies have found strongly significant relationships between depression and medication adherence in PLWH, with one study estimating noncompliance to ART regimen to be three times higher in depressed PLWH (DiMatteo et al., 2000).

Age

In most studies, poorer ART adherence has been found among younger people living with HIV (Beer & Skarbinski, 2014; Mizuno et al., 2017; Sevelius et al., 2014). Generally, older PLWH are more likely to be retained in care, fill ART prescriptions, and achieve viral suppression (Horberg et al., 2015). Likewise, one study with trans women detected significant ART adherence differences by age, whereby older participants were significantly more likely to be optimally adherent in comparison to younger counterparts (Sevelius et al., 2014).

Race

Over half of trans women living with HIV are African American (Clark, Babu, Wiewel, Opoku, & Crepaz, 2017), and many studies have observed significant racial disparities in ART adherence between African American PLWH and other racial groups (Beer, Mattson, Bradley, & Skarbinski, 2016; Simoni et al., 2012). For example, a cross-sectional study of PLWH found African American participants to have significantly reduced ART use and adherence when compared to other racial groups, whereby, 88% of African American participants were using ART in comparison to 92% Hispanics, and 93% Whites (Beer et al., 2016). Conversely, a study of trans women found significantly improved adherence among African American participants over other racial/ethnic groups (Baguso et al., 2016). While additional research on this population is needed to have a more conclusive understanding of racial disparities in ART adherence, present literature indicate that race may be an important sociodemographic determinant.

Diagnosis Longevity

Study results suggest that optimal adherence among PLWH may decline over time (Beer & Skarbinski, 2014; Langebeek et al., 2014), whereby longtime survivors, or people who are been living with HIV longer, have poorer adherence to antiretroviral regimens (Boretzki et al., 2017). For example, a study on a large national sample of PLWH involved in the Medical Monitoring Project (MMP) found significantly lower ART adherence in participants who had been diagnosed for 10 years or longer as opposed to those who had been diagnosed for 5 years or shorter (Beer et al., 2016). Similarly, a more recent study found that 82% of participants with poor adherence had been living with HIV for 10 years or longer, while nearly 60% of those with good adherence had been diagnosed for 10 years or less (Boretzki et al., 2017). Research further

shows that social network size, composition, and support for chronically ill population evolves over time. Due to the cross-sectional design, the current study design does not permit an examination of an evolution of these factors; however, the effects of time may be controlled for by considering this determinant.

Health insurance

Health insurance is critical for making medication affordable for chronically ill people (Eaddy, Cook, O'Day, Burch, & Cantrell, 2012). The out-of-pocket costs associated with not having insurance and being underinsured can reduce ART access (Holtzman, Brady, & Yehia, 2015). Insurance coverage may specifically impact ART adherence by reducing the frequency by which patients obtain prescription refills due to financial constraint or fear of out of pocket expenses (Iuga & McGuire, 2014). While having insurance makes prescription drugs more affordable, the type of coverage also matters (Bhattacharya, 2003). Among those with private insurance, access to ART varies according to prescription drug formularies in patient insurance plans. One study reported lower insurance rates among trans women living with HIV when compared to non-transgender PLWH, with 23% of trans women reporting being uninsured in comparison to 15% and 13% of non-transgender men and women, respectively (Mizuno et al., 2015).

Social Networks, Health, & HIV

The impact of social support on ART adherence among many populations is well-documented, the methodology used to examine social support in most studies of ART adherence limits understanding of support in the context of a social structure. The current study seeks to better understand the relationship between social support and ART adherence among trans women living with HIV through social network analysis. Social network analysis describes the

social environment by measuring and depicting the interconnected web of relationships in which people are embedded. Several scholars within various disciplines ranging from social psychology to anthropology have contributed the development of present-day social network theory and research methods (Scott, 2013). Among those, Shelden Stryker is recognized for building upon existing theory by explaining the reciprocal relationship between individuals and systems via the symbolic interactionist framework (Stryker, 1980). The central themes of this framework formed the theoretical basis for learning about individual's identities, roles, and behaviors by examining social systems and vice versa. While the structural aspects of networks describe characteristics such as the size, makeup, and interconnectedness of relationships, the functional aspects refer to the social exchanges and interactions between people. Scholars in graph theory are credited with first using sociograms to map relational data (Scott, 2013). The basic units of these maps feature elements designated as nodes and ties (relationships). Nodes (aka actors) represent the entities (people, places, or things) which are connected by relationships (aka vertices or edges). Figure 2.2 shows the basic units of a sociogram representing a network.

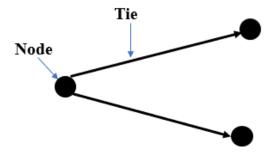


Figure 2.2 Sociogram example

Background on Social Networks, Health, & HIV

Social network research has greatly contributed to knowledge about the social embeddedness of issues ranging from obesity to cancer screening and suicide ideation (Bearman & Moody, 2004; Christakis & Fowler, 2007; Luque et al., 2016). Most network studies in HIV research have examined infection risk and transmission between people (Neblett, Davey-Rothwell, Chander, & Latkin, 2011; Rothenberg et al., 2000; Rudolph, Crawford, Latkin, & Lewis, 2016). For example, Latkin's research on injection drug users (IDUs) explored the structure and influence of needle-sharing norms within their networks; whereas, later research used network analysis to better understand social factors associated with IDUs entry into drug treatment (Davey, Latkin, Hua, Tobin, & Strathdee, 2007). Network analysis has also been applied to examining social aspects of HIV risk among black women at risk for HIV (Neblett et al., 2011), the sexual mixing patterns of MSM (Schneider et al., 2013), and the HIV risk norms among young urban fathers (Murphy et al., 2012). Researchers have only recently begun to examine the connection between social networks and ART adherence (Bogart et al., 2015; Bogart et al., 2016; Holloway et al., 2017; Wohl et al., 2010). From 2010 to 2012, Bogart et al., conducted a prospective study of the egocentric networks of HIV-positive African American women and men in Los Angeles. Findings indicate that network beliefs and attitudes are powerful predicators of ART adherence. Specifically, Bogart et al. (2015) found that expressions of HIV stigma from network members and HIV medication conspiracy beliefs significantly predict poor medication adherence among African Americans living with HIV.

Social Network Support

Social support, or the exchange of material and psychosocial resources, is the primary construct of interest in this study. Due to its profound effect on health, many theories explaining

the possible mechanisms by which support influences health have emerged. The two predominant theories explaining the psychosocial pathways between social support and health include direct effect and indirect effect hypotheses. In his seminal work on social support, occupational stress, and health, House (1981) proposed that social support could impact health through indirect and/or direct mechanisms. Specifically, House (1981) suggested that support could directly satisfy personal needs and/or eliminate a stressor that is negatively impacting health. Other researchers have further elaborated on the main effect model to explain the health benefits of social integration (Cohen, 2004; Cohen & Wills, 1985; Faber & Wasserman, 2002). According to the above theory, integration in a large network promotes health through social interactions and role expectations which promote positive affect and self-worth (Cohen & Wills, 1985; Cohen, 2004). It is believed that social embeddedness in a community has an inherently positive effect on health, regardless of situational stress. Social interactions are theorized to further promote health through social control, or role expectations, which set parameters for socially acceptable behaviors, such as, heavy alcohol use or smoking. Another proposed mechanism by which social integration is proposed to influence health is through emotional regulation, where social network members disrupt negative psychological states, and provide individuals access to information which can be used to facilitate self-care.

The other theory explains social support as indirectly influencing health by promoting coping strategies to manage the psychological effects of a stressor (House, 1981; Thoits, 1986). In 1986, Thoits conceptualized social support as a form of coping assistance which facilatates improved mental and physical health. In her article entitled, "Social Support as Coping Assistance," Thoits proposed that social support positively impacted health through the promotion of coping with stressors. This is a slightly different context given the inclusion of a

stressful experience and psychological disturbance as a prerequisite to the effectiveness of support on health through coping. In this paper, Thoits (1986) defines social support as, "functions performed for a distressed individual by significant others (p. 417)."

Many other researchers have adopted a similar lens when attempting to explain the effects of social support on health through stress and coping (Cohen, 2002). Similar to Thoits, Cohen & Mckay (1984) proposed a theory two years earlier which delineated the pathways between stress, appraisal, and coping. According to Cohen & Mckay (1984), social support can mitigate the relationship between stress and coping by transforming the primary appraisal of a stressor into a positive secondary appraisal, thereby by changing the trajectory of coping responses into more adaptive approaches for managing stress. Since the inception of social support research, researchers have debated and tested both direct and indirect hypotheses – proclaiming the relative merits of one theory over the other (Cohen & Wills; 1985; Cohen, 2004; Faber & Wasserman, 2002). Overall, the evidence agrees that social support is a positive interpersonal process associated with many physical and psychological benefits, albeit directly or indirectly.

Theorists have also distinguished between different forms of support exchanged within relationships (House, 1981; Langford, Bowsher, Maloney, & Lillis, 1997). In "Work Stress and Health," House (1981) summarized and classified prevalent conceptualizations of support in the literature under four broad categories: appraisal, informational, instrumental, and emotional. Instrumental support is defined by the provision of material/tangible resources which directly fulfill a need. An example of this type of support could be allowing a friend to spend the night when they don't have a place to stay or lending them money. Emotional support is defined by the exchange of affective resources, such as, esteem, trust, concern, and listening. An example of emotional support is giving someone a hug or expressing care for them when they are going

through a hard time. Appraisal support is characterized by the provision of affirmation, feedback, and social comparison. Seeking to inspire an individual through words of encouragement or providing reassurance for overcoming an obstacle can assist with facing a difficult circumstance. Finally, informational support includes offering suggestions, directives or information. This type of support is characterized by the sharing of knowledge that can be used to connect people with further resources that can meet their needs (House, Kahn, McLeod, & Williams, 1985).

Conceptualizations of social support can be further divided into theoretical subconstructs distinguishing between perceived versus received resources. Perceived social support refers to an individual's concept of where they could get support if they needed it, as opposed to received social support, which is an assessment of enacted support. For quite some time, theorists have debated as to whether perceptions of support were entirely based on enacted support. However, results from a meta-analysis of support studies found that they were only moderately correlated (r = .35), thus refuting the assertion that perception is reality (Haber, Cohen, Lucas, & Baltes, 2007). Yet studies evaluating the effects of perceived versus received support have found perceptions of available support to reign over support that is actually given, in terms of health outcomes, particularly among PLWH (Faber & Wasserman, 2002; Mcdowell & Serovich, 2007). For example, in a study of support among gay/bisexual men, straight men, and women living with HIV, Mcdowell & Serovich (2007) found that perceived social support was consistently a significant predictor of depressive symptoms among all study groups, while actual social support was not.

Despite conceptual differences, all types of social support have been associated with improved treatment outcomes along the HIV Care Continuum (Kelly, Hartman, Graham, Kallen, & Giordano, 2014), including ART adherence (Ammassari et al., 2002; Cochran & Beeghley,

1991; Gonzalez et al., 2011; Gonzalez et al., 2004; Simoni, Frick, & Huang, 2006). Multiple meta-analyses examining the relationship between social support and medication adherence found that social support nearly doubled and tripled the odds of medication adherence (DiMatteo, 2004; Langebeek, 2014). Studies on ART adherence in trans women report similar findings, indicating that more support facilitates improved adherence while less support predicts suboptimal adherence or nonadherence (Kalichman et al., 2017; Machtinger, Haberer, Wilson, & Weiss, 2012). This study attempts to contribute to the support literature by identifying and comparing the association between different forms of perceived support and ART adherence in trans women living with HIV.

Theoretical Framework

Pescosolido's (1991) network episode model (NEM) explains the role social of networks in healthcare utilization. The NEM is built upon the premises of rational choice theories commonly used in medical sociology and public health, such as, the health belief model and theory of reasoned action/planned behavior, to explain the social influences on health care decision making and compliance. Like rational choice theories, the NEM acknowledges that social networks play an important role in health behaviors. However, the model deviates from the underlying assumption that individuals are rational decision makers, weighing the advantages and disadvantages of health behaviors in isolation. According to the NEM, social networks are a central part of the dynamic process that individuals undergo when people are making healthcare decisions.

The model is based upon four assumptions. The first assumption is that people serve as social resources for consultation and influence on others' decision-making processes when they become ill or a managing a chronic illness. Secondly, the NEM assumes that people use a "bounded rationality" to weigh multiple factors and resources while informing their decision. The third assumption is that people go through a succession of decisions over time, developing strategies for resolving issues. Finally, the fourth assumption of the NEM is that social networks act as a foundation for the help-seeking and medical compliance decisions that individuals make. Thus, the NEM expounds upon traditional rational choice theories by accounting for the social embeddedness of individuals, emphasizing the involvement of social networks in shaping healthcare utilization and compliance through various forms of support and other processes of influence.

Theoretical constructs include the social content or episode base, social support system, and illness career (see Figure 2.3). The social content or episode base is the first part of the model, which describes the background characteristics of the individual and illness. These elements set the context for the social support system and the illness career. While the social and geographical location accounts for important demographic variables, such as, race, age, and income, the personal health background includes other important health-related factors, such as, the individual's prior history of illness and medical insurance. Finally, the illness characteristics describe variables pertaining to the unique nature of the illness (e.g. severity, visibility). The second part of the model describes the social support system. The social support system includes the characteristics of the network, such as, the network structure (e.g. size, density, multiplexity),

content (e.g. beliefs, attitudes), and functions (e.g. support) which influence the illness career. The illness career is the final part of the model. This section describes the individual healthcare utilization and compliance behaviors according to their key entrances, exits, and timing and sequencing of health care. While the model also accounts for the dynamic interaction between the social system and illness, asserting the influence of social networks on illness and the influence of illness on social networks, the cross-sectional design of the current study limits the observation of this interaction across time.

Pescosolido initially applied the NEM to investigating the interrelationship between social networks and healthcare utilization and compliance among people with mental illnesses. In 1998, Pescosolido, Wright, Margarita, & Mildred applied the NEM to exploring the complex patterns of health care utilization among low-income mentally ill Puerto Ricans. Among the many findings from this study, results indicate that perceived support significantly impacts the trajectory of mental health care seeking. Since it was first developed in 1991, the NEM has been expanded to include additional social systems, thereby accounting for the complexity of interactions between multi-level networks (Pescosolido, 2011). Additionally, since the first mental health study (Pescosolido et al., 1998), the NEM has been adapted and applied to researching a variety of health-seeking and compliance behaviors in a diversity of populations, including postpartum women (Edmonds, Hruschka, Bernard, & Sibley, 2012) youth at-risk for psychosis (Boydell, Volpe, Gladstone, Stasiulis, & Addington, 2013), and substance users (Pullen, 2013). The current study applies the original version of the NEM to a cross-sectional examination of social networks, social support, and ART adherence among trans women living with HIV.

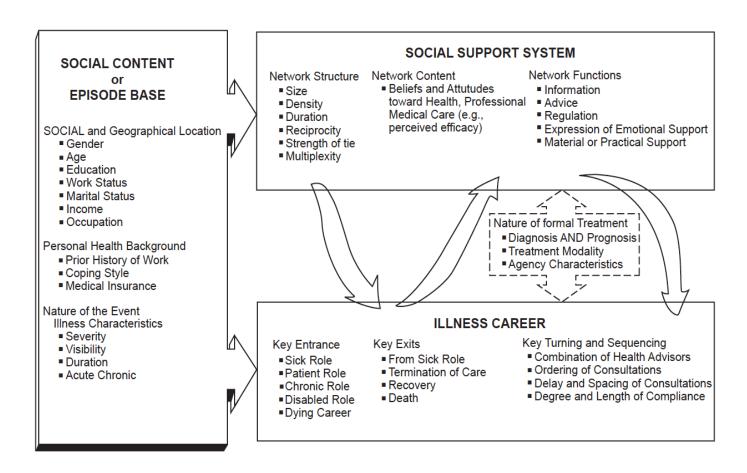


Figure 2.3 The Network Episode Model I

Source: Pescosolido, B.A., & Boyer, C.A. 2010. "Understanding the Context and Dynamic Social Processes of Mental Health Treatment." pp. 420-438 in A.V. Horowitz and T.L. Scheid, eds., A Handbook for the Study of Mental Health: Social Contexts, Theories, and Systems, Edition. New York: Cambridge University Pres

CHAPTER 3

METHODS

Design

This study seeks to increase knowledge of the social support systems of trans women living HIV through social network analysis. Social network analysis is a research method used to understand the relationships between people, organizations, places, and/or things. The units (e.g. people, places, things) are referred to as "actors" or "nodes," and the relationships connecting the actors are "ties" or "vertices (Borgatti, 2013; Scott, 2013; Wasserman, 1994)." Within social network research, different designs are used to describe and investigate the structure, composition, and interactions within a social system of nodes and ties (Marsden, 1990a; Scott, 2013). The following study uses a cross-sectional egocentric design to answer the research questions. Egocentric research aims to understand the social environment surrounding an individual ("ego"). Specifically, egocentric studies examine the structure, composition, and potential influences within personal networks. Once recruited, egos provide information concerning their personal attributes and the perceived attributes of their social network members ("alters"). Hence, the primary advantages of this research include the ability to collect rich data about smaller networks and generalize the results to the ego-network relations of a target population (Marsden, 1990b)

Pre-testing Process

The target population for the study consisted of trans women living with HIV (TWLH). Those who 1) previously received a positive HIV diagnosis from a health care provider, 2) had been prescribed ART therapy, 3) were 18 years or older of age, 4) identified as female/woman or a transgender female/woman (MTF), 5) were assigned male sex at birth, and 6) resided in the USA.

The survey underwent three phases of pre-testing with 1) research assistants within the Department of Health Promotion and Behavior at the University of Georgia, 2) subject matter experts, and finally, 3) members of the target population. First, five research assistants pre-tested the survey using alternate participant scenarios (e.g. a white "trans-identified" ego with one alter in each subnetwork vs, a black "woman-identified" ego with alters in one subnetwork). The goal of this initial pilot was to assess the flow of the survey while checking for grammatical errors and programming flaws. Next, the survey was pre-tested again for flow and errors, in addition to comprehension and appropriateness, by subject matter experts, including those within the areas of social networks, HIV research, practice, and trans health. After revising the survey based upon their feedback, the instrument was finally tested with a focus group consisting of six trans women living with HIV. The goal of this pre-test was to receive feedback on comprehension, flow, language, appropriateness, length, and cultural sensitivity. The final questionnaire was adapted based upon the collective feedback from participants involved in all pre-test phases. Key insights included designing the survey to have a mobile-friendly interface, altering language on selected HIV and transgender questions and re-arranging the survey sections to minimize the risk of missing data on network variables.

Recruitment

Potential participants were recruited though a combination of convenience sampling strategies aimed at reaching a target population representative of a diversity of social contexts across the US. Recruitment took place between February and August 2019. The first recruitment strategy included the distribution of emails and flyers to online transgender and LGBT social groups. The recruitment materials are presented in Appendix B. For online recruitment, websites and social media groups were contacted via a recruitment email or instant message sent to the group administrator. The message introduced the study, detailing the purpose, objectives, inclusion criteria, risks, benefits, and incentives. This initial contact email included the author's contact information and a copy of the study flyer to be distributed on the website and/or social media group. The recruitment flyer/announcement briefly outlined the purpose of the research, study eligibility criteria, data collection description, incentives, contact information, and the link to an online screening instrument. An additional recruitment email or message was sent to site administrators if an email/message in response to the initial contact attempt was not received. Similarly, recruitment emails (one initial and one follow-up) with the same information and content were sent to administrators at clinics and other public venues where the target population frequented. Eligible people who participated in the formative study for this research and who also consented to being contacted about future opportunities for which they might qualify, were also contacted via the method that they designated on their contact form (e.g. phone number or email). In-person recruitment also took place at community-based organizations in metro-Atlanta which provided HIV care and social services to TWLH on appointed days and times. Prior to inperson recruitment days, the researcher introduced the study to potential participants within a support group setting and provided information on how to access the survey independently

and/or provide information on when they could return to the organization to receive logistical support while completing the survey in-person. On data collection days, the researcher was present to offer support to participants who were experiencing literacy or technological barriers to accessing and completing the survey. One of the data collection sites also provided a private office space and computer so that participants could take the survey. Additional methods also included recruiting participants in-person who were in the agency on data collection days and snowball methods – where those who completed the survey were given flyers to distribute to others who might qualify. Finally, potential participants were recruited in public events hosted and attended by trans women in metro Atlanta. Logistical support with filling out the survey was also offered to three participants who called the research number provided on the research materials.

Though multiple convenience sampling strategies were concurrently employed, recruitment efforts and data collection were intentionally (and inadvertently) staged across the data collection period, where study information was disseminated to certain organizations located in different regions of the US over the course of a few weeks to a month. Recruitment efforts were also paced according to the time that it took the researcher to form alliances with inperson recruitment venues. In a similar fashion, recruitment materials were intermittently shared with certain groups with a two-three-week follow-up period. This time-phased convenience sampling strategy was used to increase the diversity of networks included in the sample. Natural data collection lulls also provided the opportunity to shift recruitment to different areas or population segments.

Informed Consent

Informed consent took place at be beginning of the survey, where participants were able to read a detailed explanation of the study procedures, risks, and benefits. It is important to note that though the consent form was originally determined to be appropriate for the target population during pre-testing, it was revised in the middle of data collection to facilitate comprehension and participation among potential participants who had literacy barriers to understanding it. The alterations were based on the researcher's observation of literacy barriers experienced by certain participants during in-person data collection and in consultation with an expert in the area of trans health. Edits to the consent form were made using an online literacy tool which searched the document and calculated readability formulas (e.g. the Flesch reading ease formula)(Readability Formulas, 2019). After using this tool, the literacy level of the consent form was reduced from a college graduate level to a sixth-grade level. Appendices C and D show the original and revised versions of the consent form, respectively. Those interested in continuing to the survey could opt in or out of participating in the research.

Screening & Eligibility

Those who chose to participate were automatically redirected to an online eligibility screening tool. The tool had a series of questions asking participants about their age, the status of HIV diagnosis, assigned sex at birth, gender identity, and ART prescription status. Eligible participants were a) 18 years of age or older, b) had been diagnosed with HIV and prescribed ART c) assigned male sex at birth, and d) identified as a women or transgender woman and e) lived in the US. Those who satisfied the screening requirements were redirected to an egocentric network survey hosted on Qualtrics.

Survey

Participation involved a 20-30-minute online survey divided into four parts: a name generator, egocentric network assessment, network generator, and egocentric questions. The first part of the survey had a series of three name generators aimed at soliciting people within the participant's personal, HIV, and gender-focused networks. The name generator is important for gathering information about the ego-alters ties, network structure, and alter attributes. A variety of network generators have been used to elicit different types of egocentric networks. The "important matters" name generator from the General Social Survey (Burt, 1984) was the first one used to construct participant networks by asking them to identify up to seven people with whom they discuss important personal matters with. The upper limit for alter nomination used in the current study is enough based upon Burt's (1984) determination of feasible egocentric network boundaries given the benefits and costs of measurement precision, measurement bias, and time constraints. The "important matters" name generator has been used in many egocentric network studies and is a good fit for soliciting the personal networks of interest for this study. The first generator asked participants to list the names of up to seven people with whom they discussed important matters or who would discuss important matters with them. The next generator asked egos to identify those from the "important matters" generators with whom they also discussed HIV-related matters. The following question asked them to list up to seven additional people with whom they discussed HIV-related matters. The final generator asked if they could identify people from both the "important" and "HIV" matters networks with whom they would discuss gender or transgender-related matters. The final question asked them to list up to seven additional people with whom they would discuss gender-related matters.

After listing up to 21 names across all three generators, participants were directed an egocentric network assessment. This consisted of a series of questions asking about the characteristics of the alters and the ego's relationship to each one. Specifically, they were asked to indicate each alter's age, race, and gender identity (e.g. transgender, male to female, etc.). They were also asked to provide details of their relationship to each alter, such as, the alter's role (e.g. biological family, chosen family, partner, etc.), how long they've known them, their communication modes, frequency of contact, and HIV status.

The name generator was followed by a network generator, asking egos who each alter knew across all three networks. The goal of this question is to describe the interconnections between the different people within their networks. In the final part of the survey, egos were asked to provide demographic and health background information about themselves. This information included questions about their age, race, relationship status, as well as, their insurance status and date of diagnosis.

Participants were compensated with a \$20 gift card or cash at the completion of the survey. Complimentary food was also offered to potential participants who consented and took the eligibility screener on in-person data collection days. All study procedures were implemented upon approval by the Institutional Review Board at the University of Georgia. An abbreviated version of the survey with study measures examined here can be found in Appendix E.

Measures

The survey consisted of items and measures corresponding with a version of the Network Episode Model (NEM) (Pescosolido, 1991) adapted to fit the research questions and target population (Figure 3.1). While the original constructs of the NEM were retained in the present study, the model was adapted to include variables and items relevant to trans women living with HIV as found in the literature and a qualitative formative study conducted by the researcher. Figure 3.1 shows the adapted version of the NEM used in the present study.

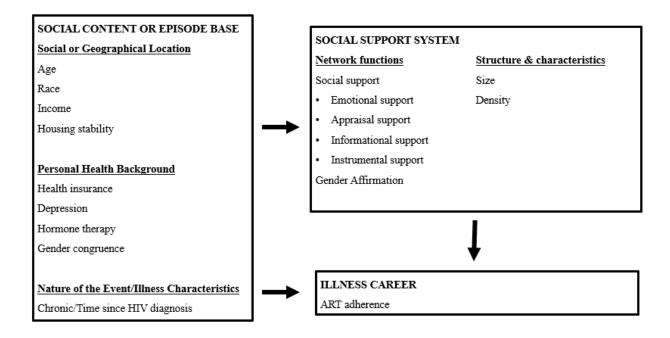


Figure 3.1 Network Episode Model for ART Adherence and Social Networks among Trans Women Living with HIV

Social Content & Episode Base

The Social Content and Episode Base is the first component of the NEM. This section establishes the foundation for defining the characteristics of the ego and the illness, which are connected to the social system and illness career. Specifically, this part of the model contains variables concerning the social and demographic location, personal health background, and the characteristics of the chronic illness.

Social & Geographic Location

Social and geographic location accounts for the demographic variables which may impact an individual's treatment utilization. Most of the variables in this study are specified in the original version of the NEM and all are substantiated by research linking them to ART adherence (See Chapter 2). For the above reasons, data were collected on the ego's age, race, education, income, and housing status.

Age

As explained in the previous chapter, age is a significant determinant of ART adherence. In this study, participants were asked to indicate their age through an open-ended response to the question, "what is your age?" This variable was coded continuously.

Race/Ethnicity

Race is an important demographic variable and risk factor for ART adherence which is included the NEM and the adapted version used in the current study. In the survey, participants were asked to identify their race/ethnicity from a selection of response categories corresponding with a diversity or racial/ethnic identities. Specifically, they were asked "which race do you identify with?" Responses were coded categorically: "White/Caucasian" (0), "Black/African American" (1), Latinx/a/o (2) "Asian" (3), "American Indian/Alaska Native" (4), "Native Hawaiian/Pacific Islander" (5), and "Other" (6).

Income

Income is another key demographic variable that is included in the NEM. Participants were asked to select a nominal response category featuring a range of values including their annual household income. This response was coded nominally, with responses ranging from "\$0-5,000 (up to \$416/month)" (coded as 0) to "greater than \$50,000 (\$4,167+/month)" (coded as 6).

Housing status

Though housing status is not included in the original NEM, it was be assessed in the present study due to the high rates of housing instability among transgender people and the impact that housing status has on ART adherence (Mizuno et al., 2017). On the survey, participants were asked to indicate their housing status by choosing from a categorical selection of responses. Specifically, participants were asked to indicate their housing status from the following options: homeless (living on the street, in a shelter, or other temporary place), doubled-up (currently living in someone else's house/apt), and stably housed (currently living in a place of their own). Responses were coded categorically, ranging from 0 (homeless) to 1 (unstably housed), and 2 (stably housed).

Personal Health Background

The personal health background is a section of the Social Content and Episode Base of the NEM which assesses other important factors that contribute to the health and wellbeing of an individual. The model, as applied to this study, measured health-related variables which research has found to have a significant effect on ART adherence among People living with HIV and trans women living with HIV (as explained in the previous chapter). These factors include health insurance and depression.

Health Insurance

Health insurance coverage was assessed by asking participants to indicate how they paid for ART. They were given the options of indicating they type of coverage that they had from a categorical selection of options "uninsured" (0), "Ryan White/AIDS drug assistance program" (1), "Medicare" (2), "Medicaid" (3), "Other" (4). These were later dichotomized to indicate whether they did (1) or didn't have insurance (0).

Depression

A shortened version of the Center for Epidemiological Studies Depression Scale (CESD) was used to measure depressive symptomology in participants. The CESD-10 has demonstrated high reliability (Cronbach's alpha = 0.88) when previously used to screen for depression in PLWH. Using 4-point Likert scale, participants indicated their level of agreement to ten statements assessing depression over the last week, such as, "I felt like I could not get going," and "I had trouble keeping my mind on what I was doing." Responses were be scored according to a frequency response scale ranging from "rarely or none of the time" (0) to "most or all of the time" (3). Afterwards, they were summed with possible scores ranging from a minimum of "0" to a maximum of "30," Higher scores correspond with increasing severity of depression, with a score of 10 or higher indicating significant depression symptoms.

Event Illness Characteristics

Time since HIV diagnosis

To assess time since diagnosis, participants were asked to indicate the date (month/day/year) that they were diagnosed with HIV. To calculate time since diagnosis (months), a new continuous variable was created by subtracting the date of diagnosis from the date that they filled out the survey.

Social Network System

The social network system is a principal component of the NEM which is central to explaining the connection between multiple aspects of the social network and the illness career. The network functions, structure, and characteristics are categories which assess variables measuring the social processes, context, and traits that are involved in treatment utilization behaviors of individuals. During the survey, an egocentric network assessment was used to collect data on the personal networks of trans women living with HIV. Ethical concerns with anonymity and confidentiality were minimized by asking egos to use a first name only when listing an alter.

Network Functions

Network functions are defined by the processes exchanged within and provided by social networks. While social networks include a range of interactions by which the health status and behaviors of individuals are impacted, the perception of social network support is the process of interest in this study. Additionally, other network functions (e.g. gender affirmation) which may interact with support and/or ART adherence or confound the relationship between these variables were also measured.

Social support

Egos were asked single-item questions corresponding with social support processes documented in the literature (appraisal, informational, instrumental, and emotional). For these, egos responded "yes" (1) or "no" (0) to questions like "Could you borrow money from [ALTER] if you needed to?"

Gender affirmation

Given the critical importance of gender affirmation as a form of support for many transgender individuals, this study measured the levels of perceived gender affirmation as a function of egocentric networks. Egos were asked about perceived gender affirmation from each alter. The questions used to evaluate network gender affirmation came from research on gender identity conflict and affirmation in the interpersonal relationships of trans women (Nuttbrock et al., 2012; Sevelius et al., 2013). Specifically, egos were asked "does [ALTER] address you by your preferred pronoun?" and "does [ALTER] treat you the way that you want to be treated as a woman/trans woman?"

Network Structure and Characteristics

Network structure and characteristics include a range of variables which define the arrangement and type of relationships. These variables are calculated based upon the data collected from the ego during the egocentric network assessment. During the egocentric network assessment, egos were asked to provide their perceptions of alter and tie characteristics, including the alters demographics and HIV status. While there are many network variables that could be approximated based upon an egocentric network assessment, this study focused on network size and density. The network structure is approximated by the ego's interpretation of the interrelationships between the alters. In this study, egos were asked to indicate to the best of their knowledge whether each alter knows each of the other alters. If they indicated "yes," a tie was counted between the given alter-alter pair. Conversely, if they indicated "no," a tie was not assigned to the given alter-alter pair. Although alter attributes are not specified as variables in the NEM, egos were also asked to identify characteristics of each alter, including their age, race, gender, and HIV status. These attributes were used for descriptive purposes (see Aim 1) and to calculate other network measures included in the model.

Network size

Network size is an important variable because it serves as an index for possible sources of support within a network. Network size was determined by summing the total number of alters nominated in a network. Given the network boundary, possible values for the network size were on a continuous scale, ranging from 0 to 21.

Density

Density measures the extent to which network members are connected to each other.

Dense networks are indicative of the overall strength of the support system surrounding the ego.

This measure was calculated by dividing the actual number of ties by the total possible ties.

Thus, network density continuously ranges from 0 to 1, with 0 indicating that none of the alters are connected and 1 indicating that everyone in the network is connected.

Tie Strength

To measure tie strength, egos were asked to indicate how close they were to each alter.

Responses ranged from not at all close (0) to very close (4).

The Illness Career

In the NEM, the illness career is defined by the actions that individuals take to manage their chronic illness. The original NEM conceptualizes the illness career as a dependent or independent variable, based upon the dynamic interplay between social networks and treatment utilization over time. While chronic HIV career may encompass multiple aspects of treatment seeking and illness management, this study focuses on a singular aspect of ART dose adherence.

ART Adherence

ART adherence was measured through the Adult AIDS clinical trials group (AACTG) adherence instrument (Chesney et al., 2000). This self-report measure has been widely used by previous researchers and demonstrates robust measurement of participants' recent and distal medication adherence (Cronbach's alpha = 0.81). Scores at or above 95% were coded as "optimal" (1) and those below 95% were coded as "sub-optimal" (0).

Percentage scores for ART adherence were calculated using the following equation:

$$1 - \frac{\text{Average no. of missed doses over the past 4 days}}{\text{No. of prescribed doses}}$$

Data Analyses

Data analyses were conducted in three phases according to the study aims. Descriptive statistics of the participants and social network were calculated in Excel, the Statistical Package for Social Sciences (SPSS), and E-Net - a software package designed for egocentric network analysis (Borgatti, 2006)(Aim 1). Next, bivariate analyses testing the association between social content and episode base variables and ART adherence were conducted in SPSS (Aim 1). Finally, hierarchical logistic regression models with individual and network-level variables predicting ART adherence were modeled in SPSS (Aim 2). The following section provides more details on the proposed analyses and organizes the analyses according to each aim.

Aim 1: Describing Networks & Compartmentalization

The objective of the first aim was to characterize the personal networks of trans women living with HIV while comparing levels of support between the different networks. The size and density of the overall network and sub-networks were calculated by in Excel, while counts, proportions, and mean statistics for network composition were calculated in E-Net. Frequencies, means, and standard deviations of measures used to describe the sample demographic, personal health background, illness characteristics, and ART adherence behaviors were calculated through bivariate analyses in the Statistical Package for Social Sciences (SPSS). Next, descriptive statistics were calculated to determine network composition, structure, and ego-alter characteristics for each subnetwork (important matters, HIV matters, and gender matters). The same measures were also compared between alters who are only in a single network versus multiple networks. Table 3.1 lists the variables and description of the descriptive measures for characterizing the egocentric networks.

Table 3.1 Var	Table 3.1 Variables & Descriptive Measures for Aim 1			
Variable	Descriptive Measure			
Composition	% Trans women, men, trans non-conforming, cis women, & men			
	% White, Black, Latinx/a/o, Asian/Pacific, & other racial identities			
	% Kin, chosen family, partner/spouse, friends, health providers, etc.			
	% HIV positive & negative			
	% Communication by email, in-person, phone, social media, texting,			
	% No conflict, a little conflict, some conflict, & a lot of conflict			
	% HIV disclosure & non-disclosure			
	% Gender disclosure & non-disclosure			
	% No gender affirmation, partial affirmation, full affirmation			
Tie	% Known for ≤ 6 months, 7-12 months, 1-2 years, ≥ 2 years or longer			
	% Contact frequency ≥ 1 year, < once/year, bimonthly, monthly,			
	weekly, daily			
	% Not at all close, not very close, close very close			
Size	Mean number of alters			
Density	Mean density			

Aim 2: Modeling support & ART adherence

The objective of the second aim was to evaluate the relationship between different types of perceived support and ART adherence. Any observations with missing data concerning ART adherence were eliminated from the analyses. It is believed that adherence data were missing systematically due to participant confusion with the response format of the adherence questionnaire, as observed during in-person data collection. The original ACTG questionnaire asks respondents to indicate the number of doses they missed on each of the past four days, but the response format used in this study pooled those responses together into one question. While putting the responses together may have reduced the time for answering separate questions, participants who were completing the survey in-person often asked the author for help in understanding how to respond to the question. Ultimately, the sample size for the second aim was reduced from 231 to 141 observations due to the missing data on the ART adherence variable.

Reliability analyses were conducted on the depression scale (Cronbach's α = 0.86), which demonstrated high reliability. Independent samples t-tests and X^2 tests were conducted on SPSS to assess significant demographic and network differences between participants with suboptimal ART adherence (< 90%) and optimal ART adherence (\geq 90%). The relationships between variables and adherence were analyzed through hierarchical logistic regression. Hierarchical regression models are nested models which can be used to examine associations between predictor variables while controlling for the effects of other factors (Field, 2013). Through various selection methods, variables are either sequentially added or eliminated from separate blocks to fit a given model.

The variable selection strategy for constructing the hierarchical logistic regression model was initially based upon a review of literature and the theoretical framework for the study, which explain the associations between study variables and ART adherence. The variable selection strategy was further refined by the results of bivariate analyses, examining the association between baseline variables and ART adherence. The purpose of the correlations was to identify any variables outside of the variables of interest which might be significantly associated with adherence. The correlations were also reviewed to assess potential issues with multicollinearity between model variables. Multicollinearity was also formally assessed via diagnostic tests. The results of these analyses indicated that multicollinearity would not be an issue, as the tolerance values exceeded .1 and none of the VIF values were greater than 10 (Field, 2013). The results of these diagnostics are available upon request from the author. Variable entry into the model began with entering depression and other demographic variables into the first block, and adding the support variables (emotional, appraisal, informational, and instrumental support) into the second. The final block contained variables from the previous block, in addition to network variables (size and density

CHAPTER 4

RESULTS

This study seeks to increase knowledge of how trans women living with HIV construct and navigate their social networks for personal, health, and gender-related resources. The goal of the first aim is to describe the structure, composition, and relationship (tie) characteristics of TWLH egocentric networks. The goal of the second aim to evaluate the relative association between different forms of perceived network support and ART adherence. The sample demographics and results of each aim are described in the following sections.

Sample Demographics

On average participants were about 32 years old and had been diagnosed for about four and a half years. When asked about their gender identity, most (84%) identified as trans women (as opposed to women) and were White (62%). Most were employed (67.8%), stably housed (70.9%), and had some form of health insurance (73%). Nearly 89% (N=204) of survey responses were completed online, while 11% (26) were in-person. Bivariate analyses of sample demographics by data collection mode showed that online participants were significantly more likely to be employed (p = .001) and stably housed (p = .000) in comparison to participants who completed the survey in-person. They were also younger on average (p = .000) and had been diagnosed for a shorter period (p = .003). The demographics of the sample are detailed in Table 4.1.

Table 4.1. Demographic Characteristics of Participants $(N = 231)$			
Variable	Mean	SD	
Age (years)	31.67	7.58	
Time since diagnosis (months)	55.68	29.5	
Depression (CESD-10)	10.82	5.64	
	N	(%)	
Data Collection			
Online	204	88.7	
In-person	26	11.3	
Gender Identity			
Woman	16	7	
Trans woman	214	93	
Race			
Black/African American	61	26.5	
Latino	21	9.1	
White	143	62.2	
Other (American Indian, Asian, Other)	5	2.2	
Annual household Income			
\$0-10,000	41	17.8	
\$10,001-20,000	60	26.2	
\$20,000-30,000	54	23.6	
>\$30,000	74	32.2	
Work Status			
Unemployed	74	32.2	
Employed	156	67.8	
Housing Status			
Homeless	20	8.8	
Doubled-up	44	19.4	
Stably housed	163	71.8	
Health Insurance			
No	61	26.5	
Yes	168	73.0	
Relationship Status			
Never married	136	59.1	
Widowed	2	0.9	
Separated	7	3	
Divorced	8	3.5	
Living with a partner	36	15.7	
Married	41	17.8	

Aim 1: Description of Networks

Data on the structural characteristics of the networks are shown in Table 4.2. On average, participant's networks had about five people in them and were moderately dense (0.51). Examples of participant sociograms are in Appendix F. They discussed important matters, HIV matters, and gender matters with a mean of two to three people. Among these networks, the important matters network had the highest density (.62), followed by the health matters (.48). The gender matters network was the least dense out of the three subnetworks (.39).

Table 4.2. Size and density of overall, important, HIV, & gender networks						
Variable	Networks	Networks				
	Overall	Overall Important HIV Gender				
	Mean, (SD) Mean, (SD) Mean, (SD)					
Size	4.59(4.64)	2.46(1.99)	2.96(2.56)	2.77(2.43)		
Density	0.51(0.40)	0.62(0.37)	0.48(0.43)	0.29(0.39)		

Statistical comparisons between the three networks were not feasible due the substantial overlap in alters between the three networks. The sample size also restricted the ability to conduct reliable analyses of differences between the people with whom they discussed exclusive matters (e.g. important matters only vs. HIV matters only). Data on the structure and composition of the overall network and each subnetwork are displayed in Table 4.3. Overall, the demographic and tie characteristics of the overall and subnetworks were comparable. They shared similar racial demographic profiles, with a comparable proportion of white and black participants, followed by Latinx/a/o and other groups. Though alters had many roles, each network was predominately composed of friends, co-workers, and chosen family, respectively. About half of the people within the overall network and subnetworks were HIV-positive. There was one notable distinction in the composition of networks by gender identity. While cisgender female alters predominated overall, important, and HIV matters networks, cisgender males comprised a larger proportion of alters in the gender matters network.

Table 4.3. Composition of important, HIV, and gender networks					
Variable Networks					
	Overall	Important	HIV	Gender	
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	
Age (Years)	35.19(11.11)	35.81(11.85)	36.11(11.69)	34.87(11.18)	
Social Support					
Informational	.78(.42)	.81(.39)	.82(.39)	.82(.38)	
Instrumental	.79(.41)	.85(.36)	.84(.37)	.84(.37)	
Appraisal	.75(.43)	.78(.42)	.80(.40)	.81(.39)	
Emotional	.75(.43)	.81(.40)	.80(.40)	.78(.41)	
	N(%)	N(%)	N(%)	N(%)	
Gender Identity					
Trans woman	284(27.3)	164(29.2)	174(25.8)	199(31.4)	
Trans man	78(7.5)	32(5.7)	45(6.7)	46(7.3)	
Gender non-conforming	381(3.1)	20(3.6)	16(2.4)	13(2.1)	
Cis man	264(25)	154(27.5)	183(27.2)	230(36.3)	
Cis woman	381(36.1)	191(34.0)	256(38.0)	146(23.0)	
Race					
White	462(44)	257(45.7)	301(44.4)	297(46)	
Black	436(41.5)	239(42.5)	302(44.5)	272(42.2)	
Latinx/a/o	108(10.3)	46(8.2)	58(8.6)	56(8.7)	
Asian/Pacific	28(2.7)	11(2.0)	11(1.6)	11(1.7)	
Other	16(1.5)	9(1.6)	6(0.9)	9(1.4)	
Role					
Relative	99(9.4)	69(12.3)	68(10)	57(8.8)	
Chosen Family	117(11.1)	83(14.7)	84(12.3)	77(11.9)	
Partner/Spouse	57(5.4)	44(7.8)	39(5.7)	46(7.1)	
Friend	426(40.3)	233(41.4)	252(37)	239(36.9)	
Health Provider	109(10.3)	29(5.2)	62(9.1)	52(8)	
Co-worker	176(16.7)	61(10.8)	90(13.2)	89(13.7)	
Neighbor	65(6.2)	9(1.6)	16(2.3)	22(3.4)	
Classmate	74(7.0)	19(3.4)	21(3.1)	24(3.7)	
Other	17(1.6)	3(0.5)	6(0.9)	8(1.2)	
HIV serostatus					
Positive	475(46.0)	256(46.3)	304(45.6)	340(53.5)	
Negative	558(54)	297(53.7)	362(54.4)	296(46.5)	

Egos had similar relational/tie and communication characteristics with alters across networks. These characteristics are presented in Table 4.4. They had known most of their alters for at least a year and contacted most of them at least once every month. Multiple communication methods were used to contact alters. Egos mostly communicated with their overall network either in-person (46.6%) or by phone call (48.5%). While the most common methods of communication in the important matters network included phone calls (46.5%) and texting (40.3%), communication methods were mostly shared between phone calls (35.2%) and texting (32.7%) in the health matters networks. Phone calls (41.2%) and in-person interactions (39%) predominated communication methods with people within the gender matters network. They were close to many alters, perceived full gender affirmation by most. Overall, both gender and HIV status disclosure were high across all networks.

Table 4.4 Ties and communication with alters in overall, important, HIV, & gender networks

Variable	Overall	Important	HIV	Gender
	N(%)	N(%)	N(%)	N(%)
Relationship Length				
≤ 6 months	88(10.7)	39(9.1)	47(9)	47(9.9)
7-12 months	148(18.0)	64(15)	71(13.6)	75(15.8)
1-2 years	151(18.4)	69(16.1)	100(19.2)	80(16.8)
≥ 2 years	435(52.9)	256(59.8)	303(58.2)	274(57.6)
*Communication				
Email	64(6.1)	12(8.3)	15(9.1)	15(8.5)
In-Person	492(46.6)	55(38.2)	30(18.2)	69(39)
Phone	512(48.5)	67(46.5)	58(35.2)	73(41.2)
Social Media	295(27.9)	43(29.9)	50(30.3)	51(28.8)
Texting	396(37.5)	58(40.3)	54(32.7)	59(33.3)
Other	13(1.2)	2(1.4)	5(3.0)	2(1.1)
Contact Frequency				
≥ 1 year	54 (5.1)	25(4.4)	28(4.1)	23(3.6)
< once/year	32(3.0)	15(2.7)	18(2.7)	12(1.9)
Bimonthly	105(9.9)	33(5.9)	64(9.4)	53(8.2)
Monthly	143(13.5)	61(10.9)	77(11.4)	73(11.3)
Weekly	344(32.6)	189(33.6)	210(31)	221(34.2)
Daily	373(35.3)	239(42.5)	281(41.4)	265(41)
Tie Strength				
Not at all close	47(4.5)	16(2.9)	19(2.8)	19(2.9)
Not very close	82(7.8)	34(6.1)	50(7.4)	28(4.3)
Somewhat close	173(16.5)	66(11.8)	93(13.7)	96(14.8)
Close	236(22.3)	120(21.4)	147(21.7)	133(20.6)
Very close	511(48.4)	325(57.9)	369(54.4)	371(57.3)
Multiplexity				
Single tie/role	851(86.4)	455(83)	527(83.8)	523(85.2)
Multiple ties/roles	134(13.6)	93(17)	102(16.2)	91(14.8)
Conflict				
Not at all	586(56.5)	350(63.2)	406(60)	387(61.1)
A little	275(26.5)	125(22.6)	171(25.3)	158(25)
Some	123(11.8)	56(10.1)	67(9.9)	64(10.1)
A lot	54(5.2)	23(4.2)	33(4.9)	24(3.8)
HIV Disclosure				
No	257(24.4)	117(20.8)	130(19.1)	139(21.5)
Yes	797(75.6)	446(79.6)	551(80.9)	508(78.5)
Gender Disclosure				
No	231(22.0)	103(18.3)	126(18.5)	120(18.7)
Yes	819(78.0)	460(81.7)	554(81.5)	523(81.3)

Gender Affirmation				
Not Affirming	156(14.8)	77(13.7)	87(12.9)	80(12.4)
Partly Affirming	214(20.4)	86(15.3)	113(16.7)	106(16.5)
Fully Affirming	679(64.7)	400(71.0)	477(70.5)	457(71.1)

^{*}Percentages do not add up. Communication modes weren't mutually exclusive (e.g. email and text-messaging). Percentages are comparisons between the variable and all other options

Egos discussed more than one issue with nearly two-thirds of alters. Table 4.5 describes the extent of alter overlap between the important, HIV, and gender matters discussion networks.

Table 4.5 Frequency and degree of alter overlap across discussion networks			
Variable	N(%)		
Alter overlap			
No	507(48.0)		
Yes	545(51.8)		
Degree of overlap			
No overlap (one network)	507(48.2)		
Two networks	268(25.5)		
Three networks	277(26.3)		

Given the sizeable extent of network overlap, additional analyses were conducted to expand this aim by exploring potential differences between the alters with whom egos discussed one or multiple issues with. These data are displayed in Table 4.6. The people they discussed more than one issue were significantly more likely to be cis male and trans female (p = .022). In terms of roles, egos discussed multiple matters with a significantly higher proportion of chosen family (p = .000), partners/spouses (p = .000), and friends (p = .003), while they discussed only one matter with neighbors (p = .013), classmates (p = .000), and health providers/case workers (p = .002).

Variables	Network Number		Chi ² /F
	One network	Multiple networks	
	Mean(SD)	Mean(SD)	
Age (Years)	34.11(10)	36.24(11.9)	21.38***
	N(%)	N(%)	
Gender Identity			
Trans woman	127(25.5)	156(29.1)	11.46**
Trans man	49(9.8)	28(5.2)	
Trans non-conforming	19(3.8)	13(2.4)	
Cis man	118(23.6)	145(27.1)	
Cis woman	186(37.3)	145(27.1)	
Race	. ,		
White	215(42.8)	244(44.9)	45.9***
Black	178(35.5)	258(47.4)	
Latinx/a/o	74(14.7)	33(6.1)	
Asian/Pacific & Other	35(7)	9(1.7)	
Role			
Relative	39(7.7)	59(10.8)	3.053
Chosen Family	26(5.1)	91(16.7)	35.57***
Partner/Spouse	18(3.6)	39(7.2)	6.66**
Friend	180(35.5)	243(44.6)	9.02***
Health Provider/Caseworker	68(13.4)	41(7.5)	9.81**
Co-worker	91(17.9)	85(15.6)	1.04
Neighbor	41(8.1)	24(4.4)	6.15**
Classmate	50(9.9)	24(4.4)	11.97***
Other	8(1.6)	9(1.7)	.925
HIV serostatus		·	
Positive	225(45.5)	249(46.6)	.143
Negative	270(54.5)	285(53.4)	

Egos were also more likely to have multiplex relationships with alters who were in multiple networks (p = .000) and to have known them for more than two years (p = .000). They were also more likely be very close to them (p = 000), to have daily contact with them (p = .000) and do so through email (p < .01), phone call (p < .01), and in-person interactions (p < .01). Finally, egos disclosed their gender identity (p = .000) and HIV status (p = .000) to a significantly higher proportion of alters in multiple discussion networks and perceived higher affirmation from them (p = .000). Additional details on tie and communication characteristics are outlined in Table 4.7.

Table 4.7 Tie & communication characteristics of alters in one vs. multiple networks				
Variables	ariables Network Number			
	One networks	Multiple networks		
	N(%)	N(%)		
Relationship Length				
\leq 6 months	55(13.1)	33(8.3)	56.73	
7-12 months	105(25)	42(10.5)		
1-2 years	89(21.2)	61(15.3)		
≥ 2 years	171(40.7)	263(65.9)		
*Communication Method(s)	, , ,	, ,		
Email	44(8.7)	19(3.5)	12.58**	
In-Person	161(31.8)	329(60.4)	86.4	
Phone	203(40)	309(56.7)	29.17	
Social Media	151(29.8)	143(26.2)	1.64	
Texting	177(34.9)	219(40.2)	3.11	
Contact Frequency				
≥ 1 year	39(7.8)	14(2.6)	94.4	
< once/year	23(4.6)	9(1.7)		
Bimonthly	70(13.9)	35(6.4)		
Monthly	94(18.7)	49(9.0)		
Weekly	160(31.8)	183(33.6)		
Daily	117(23.3)	254(46.7)		
Tie Strength				
Not at all or not very close	102(20.4)	26(4.8)	136.80***	
Somewhat close	113(22.6)	59(10.8)		
Close	128(25.6)	108(19.8)		
Very close	157(31.4)	352(64.6)		
Multiplexity				
Single tie/role	418(90.5)	429(82.7)	12.67***	
Multiple ties/roles	44(9.5)	90(17.3)		
Conflict				
Not at all	225(45.3)	359(66.9)	53.63***	
A little	155(31.2)	120(22.3)		
Some	81(16.3)	40(7.4)		
A lot	36(7.2)	18(3.4)		
HIV Disclosure	, ,			
No	170(33.7)	85(15.6)	46.45***	
Yes	335(66.3)	460(84.4)		
Gender Disclosure				
No	152(30.3)	78(14.3)	38.68***	
Yes	350(69.7)	466(85.7)		
Gender Affirmation				
No	95(19)	60(11)	85.59***	

Partial Affirmation	153(30.5)	61(11.2)	
Full Affirmation	253(50.5)	423(77.8)	
*p < .10, **p < .05, ***p < .01			

Egos perceived all forms of social support from a significantly higher proportion of alters with whom they discussed multiple issues with. The most notable differences in the perceived proportion of those who would provide instrumental (.68 vs. .89, p = .000) or emotional aid (.63 vs. .86, p = .000). The differences in each form of perceived support are shown in Table 4.8.

Table 4.8 Social support characteristics of alters in one vs. multiple networksVariablesNetwork NumberChi²/F				
Variables	Network Numb	Network Number		
	One Network	Multiple Networks		
	Mean(SD)	Mean(SD)		
Social support				
Informational	.68(.47)	.87(.34)	-7.29***	
Instrumental	.68(.47)	.89(.31)	-8.38***	
Appraisal	.65(.48)	.85(.36)	-7.53***	
Emotional	.63(.48)	.86(.34)	-9.02***	
Emotional $p < .10, p < .10$.86(.34)	-9.02*	

Aim 2: Social Network Support & ART adherence

The objective of the second aim is to evaluate the impact of different forms of support on ART adherence, while controlling for the additional effects of individual and network attributes. Nearly 70% of participants reported taking ART doses as prescribed \geq 95% of the time, while nearly 30% did not. Table 4.9 details the demographic characteristics of the sample included in the analyses for the second aim according to adherence. Bivariate analyses detected significant differences in depression (r = -.21, p < .05), network size (r = -.26, p < .01), emotional support (r = .20, p < .01), and appraisal support (r = .19, p < .01) in participants with optimal and suboptimal adherence. Those with optimal adherence had lower odds of being depressed, and

higher odds of perceiving higher appraisal and emotional support from their network. Though differences in informational and instrumental support did not reach statistical significance, those with suboptimal adherence perceived that a lower percentage of their network would provide these forms of support in comparison to participants with optimal adherence. Similarly, suboptimally adherent participants also perceived that a lower percentage of their network affirmed their gender identity through pronouns (mean difference = 8%) and treatment (mean difference = 6%) compared to optimally adherent participants. The results of the simple correlation between variables are in Appendix G.

adherence	Sub-optimal	Optimal	<i>P</i> -value
	Adherence ^a	Adherence ^a	P-value
	(≤ 95% adherence)	(≥ 95% adherence)	
	N(%)	N(%)	
N = 141	44(31.2)	97(68.8)	
Variables	(61,2)	<i>y r</i> (ce.c)	
	Mean(SD)	Mean(SD)	
Age (Years)	32.26(6.06)	32.12(8.69)	.132
Diagnosis Time (months)	77.20 (83.07)	55.25(78.13)	.875
Depression (CESD-10)	12.28 (6.06)	9.61(5.73)	.014**
Appraisal Support	71.95(33.39)	83.91(26.78)	.040*
Emotional Support	73.05(29.43)	85.40(27.89)	.018**
Informational Support	78.19(29.69)	84.52(29.72)	.243
Instrumental Support	77.99(28.41)	86.02(27.01)	.244
Total Network Size	5.93(3.90)	4.01(3.08)	.005***
Total Network Density	.51(.32)	.62(.44)	.120
·	N(%)	N(%)	
Method			
Online	39(32)	5(26.3)	.621
In-person	83(68)	14(73.7)	
Race			
White	19(43.2)	56(57.7)	.233
Black	18(40.9)	32(33)	
Other	7(15.9)	9(9.3)	
Annual Household Income			
\$0-10,000	15(34.1)	18(18.8)	.118
\$10,001-20,000	13(29.5)	33(34.4)	
\$20,000-30,000	7(15.9)	29(30.2)	
>\$30,000	9(20.5)	15(16.7)	
Work Status			
Unemployed	18(40.9)	44(45.4)	.622
Employed	26(59.1)	53(54.6)	
Housing Status			
Homeless	6(14)	10(10.5)	.386
Doubled-up	8(18.6)	28(29.5)	
Stably housed	29(67.4)	57(60)	
Health Insurance			
No	17(38.6)	31(32.3)	.463
Yes	27(61.4)	65(67.7)	

The results of the nested logistic regression analyses are shown in Table 4.10. A few of the demographic variables which differentiated between online and in-person participants were entered into the first model to control for potential within-sample differences. Overall, findings indicated that depression significantly predicted ART adherence in all tested models. None of the demographic variables (age, housing, and diagnosis time) were significant predictors. Adding social support variables into the second block significantly improved the fit in comparison to the null model (Model $X^2 = 20.29$, p = .016) but it did not improve model fit in comparison to the previous one, without support (Block $X^2 = 8$, p = .09) and none of the support variables were significant predictors. The addition of network measures (size and density) significantly improved model fit over the null and previous models (Block $X^2 = 6.84$, p = .033, Model $X^2 =$ 27.14, p = .004). Among the support variables, increased emotional support was marginally associated with increased odds of ART adherence (aOR = 1.03, p = .046) after adjusting for the effects of other variables. Depression and network size were also individual and network-level variables which also predicted lower odds of ART adherence (aOR = .91, p = .016 and aOR = .91) .85, p = .018).

N = 135	gistic regressions predicting ART adherence from support Optimal ART Adherence (≥ 95% adherence)			
Variables	β	aOR ^a	CI _p	
Block 1	•			
Age	.039	1.04	.980, 1.11	
Housing (Ref) ^e				
Housing (1)	.796	2.22	.556, 8.84	
Housing (2)	169	.845	.245, 2.91	
Diagnosis Time	005	.995	.989, 1.00	
Depression (CES-D 10)	093	.911*	.849, .978	
R^{2} c	.087			
Block X ^{2 d}	12.28*			
Model X ^{2 d}	12.28*			
Block 2				
Age	.041	1.04	.978, 1.11	
Housing (Ref) ^e				
Housing (1)	.936	2.55	.544, 11.95	
Housing (2)	319	.727	.183, 2.89	
Diagnosis Time	006	.994	.988, 1.00	
Depression (CES-D 10)	091	.913*	.847, .984	
Appraisal Support	.012	1.01	.991, 1.033	
Emotional Support	.018	1.02	.995, 1.04	
Informational Support	002	.998	.977, 1.02	
Instrumental Support	010	.990	.963, 1.02	
$R^{2 \text{ c}}$.141			
Block X ^{2 d}	8.01			
Model X ^{2 d}	20.29*			
Block 3				
Age	.037	1.04	.972, 1.11	
Housing (Ref) ^e				
Housing (1)	.862	2.37	.483, 1.61	
Housing (2)	463	.629	.158, 2.51	
Diagnosis Time	001	.999	.991, 1.01	
Depression (CES-D)	096	.909*	.841, .982	
Appraisal Support	.011	1.01	.989, 1.03	
Emotional Support	.025	1.03*	1.00, 1.05	
Informational Support	002	.998	.976, 1.02	
Instrumental Support	020	.980	.951, 1.01	
Network Size	161	.851*	.745, .972	
Network Density	.588	1.80	.549, 5.90	
R^{2} c	.182			
Block X ^{2 d}	6.84**			
Model X ^{2 d}	27.13**			

^a OR = Odds Ratio ^b CI = Confidence Interval ^c R^2 = Cox & Snell R-square d X^2 = Chisquare statistic ^eRef = reference category *p < .05, **p < .01

CHAPTER 5

This was a good survey...no seriously - you really got me thinking about the people in my life and who I can depend on, you know?...and like...I mean — I may need to cut some people off. Like all the way off [laughter].

- study participant

DISCUSSION

A sage proverb states that "a man is known by the company he keeps." In other words, the relationships in which individuals are embedded are most often indicative of who they are, what they do, and the things that they value. The reverse is also implicit – knowledge of communities is revealed by learning about the people who comprise them. The study of social networks is centered on achieving a better understanding of individuals and communities by illuminating the characteristics of both. The goal of this study is to increase knowledge about the communities of trans women living with HIV by analyzing their personal networks. Identifying the individuals with whom TWLH interact with, in addition to how they compartmentalize their relationships is important because it provides insight into the nuanced ways that they may solicit help and resources. Additionally, taking inventory of their perceived network support, while exploring how these factors relate to ART adherence carries multifaceted implications, extending to individual, public, and economic domains.

Aim 1: The Company She Keeps

The TWLH in this study were demographically similar to those in previous studies, in terms of age and income (Reback, Clark, Fletcher, & Holloway, 2019; Sevelius et al., 2014). Yet they contrasted from those in other studies, in that many were employed and stably housed with health insurance. They were also reasonably heterogenous with nearly a third identifying as women of color. As previous studies of trans women collect data in-person, these differences may emphasize the strengths of sampling participants through multiple online and physical venues.

Network Structure

Participants had about five people on average with whom they discussed important, HIV, and/or gender matters, and a couple of people with whom they would discuss each issue with. Other studies with PLWH have found that network size can range from 2-17, depending on the target population and network generator (Holloway et al., 2017; Hoover et al., 2016; Wohl et al., 2010). Most recently, in a study with high-risk trans women, Reback et al. (2019) reported an average network size of 9-10 people. The relatively smaller average network size of the participants in this study in comparison to that found in Reback et al. (2019) research may be reflective of differences in the study aims and methodology (e.g. name & network generators). It may also reflect the social network dynamics of chronic illness management as found in longitudinal studies of other populations (Abbott, Bettger, Hanlon, & Hirschman, 2012; Perry & Pescosolido, 2012). When following people newly diagnosed with mental illness over time, Perry and Pescosolido (2012) found that while network size increased at the onset of illness, it decreased over time as participants became better at managing their chronic illness independently.

Qualitative research with trans women also suggests that their network size may decrease after HIV diagnosis due to voluntary isolation stemming from fear of rejection and concerns with confidentiality issues (Sevelius, 2013). Most of the participants in this study indicated that they had disclosed their HIV status to many in their networks. Gender identity disclosure was also high with nearly 8 out of 10 alters aware of their gender identity. However, HIV and gender identity disclosure carry great social risks. Many PLWH and trans individuals risk stigma from family members and partners after disclosing their HIV status (Ciambrone, 2002; Hoover et al., 2016). Research examining the disclosure networks of PLWH found that those with larger disclosure were 77 times more likely to perceive HIV-related discrimination (Hoover et al., 2016). Negative outcomes of gender identity disclosure also bear mental and emotional consequences lasting for many years after (Nuttbrock et al., 2012; Reisner et al., 2016). Though exploring participants' disclosure outcomes was beyond the scope of this study, it is important to acknowledge the potential impact that these may have on the size of their networks.

Density is another structural element describing connections between different people within networks. Though it is often neglected in many studies with PLWH, connectivity is central to understanding the dispersion of information and resources throughout a network.

Egocentric studies reporting density in PLWH networks have found estimates ranging from .13 (Hoover et al., 2016) to .34 (Holloway et al., 2017). The density of the overall network in this sample indicates that at least half of the alters know each other. The implications of this finding depend on the characteristics of the network. For example, a study of HIV risk among urban fathers found a positive correlation between increased network density and the number of friends who encouraged HIV risk behaviors (Murphy et al., 2013). Conversely, other studies have found greater network density to positively predict cancer screening among Peruvian women (Luque et

al., 2016), and less suicide ideation in teenage girls (Bearman & Moody, 2004). In general, high-density networks suggest social system stability and solidarity which may be advantageous if the relationships are positively supportive and promote positive norms. It could also be disadvantageous if the alternative is true. High density can also limit the acquisition of novel information and ideas due to the embeddedness of a closed system (Crossley et al., 2015; Granovetter, 1983; Valente, 2010). The moderate density of this sample's overall network suggests the potential for reinforcement of support and norms, as well as the influx of new trends or perhaps innovation.

Given the higher proportion of blood relatives, chosen family members, and friends in the important matters network, it's not surprising that more people know each other than those in the health and gender matters networks. Lower density connections within the health matters network may have implications for the availability of health information and resources. Less connectivity between health consultants may also reflect diversity in conversations with lay people and health professionals. Health providers comprised less than 10% of participants' HIV discussion network. A higher proportion of HIV-related discussions were with kin, friends, and chosen family. More remains to be known about the content of these discussions. However, this information is key to understanding the potential influence that structure might have on the beliefs, attitudes, and decisions that TWLH make. For example, discussing personal challenges with living with the virus, or barriers to care, can lead to the receipt of necessary resources. Studies in medical sociology have also found that people often consult with lay members of their community in consideration of professional health advice (Perry, Pullen, & Pescosolido, 2016; Pescosolido, 1992). Most often these consultations, along with other features of the network, can influence people's trust and use of professional health services. In an egocentric study with cispeople living with HIV, researchers found that over half of participants had a least one alter who expressed HIV conspiracy beliefs and that these beliefs were significantly associated with suboptimal ART adherence (Bogart et al., 2016). This finding stresses the importance for health providers to understand the nature of health consultations with lay network members. People with whom TWLH are comfortable discussing HIV issues with can become treatment supporters, working alongside clinicians, if adequately informed and trained (Duwell et al., 2013; Nakamanya, Mayanja, Muhumuza, Bukenya, & Seeley, 2019).

Lower density in the HIV matters network could also suggest gaps in provider communication. Best practices for the provision of care for trans and non-binary individuals include ongoing cooperation between service providers (Reisner et al., 2015; Reisner, Radix, & Deutsch, 2016). As concerns with hormone-ART interactions are a significant barrier to HIV care engagement (Sevelius, Patouhas, Keatley, & Johnson, 2013), more research is needed to explore the structure of provider networks, as well as, patient-provider communication.

The low density of the gender matters network is interesting given that it is similar in size to the important matters network. This finding is surprising given research suggesting strong gender-focused mentorship and communication within trans communities (Barrington et al., 2012; Sevelius, 2013; Tucker, Arandi, Bolaños, Paz-Bailey, & Barrington, 2014). It is possible that having a lower density gender discussant network could have a protective effect against involuntary disclosure of private issues. TWLH may intentionally engage in discussion about gender with different people who do not know each other because it may lower the risk having their issues shared through a grapevine of gossip (Reisner et al., 2009; Small, 2017). It is also possible that TWLH who are earlier in their transition confide in others about gender identity within disparate online communities.

Composition & Communication

Networks were diverse in terms of race, gender, and role. They also varied in terms of relationship length, contact frequency, and closeness. Participants used multiple modes of communicating with alters. Though phone calls and in-person contact were common across networks, participants communicated with nearly 70% of their network via social technology (text messaging and social media). Other network studies with trans women and MSM likewise found high social technology use among participants (Holloway et al., 2017; Reback et al., 2019). These communication channels present an opportunity to learn about the online support communities of trans women living with HIV and signify the potential to intervene on relationship factors and health issues through social technology.

Compartmentalization

Not surprisingly, the people with whom participants discussed multiple matters with were individuals who they had known for at least a year, interacted with on daily basis, were very close to, and had very little conflict. Social support and gender affirmation were high across subnetworks. It makes sense that individuals would surround themselves with people who make them feel respected and cared for. Though at least 1 in 4 alters were not perceived to be supportive if ever needed and a third of them were not fully affirming. The impact of non-affirming actions can vary according to the source, and the stage of life that the individual is in. In 2009, Nuttbrock explored the impact of gender affirmation across trans women's life course. Results showed that while gender identify conflict and affirmation from peers and family were consequential to depression during adolescence, the burden of significance shifted to sexual partner's actions during middle aged years. Though the sample size and design limited ability to explore these factors, there is more to be learned about how sources of affirmation or a lack thereof might impact health outcomes beyond depression.

The data also show that TWLH may selectively compartmentalize issues with some individuals over others. The functional specificity hypothesis substantiates these findings, explaining how people selectively activate certain individuals within their network according to specialized needs (Wellman & Wortley, 1990). In 2010, Perry and Pescosolido explored this phenomenon among people with mental illnesses. In this study, the researchers used a series of name generators to examine the different people with whom participants discussed different types of problems. Though participants had network members with whom they discussed multiple issues, they most often compartmentalized discussions within distinct groups. The authors went on to compare the different characteristics of people in the important versus health

matters group. Statistical comparisons between the important, health, and gender matters networks were not feasible for this study; nonetheless a few expected and surprising observations emerged. These findings will be interpreted in conjunction with the network overlap data.

Many network studies identify family members as key confidants (Amirkhanian, 2014; Gage, 2013; Perry & Pescosolido, 2012). Conversely, family members were among the lowest proportions of other relationship-roles within TWLH networks. Additionally, family were neither more nor less likely to overlap discussant networks. The diminished presence of family may be indicative of selective activation processes over time. Research examining the support networks of people with other chronic illnesses find that though family members are instrumental during the initial stages of treatment, their presence attenuates over time as chronically ill people began to activate support from those they meet within the health care system (Gage, 2013; Hill, Huff, & Chumbler, 2018; Perry & Pescosolido, 2012). Most of the research within this area has been conducted on cisgender heterosexual populations and does not account for the social context and experiences of trans-identified individuals who are living with an incredibly stigmatized health condition. Therefore, it also does not account for the high prevalence of rejection, abuse, and trauma inflicted on many trans individuals by their families (Hughto, Reisner, & Pachankis, 2015; Koken, Bimbi, & Parsons, 2009). While some trans individuals have family members who are supportive of their gender identity and expression, many others recount negative and hurtful experiences with their biological family. For example, half of all participants in the most recent USTS reported experiencing some form of rejection and/or violence from their family (Guay et al., 1999; James et al., 2016). Like TWLH, non-trans people living with HIV also experience voluntary and involuntary isolation from their families due to judgment and stigma (Ho & Mak, 2013; Larry Nuttbrock et al., 2012). Consequently, the intersectionality of HIV and gender

stigma make TWLH exponentially vulnerable to experiencing isolation from their biological family (Logie et al., 2011). These events can be extremely damaging to the relationship and the individual. Given the potential for family conflict as found in the other studies, it is reasonable to believe that this could also explain the lower proportion of relatives in the networks of TWLH.

Widespread rejection from biological relatives has led to the development of "chosen families" in the LGBT community and amongst people living with HIV (Grant, Vance, Keltner, White, & Raper, 2013; Grant, Vance, White, Keltner, & Raper, 2013; Weeks, 2004). The critically acclaimed documentary, "Paris is Burning," is often credited with bringing LGBTfocused chosen families into public purview (Livingston, 1990). The documentary shows how discrimination led to the development of familial-like structures amongst LGBT people who shared similar social and personal characteristics in the early stages of the US HIV epidemic. Many of the individuals featured in the film were drag queens and trans women, and many more were also deeply affected by the acute HIV infection epidemic that was sweeping through the community. In years following, sociologists began to conceptualize and define the tendency for similar people to gravitate towards one another as homophily and experiential similarity (McPherson, Smith-Lovin, & Cook, 2001; Suitor, Pillemer, & Keeton, 1995). While homophily is a feature which describes the tendency for networks to share similar characteristics and behaviors, experiential similarity refers to common experiences that people share. Given the historical context of chosen families and research documenting high homophily and experiential similarity within the networks of people with chronic illnesses, it was not surprising to see a large proportion of chosen family, trans individuals, and people living with HIV in this sample's networks (Bogart et al., 2016; Gage, 2013; Perry & Pescosolido, 2010; Reback et al., 2019). The observed differences in the compartmentalization of discussions between different groups is

intriguing. Trans women and chosen family members were amongst the few groups with whom participants were significantly more likely to discuss multiple issues with. While this finding is expected given the connectedness between trans women and chosen family, participants were not significantly more likely to discuss more than one problem with trans men and people living with HIV. This finding suggests that TWLH selectively divulge things to people with varying degrees of similarity. For the sake of inclusiveness, many support programs invite multiple trans-, non-conforming people to participate. However, the effectiveness of discussion may be influenced by the characteristics of those within the support group. While trans women and trans men both identify their gender in opposition to their assigned sex at birth, trans women uniquely share the attributes and experiences of trans womanhood. Hence, peer groups exclusive to trans women may be more effective in promoting open discussion of life issues than peer groups including people of other trans or non-binary identities.

People living with HIV constituted half of all subnetworks. This data suggest that peers can play a role which traverses health-related issues. Though it was surprising to see that egos were not more likely to discuss more than one issue with them given their representation. The high prevalence of HIV within the trans community may at least partially explain the occurrence of positives in each subnetwork. It is possible that peers may meet within common spaces (e.g. support groups, clinics) but develop relationships that are marginalized to those confines. They also may prioritize the discussion of one issue versus another with certain individuals. For example, it is reasonable to assume that if an ego develops a relationship with a person they met in a gender-focused forum, they may only discuss that issue with them despite also having HIV in common. As many interventions and programs use peers to help clients navigate treatment barriers, additional research is needed to evaluate peer relationships among trans women living with HIV, including the relative strengths and limitations of peer support.

Despite a lack of homophily, cis women comprised a sizeable proportion of TWLH networks. This finding was somewhat surprising yet plausible given research showing that cis women are socialized to be more social and nurturing and often comprise a large proportion of networks due to these characteristics (Barbee et al., 1993; Nakamanya et al., 2019; Wellman & Wortley, 1990). It was interesting to observe a higher proportion of cis men in the gender matters network in comparison to cis women. Further exploratory analyses revealed that cis male alters were equally distributed across different roles (e.g. friends, chosen family), though they comprised a larger proportion of spouses/partners than other gender identities (data available upon request from author). Moreover, only a small percentage of spouses/partners were included in the gender matters network. While detailed information about the specific roles of kin and chosen family were collected (e.g. father, brother, etc.), the small sample size limited the ability

to make a meaningful comparison between those roles. Given the potential importance and impact that cis men may have on TWLH, future research should seek identify the reason why TWLH discuss gender issues with cis men, the roles of cis males, as well as the influence that these conversations may have on their health and well-being.

Above all other groups, friends were most often nominated as people TWLH would discuss important, HIV, and/or gender matters with. Studies of other PLWH and LGB networks also report the social prominence of friends (Cederbaum, Rice, Craddock, Pimentel, & Beaver, 2017; Halperin, Pathmanathan, & Richey, 2013; Holloway, Schrager, Wong, Dunlap, & Kipke, 2014). In a recent study of HIV-positive MSM, researchers found that friends comprised more than 75% of network ties, whereas, family members made up a considerably smaller proportion (Holloway et al., 2017). Like bonds with chosen family, friendships are constructed and maintained on traits of emotional attachment, including, trust, reciprocity, and care. Yet in comparison to family or spousal bonds, friendships have the additional level of autonomy which allows for relationship elasticity (Wiseman, 1986). If the expectations of friendship are violated, a strong tie can deteriorate to nonexistence (Wiseman, 1986). Thus, the qualities of friendship involve both elements of stability and instability. The structure of friendships may also factor into their stability, support, and influence. Triads, or ties that are reinforced by ties with others create more stable relationship structures and exert a more powerful reinforcement of ideas and behaviors (Bearman & Moody, 2004). Research on the friendships of trans and non-binary individuals show that despite ongoing support, friendships can be a source of stress and microaggressions (Galupo, Henise, & Davis, 2014; Whitley, 2013). While the occurrence of these events ventures beyond the scope of this study, more research within this area is warranted given the breadth and depth of discussions that transpire between TWLH and their friends.

Aim 2: Alone in a Crowd

The goal of the second aim was evaluate the relative association between different types of social support with ART adherence. The prevalence of suboptimal ART adherence in this sample was comparable to that found in recent studies of TWLH who are linked and engaged in care (Dowshen et al., 2016; Mizuno et al., 2015). It was expected that optimal and sub-optimal adherers would vary significantly by factors previously shown to reduce adherence, but none of these variables were significant predictors of ART adherence. There may be other factors which explain the lower adherence among 30% of participants, such as self-efficacy to adhere, substance use, and pill burden (Langebeek et al., 2014). Anticipated and experienced transphobia within healthcare settings is further damaging to ART access and adherence (Mink et al., 2014). The mistreatment of trans people in health care settings ranges from not using the proper gender pronoun to name-calling and service refusal (James et al., 2016). Future studies which explore the significance of previously identified correlates of ART adherence, in addition to relevant factors like experiences of transphobia in health care are urgently needed.

The group of participants included in the second aim also perceived high social support from their networks like those in the first aim. Emotional and appraisal support were significantly correlated with ART in bivariate analyses; though emotional support was only marginally predictive of ART adherence the final model. The lack of association between the support variables and ART adherence was unexpected yet may reflect the model choice. While specifying the association between different types of support may be helpful for the development of support programs in theory, using a statistical model which adjusts for the shared variance between different types of support may not be the most feasible approach. Many of the support variables were significantly correlated with one another, depression and ART adherence

(Appendix F). Perhaps, a structural equation model, which maps out theoretical causal pathways between variables would be a better fit given the descriptive results and evidence linking various forms of social support to depression, and ART adherence.

Also, though the association between support variables and ART adherence did not research statistical significance, the results may be practically significant in terms of understanding the support systems in which optimal versus suboptimal adherers are embedded. Participants with suboptimal adherence perceived lower proportions of each type of support from their network. For example, suboptimal adherers perceived that 73% of their network would provide them with emotional support if they needed it, compared to the 85% of network members with whom optimal adherers felt would emotionally support them. It is important that practitioners recognize when clients are lacking certain types of support and seek to address them through the counseling, programs, and other services. Alliances between different organizations can also help fill support service voids through strong referral networks.

There may be other factors, such as gender identity and norms, which can explain the lack of association between support and ART adherence. Contradictory findings concerning relationships between social network support and health by gender have been noted throughout the literature (Seeman & Syme, 1987; Shumaker & Hill, 1991). These studies find that while social network support has a positive effect on men's health, it may have a null or negative effect on women's physical health. It is hypothesized that gender role socialization plays an important role in the paradox between gender, support, and health within this research. Women are socialized to offer and receive more emotional support (Barbee et al., 1993; Turner, 1994). As the managers and caretakers of networks, women's social obligations of providing for others may supersede the ability to care for themselves. Moreover, the intensity of emotional

investment and social engagement that women have with their networks can also increase their exposure to relationship stressors (Turner, 1994). Research exploring the gender paradox in support and health has only observed cis men and women. Though not all trans women conform to normative standards for femininity and socializing, for some, conformity to femininity norms is intrinsic to their transition and affirmation of womanhood (Melendez & Pinto, 2007; Sevelius, 2013). For example, it is not uncommon for those who belong to a chosen family to become adoptive mothers and assume the responsibilities that go along with that role (Downing, 2013; Sevelius, 2013). While the research design limits interpretation of whether a gender paradox could be contributing to the null association between social support and ART adherence, more research is needed to understand how trans women may experience social support in relation to their health and gender identity.

The finding regarding network size emphasizes the importance of examining network structure when evaluating social support and other health outcomes. It is well-known that larger networks indicate greater social capital and the potential for accessing more resources from more people (Crossley et al., 2015). Yet, a trade-off exists between network size and exhaustion of resources, whereas, when networks are larger, an individual may reach a capacity to where they lose the ability effectively manage relationships (Crossley et al., 2015; Valente, 2010). Hence, while large networks offer more opportunities for obtaining support, increasing network size typically results in diminishing returns on health. Like the social support paradox, the negative effect of network size on health can be exacerbated by gender. Specifically, studies have found that increasing network size adversely impacts mortality risk in certain groups of women (Shumaker & Hill, 1991; Shye, Mullooly, Freeborn, & Pope, 1995). Researchers have attributed these findings to increased social obligations as women's network size increases. Though no

such comparisons exist between trans and non-trans networks, research has found trans women's networks to exceed the average network size of the general population and other LGB people (Barrington et al., 2012; Lombardi, 1999). Moreover, larger networks may also increase exposure to negative social influences. The results of previous network studies illuminate the power of having one network member who expresses stigmatizing or conspiracy beliefs. In these studies, having one negative influence from a certain network member significantly predicted lower ART adherence in PWLH (Bogart et al., 2015; Bogart et al., 2016). Research exploring the occurrence of negative influences within TWLH networks may help clarify whether exposure risk increases also with network size.

Finally, this study found that participants had significant depressive symptoms despite feeling highly supported. In turn, depression increased the odds of suboptimal adherence to ART. This finding was not unexpected given evidence demonstrating the adverse effect of depression on non-compliance to ART regimens (Gonzalez et al., 2012). Confidants can positively impact mental health care seeking and outcomes through multiple means. In a recent egocentric study, Holloway et al. (2017) similarly found a negative association between ART adherence in MSM living with HIV. Yet having at least one network member provide medication reminders significantly buffered the negative association between depression and ART adherence.

Networks can also facilitate depression treatment by encouraging people to seek therapy or by promoting therapy use norms within the community. In 2007, researchers (Vogel et al, 2007) found that these factors were determinants of college students' attitudes and therapy-seeking, whereas, 78% of those who sought therapy had been encouraged by someone in their network to seek therapy and 92% of therapy users knew of someone who had previously used therapy (Vogel, Wade, Wester, Larson, & Hackler, 2007). It is unknown whether or how many participants were currently engaged in therapy at the time of taking the survey, but it is important to gain a better understanding of the barriers and facilitators to depression among TWLH. Future research should investigate network factors which might assist with intervening on depression among TWLH.

Limitations

The study conclusions are subject to the limitations of the study design, data collection methods, and assumptions. Firstly, the cross-sectional design limits the ability to make causal inferences. Without prospective data, it is difficult to understand how or whether relationships between change and how these changes might impact how the data is interpreted. The interpretation of cross-sectional networks is also limited to measuring relationships during one point in time. Social networks often shift over time, events, and circumstances. Longitudinal data would enhance the observation of both individuals and their networks.

Egocentric data is commonly subject to bias due to the subjective view of the participants providing accounts of their friends' characteristics and behaviors. Considerable error is introduced if participants intentionally or unintentionally misreport data concerning their friends. Self-report measures such as the ACTG Questionnaire also have limitations for the same reasons. Medication monitoring bottles (MEM caps) or clinical biomarkers (e.g. viral load) can increase reliability of these measures. Also, using multiple convenience sample methods (online and inperson) may have enhanced sample diversity, however, it may have limited the generalizability of the results. While snowball methods are useful for engaging hard-to-reach populations, they are subject to bias given that old participants are more likely to recruit similar new participants.

The provision of logistical support to people in-person and on the phone may have also biased their responses. People who took the survey through these means were able to ask the researcher for clarification, while people who took the survey online were not. In contrast, online data collection limited the ability to assess factors such as the state of the participant while taking the survey. Also, though multiple measures were taken to prevent ineligible people from taking the survey and to prevent people from taking the survey more than once, there is no way to be certain whether either occurred.

Strengths & Implications

The findings from this study have important implications for understanding the structure and characteristics of TWLH communities. Implications for practice include increased availability of psychotherapy and the implementation of treatment supporter interventions.

Implications for research include the development of studies examining social technology use, social roles among TWLH in relation to their networks, and the development of multi-level interventions. Finally, policy implications extend to grant-funding and resource allocation.

Cognitive-behavioral therapy has been proven to help treat depression by promoting emotional regulation and coping. It has also been linked to improved ART adherence (Renaud, Russell, & Myhr, 2014; Safren et al., 2009). Yet results are variable depending on the population. Trans individuals' stand to benefit most from gender affirmative CBT (Austin & Craig, 2015). Practitioners who are trained or experienced in these methods are scarcely available. In a qualitative study of barriers to care engagement, researchers found that TWLH described wanting greater access to psychotherapy as opposed to medication (Sevelius et al., 2013). It is important that practices make these types of therapy accessible to those who may need it. This may be a simple as checking in with clients to assess their mood and referring them to local counselors and/or offering continuing education opportunities for therapists who need training on gender-affirmative CBT within the area.

Treatment support via social networks may be a cost-effective and sustainable method of improving ART adherence (Duwell et al., 2013; Holloway et al., 2017; Kunutsor et al., 2011). This study found that on average TWLH have at least a couple of HIV confidants who could potentially serve as treatment supporters. Successful treatment supporter interventions begin with having participants complete a brief social network inventory from which they identify someone who they trust to provide them with medication reminders. After a supporter is selected, they participate in a series of trainings in which they were educated on ART adherence and effective emotional support strategies (Duwell et al., 2013; Kunutsor et al., 2011). Given the high proportion of other people living with HIV within TWLH networks, multilevel interventions might also increase the reach and impact of interpersonal & network-level treatment support.

Many trans women in various stages of identity, expression, and transition gravitate to online communities because they are safe spaces for receiving various forms of support given common experiences (Clark, Fletcher, Holloway, & Reback, 2018; Jackson, Bailey, & Foucault Welles, 2018). The fact that most of this sample was recruited online highlights the potential of social media to shape and transform the social networks of trans women living with HIV. Social technology may also be a driving factor in increasing network size. Still it is unclear as to whether participants in this sample nominated alters who they met online. Additional research is needed to explore social technology use within the TWLH and how that might shape their networks. Technology may also present alternative venues for facilitating online HIV support and ART adherence based on empirical evidence.

It is also important to examine social expectations providing support to others, especially in the context of their relationships to partners, chosen family and friends. The lack of compartmentalization of discussions with partners, chosen family, and friends suggests these may be good candidates for learning about TWLH. It is likely that they are also very similar in their beliefs and behaviors. Though behavior change may be facilitated by focusing on weaker ties, like classmates and coworkers. As explained in the previous section, weaker ties provide access to new information, ideas, and suggestions that can influence the entire network (Granovetter, 1983). TWLH may also share deeply personal issues with weaker ties due to concerns with close ties' perceptions of them and/or confidentiality (Small, 2017). A qualitative examination these relationships may also reveal important information about other social mechanisms of influence, such as, social norms and social control (Berkman et al., 2000).

Finally, the demographic differences between TWLH who were recruited in-person versus online suggest the imminence of housing and employment aid for certain segments of the trans population. It is possible that those who were recruited through agencies were present because they needed resources. However, the number of non-profits serving TWLH are exceeded by the increasing population size and demand. Policies are urgently needed to increase resources and decrease economic disparities which destabilize health. Short-term ancillary services may include the provision of housing vouchers and food pantry access. Long-term opportunities, such as GED programs, professional development services, and employment are most effective for sustaining positive outcomes.

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APPENDICES

A

Survey Pre-test



Survey Pretest Instructions

Thank you for reviewing my survey! The purpose of this pretest is to understand the flow of questions, how easy it is to understand, as well as, to get feedback you may have for overall improvement. Those who are eligible to take the survey will specifically be:

- 18 years or older
- Diagnosed with HIV by a health provider
- Prescribed antiretroviral medication
- Identify their gender as a female/woman or transgender woman
- Assigned male sex at birth

Please respond to the following questions during/after you take the survey:

How long did it take you?

How easy was it to understand the survey instructions?

Were any of the instructions or questions confusing?

Are there sections of questions that should be rearranged?

Did you see any grammatical or spelling errors, etc.

Any other suggestions for improvement?

Do you know of any groups (online or in-person) that I should market this survey to?

Thanks so much for your time and consideration. Contact me if you have any questions!

Recruitment Materials



THIS STUDY IS UNDER THE SUPERVISION OF DR. NATHAN HANSEN IN THE DEPARTMENT OF HEALTH PROMOTION & BEHAVIOR @ THE UNIVERSITY OF GEORGIA. FOR MORE INFORMATION CONTACT MIRANDA @ 678.453.6187



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INITIAL STUDY CONSENT FORM (FEB-MAY 2019)

Welcome to the TRANSSFORM survey!

You are invited to participate in the Trans women's Social Support for Medication adherence (TRANSSFORM) study. TRANSSFORM is a research project conducted by Miranda Hill, a PhD candidate at the University of Georgia. The purpose of TRANSSFORM is to investigate support in the relationships of transgender women living with HIV.

The findings from this project will help improve understanding of how relationships impact HIV-positive transgender women. The information that you provide will go into programs designed to educate family, friends, and peers on how to best support improved health. You will receive a \$20 gift card for participating in the research.

Eligible participants must have been assigned male sex at birth yet identify as a woman or transgender woman, be 18 years or older, have been diagnosed with HIV by a health provider, and prescribed antiretroviral therapy (ART).

Participation will involve the completion of a survey that should take about 30-40 minutes. Your involvement is voluntary, and you may choose not to participate or to stop at any time without penalty or loss of benefits to which you are otherwise entitled. The decision to take part (or not take part) in the research will not affect your treatment or health care services. If you decide to stop or withdraw from the study, the information that can be identified as yours will be kept as part of the study and may continue to be analyzed, unless you make a written request to remove, return, or destroy the information.

This research involves the transmission of data over the Internet. Every reasonable effort has been taken to ensure the effective use of available technology; however, confidentiality during online communication cannot be guaranteed. Any data containing individually identifying information will be securely stored on a password-protected computer or locked file cabinet. You must provide your contact information in order to receive a gift card. The information that you provide will not be associated with your research records and will only be stored by the University business office for a specified time (according to University policies) the purposes of documenting financial transactions related to research. Only researchers working directly on this project will have access to the information unless you opt to receive the gift card.

There are some minimal risks or discomforts associated with this research. They include discomfort associated with the collection of information that may cause embarrassment and may be considered to be an invasion of privacy.

If you have any questions about this research project, call Miranda Hill at (678) 453-6187 or her faculty advisor, Dr. Nathan Hansen at (706) 542-4364. Questions or concerns about your rights as a research participant should be directed to the chairperson, University of Georgia Institutional Review Board, telephone (706) 542-3199; email address irb@uga.edu.

Indicate whether or not you consent to participate in the above-described project by clicking the button below

Thank you for your consideration!

Sincerely,

Miranda Hill, M.P.H.

D

REVISED CONSENT FORM (MAY – AUG 2019)

You are invited to take part in the Trans women's Social Support for Medication adherence (TRANSSFORM) study.

This study is being done by Miranda Hill, a PhD student at the University of Georgia. The goal is to learn more about the support systems of trans women living with HIV in the U.S.

Your data will be used to create and improve support programs. Participation includes a 30-40-minute survey and a \$20 gift card.

To participate, you must

- Be a woman or trans woman
- have been assigned male sex at birth
- are 18 years or older
- be HIV-positive
- have a prescription for HIV medicine (antiretroviral therapy or ART)

About the study

- The study is voluntary
- You can stop at any time without losing benefits
- Taking the survey (or not) won't affect your health services
- If you want to stop, your data will be stored, unless you tell us that you want it to be deleted

About your information

- Your contact information is optional, but it is needed to get a \$20 gift card
- Your information won't be linked to your survey
- It will only be used to keep track of finances

Online surveys have security risks, but we plan to keep your data secure by:

- Allowing only researchers to access to your survey
- Storing your data on a password-protected computer

Risks and Discomforts

- This study has a couple of risks/discomforts

- The questions may cause some people to feel embarrassed
- Some people may also feel like the questions are invading their privacy

Contact Information for questions

For study information - Miranda Hill (678) 453-6187 or Nathan Hansen (706) 542-4364 (faculty advisor)

For questions about your rights - University of Georgia Institutional Review Board (706) 542-3199 or irb@uga.edu

Choose one of these options to either a) consent to taking the survey or b) not consent and exit the study

 \mathbf{E}

SURVEY

Start of Block: Screening
Eligibility Thank you for your interest in participating in the study. Please answer the following questions to determine your eligibility
3 Are you 18 years or older?
○ No
○ Yes
Eligibility Unfortunately, you are not eligible to participate in the TRANSSFORM study. Thank you for your time and interest.
Sex What sex were you assigned at birth, on your original birth certificate?
O Male
○ Female

ART-type What HIV medications are you currently taking? You can list up to 4 diffe	erent ones.
O Medication #1	
O Medication #2	
O Medication #3	
O Medication #4	
20 The next section of the survey asks about the HIV medications that you took over days.	the last four
Many people find it hard to always remember their pills. Please tell us what you are a doing. Don't worry about telling us that you don't take all your pills. We need to know what is really happening, not what you think we "want to hear."	actually
ACTG-1 Each day, how many doses of HIV medication are you supposed to take? The many times during the day are you supposed to take HIV medication?	hat is, how

	think about the past 4 days. How many doses of HIV medication did you miss
each day?	
	Yesterday
	2 days ago
	3 days ago
	4 days ago
	igible to take the survey. Before you start, here's a brief overview: The survey will king about the people within your social circle and your relationship with each
Then I'd like	to know what these people are like and whether or not they know each other.
Finally, the su	rvey will end with asking general questions about you and your health.

IM Think about the most important people in your life right now.

Who are the people in your life right now who you feel you can talk to when important issues come up and who would also talk to you about important issues, whether you want them to or not?

They can be anyone in your social circle; family, close friends, spouses/partners, roommates,

O Name	
O Name	
End of Block: Name Generator 1	
Start of Block: Name Generator 2	

healthcare professionals, or enemies. People who live nearby or people who live far away.

Don't put their full name. Just put their first name and last initial only.

HM1 Have you discussed HIV or HIV-related issues with any of these people during the past few months?

Who can you depend on when you want to talk about HIV? Who would approach you to talk about HIV issues, whether you wanted them to or not?

Select all of t	he names which apply.
	ALTER #1
	ALTER #2
	ALTER #2
	ALTER #4
	ALTER #5
	ALTER #6
	ALTER #7

HM2

Who else have you discussed HIV or HIV issues with? Just put their first name and last initial only.

healthcare professionals.	
O Name	
GM1 Who have you talked about gender or transgender issues with over the	e past few months?

Remember, they can be anyone in your life including family, friends, and caseworkers or other

would approach	ch you to talk about transgender-related things, whether you want them to or not?
	ALTER #1
	ALTER #2
	ALTER #3
	ALTER #4
	ALTER #5
	ALTER #6
	ALTER #7
	ALTER #8}
	ALTER #9
	ALTER #10
	ALTER #11
	ALTER #12
	ALTER #13
	ALTER #14

Who can you depend on when you want to discuss your gender or anything related to that? Who

put their first name a	and last initial o	only.			
O Name					
O Name					
O Name					
O Name					
O Name					
O Name					
O Name					
End of Block: Nam	e Generator 3				
Start of Block: Alte	er Matrix Ques	stions			
ATo the best of your	r knowledge, w	hat is each pers	son's age?		
O ALTER #1 _					
O ALTER #21	}				
_					
To the best of your k			on's gender?		
	Cisgender, male	Cisgender, female	Transgender, male to female	Transgender, female to male	Gender non- conforming
ALTER #1	0	0	0	0	0
ALTER #21}	0	\circ	0	0	\circ

GM2 Are there any other people who have discussed gender-related things with you over the past few months? Who else can you depend on when you want to talk about gender issues? Just

	White/Ca	ucasian	Black/Africar American	Latinx/a/o or Hispanic	Asian/Pacific Islander	Other
ALTER #1			\circ	\circ	\circ	\circ
ALTER #21}	(0	0	0	0
ow are you connec ne (<i>Chosen family</i> 1 ou)						
	Blood relative	Chosen Family	Partner	Friend	Co- worker Provide	er/Caseworl
ALTER #1						
ALTER #21}						
ALTER #21} LTER-relative Hov	_		-			
	w is each p	erson rela Father	_	hild Aunt	Uncle Cousin	n Other
	_		-	hild Aunt	Uncle Cousin	

What role does each	member of you	our chosen family play i Sister/Brother/Sibling	=	Uncle Cousin O
ALTER #1				
ALTER #21}				
How much does each	person hassl Not at al	e you, cause you proble l A little	ms, or make your Some	life difficult?
ALTER #1	0	0	0	0
ALTER #21}	0	\circ	\circ	\circ
Who would give you	information,	suggestions, or guidanc	ee if you needed it	? Yes
ALTER #1		0		0
ALTER #21	}	\circ		\circ
	·			

	No	Yes
ALTER #1	0	0
ALTER #21}		0
could you turn to if you neede	ed advice to help make a decisi	
	No	Yes
ALTER #1		\circ
ALTER #21}	0	\circ
would be available to talk to	you if you were upset, nervous	
would be available to talk to	you if you were upset, nervous. No	, or depressed? Yes
would be available to talk to y		
ALTER #1 ALTER #21}		Yes
ALTER #1 ALTER #21}	No O O O O O O O O O O O O O O O O O O O	Yes Output Decrease of the status?
ALTER #1 ALTER #21} ER-HIVstatus To the best of y	No O O O O O O O O O O O O O O O O O O O	Yes Output Decrease of the status?

			No		Yes			
ALTER #1 ALTER #21}					\bigcirc			
			0					
TER-length How	v long have yo		nch person?	1-2 years	s 2 yea	ars or more		
ALTER #1	0		0	0		0		
ALTER #21}	0		\circ	0		\circ		
TER-frequency l	How often do y	you interact	t with each per Monthly	Every couple of months	Every year or so	Less tha once a year		
TER-frequency l				Every couple of				

ALTER-communicate with a		you typically	interact? Y	ou can selec	et all the ways	s that you
communicate with ea	In person	Phone call	Texting	Social media (Facebook Instagram, etc.)		Other
ALTER #1						
ALTER #21}						
ALTER-close How of	olose are vou	to each person	n?			
ALTER-close flow C	Very close	_	Son	newhat lose	Not very close	Not at all close
ALTER #1	0	0 0		0		0
ALTER #21}	0	\circ		\circ		\circ
ALTER #2	1		ntus? No		Yes)

Gender identity is defined as the gender/genders that you experience yourself as; it doesn't have to be related to your assigned sex at birth.

ho is aware of your gender?		
	No	Yes
ALTER #1	\circ	0
ALTER #21}	\circ	0
LTER-affirm1 Who addresses y		
	No	Yes
ALTER #1	\circ	\circ
ALTER #21}	\circ	\circ
LTER-affirm2 Who treats you t	he way that you want to be trea	ted as a woman/trans woman [°] Yes
ALTER #1	0	0
ALTER #21}	0	0

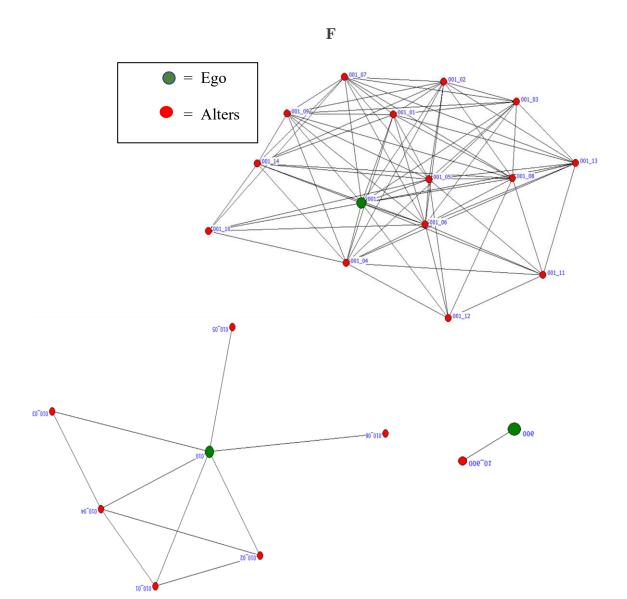
Select all of the people who ALTER #1 knows or who knows them	
ALTER #2	
ALTER #21}	
Select all of the people who $\{e://Field/GM13\}$ knows or who knows them	
ALTER #21}	
End of Block: Networkgenerators	
Start of Block: Ego Demographic *	
EGO-age What is your age?	
$X \rightarrow X \rightarrow$	
EGO-race Which race do you identify with?	
O White/Caucasian	
O Black/African American	
○ Latino/a/x or Hispanic	
Asian/Pacific Islander	
Other	

EGO-relationship1 Are you currently married, living with a partner, divorced, separated, widowed, or have you never been married?
O Married
Living with a partner
ODivorced
○ Separated
O Widowed
O Never been married
EGO-employmentstatus Are you currently employed? O Yes
○ No
EGO-annualincome What is your best estimate of how much money came into your household last year?
\$0-10,000 (up to \$833/month)
\$10,001-20,000 (up to 1,666/month)
\$20,001-30,000 (up to \$2,500/month)
O over \$30,000 (\$2,501+/month)

EGO-housing	What best describes your current housing situation?
O Homel	less (living on the street, in a shelter, or other temporary place)
ODouble	ed-up (currently staying at someone else's house/apt)
O Stably	housed (currently living in a place of your own or with a roommate)
EGO-insurance	ee Do you have any assistance or insurance coverage to help you pay for ART?
○ No	
O Yes	
$X \rightarrow X \rightarrow$	
	cetype What type of assistance program do you have to help pay for ART? (select pices that apply)
	Ryan White/AIDS drug assistance program (ADAP)
	Medicare
	Medicaid
	Private insurance (United Healthcare, Blue Cross, etc.)
	Other

EGO-CESD Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
I felt like everything was an effort	0	0	0	0
I felt like I could not get going	0	0	0	\circ
I had trouble keeping my mind on what I was doing	0	0	0	0
I was bothered by things that usually don't bother me	0	\circ	0	\circ
I felt depressed	0	\circ	\circ	\circ
My sleep was restless	0	\circ	0	0
I felt lonely	0	0	0	\circ
I felt fearful	0	\circ	\circ	\circ
I felt hopeful about the future	0	\circ	\circ	\circ
I was happy	0	\circ	\circ	\circ



Variables	1	2	3	4	5	6	7	8	9	10	11
1. Network Density	-										
2. Appraisal Support	- .130 *	-									
3. Emotional Support	.046	.533	-								
4. Informatio nal Support	.032	.663 **		-							
5. Instrument al Support	.029	.705 **	.591 **	.708 **	-						
6. Depression	.081	- .151 *	040	095	- .195 **	-					
7. Age	.053	066	002	009	109	.101	-				
8. Housing Status	.087	.129	.087	.041	.131	- .210 **	069	-			
9. Diagnosis Time	.084	038	.017	.063	074	.085	.575 **	- .214 **	-	-	
10. ART Adherence	.204	.141	.135	.037	.129	.129	- .212 *	046	- .058 *	-	
11. Network Size	.057	- .267 **	123	- .214 **	- .299 **	.238	.265	- .154 *	.382	- .236 **	
Mean	.51	81.7 7	78.3 7	83.2	85.9 3	10.8	31.6 7	1.63	55.6 8	.87	4.5 9
Standard Deviation	.40	27.5 5	31.8	27.8 5	25.3 5	5.64	7.58	.64	68	.28	4.6