SOCIAL PATTERNS AND PATHWAYS OF HIV CARE AMONG HIV-POSITIVE

TRANSGENDER WOMEN

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Dedication

Dedicated to my mother, Faye Ann Hines (1949-1998)

There are so many things that I would like to say to you, but there are not enough pages to express my thanks for all that you invested in and sacrificed for me throughout my formative years. I wish that you were here to celebrate the many wonderful accomplishments that I have made since you transitioned, and to enjoy your granddaughter, Imani and your grandson, Reid. I know that you would be pleased and proud of the woman and mother your little girl grew up to be. Thank you for always encouraging me to do my best and for believing me in when I doubted myself. I love you.

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Preface

In conducting this study on the *Social Patterns and Pathways of HIV Care among HIV-Positive Transgender Women* it was my ambition to shed light on a population of women who are often overlooked, ridiculed, and misunderstood. I made it my personal mission to give voice to these women who were essentially voiceless and hidden, and to educate my peers and colleagues about the need to include them in research, and to treat them as human beings.

When I presented my idea for this study to the faculty in the T32 Health Behaviors Research Training Program in 2010 I was met with some resistance and encouraged to pursue a different topic. The concerns of the faculty were valid in that I could not answer the basic questions of, "How many people are transgender?" and "How many transgender people have HIV? All that I had to go on at the time were estimates from surveys that had been conducted in large metropolitan areas and a small, but slowly growing body of literature that suggested it was time to pay attention to the transgender population. Unfortunately it was not enough for me to say, "Well, we need to do this study because so little is known about this population."

Fortunately, as I was preparing my F31 application in the spring of 2011, the Institute of Medicine released its groundbreaking report: *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. I vividly remember the day that this report was released because I received an email from Dr. Susan Rawl with a link to the IOM report that read, "What an awesome argument you are making for the need for this

important study. Congrats!" This was huge victory and game-changer for me in that it gave credence to my proposed dissertation topic and gave me the momentum to push forward.

As I progressed through course work, attended various conferences, and talked to people in the community about my work I quickly learned that everyone was not an advocate for transgender health. I was often (and still am) asked questions like, "How can you work with *those* people?" To which I would politely respond, "Because they are people, and they matter." We often talk about the stigma, discrimination and prejudices that people have towards gender and sexual minority populations. But we rarely talk about the stigma and discrimination towards researchers who are involved in HIV and LGBT research. This is something that I have personally experienced. Since pursuing the topic of HIV in transgender women, I have been asked (or it has been assumed) questions such as: "Are you a lesbian?" "Are you HIV-positive?" "Do you believe that being transgender is a sin?" Fortunately, I have tough skin-you have to in this line of work, so these questions did not emotionally distress me. But what these experiences have done is make me more empathetic and compassionate towards transgender people and other LGB people who live with this chronic stress and discrimination every day.

I am often curious as to why people feel entitled to interrogate me or other researchers involved in similar work about our gender and sexuality; particularly when these questions are not asked of scientists who conduct research in other areas such as cancer, diabetes, asthma and so on. I think it speaks to the

pervasiveness of homophobia, heterosexism, and sexual prejudice in our society, and helps explain why transgender and other LGB health issues and concerns were ignored for so long. This phenomenon that is still very perplexing to me and perhaps is something that I will explore more formally later on in my research career.

In the four years since the preliminary work for this dissertation study began, transgender health issues have become a top research priority and the NIH and other national agencies have earmarked more funds towards research in this area. Also in the last four years we have witnessed an uprising within the transgender population. Now, more than ever we see transgender people being celebrated in pop culture, being cast in television series, signing major book deals and modeling contracts, and more than anything, demanding equal rights.

While progress is being made, we must be mindful that the transgender population is not a monolithic group and that the transgender men and women that mainstream society encounters via social media and pop culture enjoy a certain amount of social and class privilege that is not awarded to the average transgender person in this country. Therefore we must continue to advocate for equality and acceptance for the transgender men and women who exist outside the realm of stardom. Still, this remains a very exciting time for transgender people and transgender allies in this country, and I am very excited to be part of this movement and to be a pioneer for nursing-led transgender health research.

Dana D. Hines

SOCIAL PATTERNS AND PATHWAYS OF HIV CARE AMONG HIV-POSITIVE

TRANSGENDER WOMEN

Transgender women have the highest HIV prevalence rates of all gender

and sexual minorities, yet are less likely to enter and be retained in HIV care. As

a result, they are at high risk for HIV-related morbidity and mortality. This study

aimed to describe the illness career of transgender women living with HIV and to

describe how interactions with health care providers and important others

influenced their illness trajectory. The findings are a theoretical model that

includes four stages: *Having the world come crashing down, shutting out the

world, living in a dark world, and reconstructing the world*. Relationships within

the social network (family, friends, and romantic partners) and the network of

health care providers provided the context of the women's illness careers. Pivotal

moments marked movement from one phase to the next. *Having the World

Crashing Down* was the first stage that occurred when the participants were

diagnosed with HIV. They felt that their lives as they knew them had been

destroyed. They indicated that the "whole world just shattered" the moment they

found out they had HIV. *Shutting Out the World* occurred next. During this stage,

many participants experienced withdrawal, denial, social isolation and loneliness.

As they struggled with their diagnosis, they often avoided HIV care and avoided

contact with important others. During the third stage, *Living in a Dark World*,

participants descended into a dark phase of self-destructive life and health-

threatening behaviors following their diagnosis. During the fourth stage,

Reconstructing the World, participants began to reestablish themselves in the world and found new ways to reengage with important others and resume meaningful life activities. Findings confirm that the illness careers of HIV-positive transgender women are influenced by the social context of the health care setting and interactions with health care providers and important others.

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Chapter I: Introduction

Significance of the Problem

Human Immunodeficiency Virus (HIV) continues to be one of the most significant and preventable diseases threatening public health in the world. In the US alone there are more than one million people currently living with HIV.[1] Despite public health interventions such as condom use and needle exchange programs aimed at reducing behavioral risks and new prevention strategies such as pre-exposure prophylaxis (use of antiretroviral treatment[2] in uninfected, high-risk populations), there are approximately 56,300 newly reported cases of HIV each year.[1,3,4] Of the one million people livings with HIV/ Acquired Immunodeficiency Syndrome (AIDS), 42-59% of do not receive HIV care, and nearly one third fail to make their initial medical visit to establish care.[5-12]

Timely access to HIV care and treatment following an initial HIV diagnosis and retention in care throughout the course of illness plays a vital role in reducing HIV transmission and decreasing HIV-related morbidity and mortality. [5-7,10-16] However, more than one-third of all new HIV cases are diagnosed late, meaning that AIDS progression occurs within one year or at the same time of the initial HIV diagnosis.[1,17] Advanced disease progression at initial diagnosis suggests missed opportunities for HIV testing, delays access to recommended anti-retroviral therapies, which can reduce HIV transmission rates,[1,17] and contributes to the more than 18,000 AIDS related deaths that occur annually in the US.[18] Lack of routine HIV testing also contributes to poorer health outcomes, particularly among high-risk populations such as African Americans, intravenous

drug users, men who have sex with men (MSM), African American transgender women, and Hispanic/Latinos,[19-21] and higher medical expenditures.[1,17]

Human Immunodeficiency Virus among Lesbians, Gay, Bisexual and Transgender Populations

Data on HIV transmission among women who have sex with women, or lesbians, is scarce. Though female-to-female transmission is plausible, there have been no confirmed cases of female-to-female transmission in the US.[22,23] Similar to the transgender population, the lack of data on HIV transmission among lesbians has resulted in this population being ignored within the broader spectrum of HIV research.[23-25] By comparison, gay and bisexual men (men who have sex with men or MSM) are most severely impacted by HIV and accounted for more than half of all newly diagnosed cases of HIV in the US from 2008-2010.[3] Within this subpopulation of MSM, Black MSM aged 18-25 have the highest rates of new infection.[3] [26]

Male to female (MTF) transgender women are biological men who identify and live their lives as women. Transgender women are often classified within the population of MSM, yet have unique social and behavioral characteristics that has led to them being one of the sub-populations most severely impacted by HIV.[21,27]

Transgender Population

The transgender population makes up an estimated 0.5 to 1 percent (about 700,000) of the US population.[28,29] Estimates vary in part because transgender persons often identify themselves as their psychological, rather than natal, gender and because the varying definitions of transgender are difficult to standardize for population-based surveys.[28,30] Lack of conceptual clarity regarding transgenderism, the absence of direct survey questions about biological sex at birth and preferred gender identity, and fear of discrimination associated with claiming a transgender identity are among the other major factors contributing to these poor estimates.[28,31,32]

In its broadest sense, the term transgender is used to characterize people whose gender identity, expression or behavior, does not conform to the norms and expectations traditionally associated with their biological sex assigned at birth.[30,31,33-38] Within the transgender spectrum are gender subgroups which include cross-dressers (transvestites), transsexuals, gender-queer, male-to-female, and drag queens/kings.[32,36,39] Collectively this group may also be referred to as gender variant or gender-nonconforming people.[40,41] These classifications are not static, have diverse meanings and interpretations,[25,37] vary widely among racial and ethnic groups, cultures,[42] and among transgender people themselves. In addition, all people in the transgender community do not readily accept these classifications.[32,39] Because this study focuses on transgender women, it is essential to clarify, to the extent possible, the variations and areas of overlap within the broad category of transgender. The term

"transgender" will be used to describe the participants in this study because it is considered broad enough to encompass the wide range of gender variant people or subgroups that fall within the larger classification of transgender.[40,43] A brief description of each subgroup follows.

Cross-dressers, also known as transvestites[41] are biological men, usually heterosexual,[37,39,40,44] who dress in women's clothing, shoes, make-up, and wigs for sexual release and pleasure on a part-time basis.[37,45,46] Cross-dressers often conceal their practice of wearing women's clothing and once they have used the garments to complete their sexual acts, discard of the clothing.[37,46] Within the gamut of cross-dressers or transvestites, and across the lifespan, gender expressions and identities vary. For instance, cross-dressing before the age of 10 is thought to be more predictive of transsexualism, which is characterized by a desire to change one's biological sex, and not sexual gratification.[40,45] "Committed cross-dressers", are men who regularly dress in women's clothing as part of their dual gender identity and in order to, express their feminine identity and play a feminine role.[37]

Transsexuals (TS) are biological men who cross dress as a means for expressing their psychological female gender identity, not to experience eroticism or sexual pleasure, and who desire sexual reassignment surgery and other physical transitions.[37,39,41,45] Transsexuals often feel strongly that they were born into the wrong body and, as a result, experience a great amount of psychological and emotional distress. This distress is often categorized as Gender Dysphoria (GD). GD, previously known as Gender Identity Disorder and Gender

Incongruence in the DSM-V,[37] and as pathological mental disorder among other helping and psychiatric professions.[39,41] A more detailed discussion of GD is presented in the *Illness Career* section.

Gender-queer refers to the deliberate mixing and matching of gender roles and gender-assumed clothing, in order to defy societal assumptions about gender.[37] Gender-queer people may or may not refer to themselves as transgender or may consider themselves to be androgynous,[37] but usually have no desire to undergo sex reassignment.[40]

Male-to-female, or transwoman, refers to a biological male who has undergone sexual reassignment surgery, *or*, who identifies as a woman, but has not been sexually reassigned.[41] Other variations of male-to-female include woman, transgender woman, and transsexual woman.[37]

Drag queens are usually, but not always, gay men,[44] "perform" drag or dress as caricatures of women.[37,38] Drag queens typically do not desire to have a woman's body, however, some do undergo breast augmentation or acquire breasts through hormone therapy.[44]

Walker and Avant state that conceptual clarity on a phenomenon of interest allows researchers to "get inside" a concept and see how it works.[47] Further, having a clearly defined concept ensures that anyone who sees the concept and its definition can understand exactly what is being discussed, described, explained or predicted.[47] As a concept "transgender" reflects the ambiguity that calls for a concept analysis, yet because it encompasses such an array of variations may defy conceptual clarity. In addition because gender and

sexuality, both defining characteristics of transgenderism, are fluid[48] in nature

and thought to exist along a continuum, the definition of transgender may always

be tentative.

Heightened Health and Human Immunodeficiency Virus Risk in Transgender Women

Transgender identity, sex work, drug abuse, unmonitored use of

hormones, social norms regarding gender and sexuality, and transgender

discrimination and stigma contribute to the heightened health and HIV risks

among transgender women. A discussion of each factor and how it contributes to

illness and HIV risks follows.

Transgender Identity

Two major factors that set transgender women apart from MSM in the HIV

epidemic and underscore the need to treat them as a separate population is their

need to resolve their sexual identity and gender identity confusion and their

desires to achieve a feminine appearance and state of mind.[42,49] This resolution

often manifests itself through high-risk sex acts, such as unprotected receptive

anal intercourse, which validates and reinforces their feminine identity.[42,50-52]

Engaging in unprotected receptive anal intercourse significantly increases HIV

risk for both MSM and transgender women. Transgender women, however, use

this act as a means to establish social acceptance as a woman, gain emotional

support and love from their male romantic partners, and to attain financial

support.[51,52] In addition, because transgender women often engage in

commercial sex with heterosexual men, [53] they function as a bridge to infection to

heterosexual women and are a key risk group for HIV transmission.[54,55]

Sex Work

Transgender female sex workers constitute another subset of transgender women who are at risk for HIV and poor health outcomes. Not having insurance and a regular source of medical care adds to their poor health trajectory.[56]

Sex work has been regarded as a rites of passage for transgender women, especially those who are younger in age and who are African American, and those beginning their gender transformation.[57] Even young (those under 30 years of age)[56] transgender women and those who have never engaged in commercial sex work, embark on this path as a means of establishing ties with other transgender women in the community and gaining social support.[57] While reports vary on consistency of condom use in this population, it has been reported that efficacy to negotiate condom use decreases during times of financial hardship and when transgender women can earn more money for performing sex acts without protection.[51,56,57]

Structural barriers such as lack of job training, educational training, and non-inclusive work environments potentiate their grave economic situation, further increases their dependency on sex work for survival, and magnifies their vulnerability to violence and abuse.[57] Prior history of incarceration, unstable housing, and minimal monthly income are other structural factors that reinforce their economic need to remain engaged in commercial sex work and other illegal activities.[19,30,33,55,58] Taken together, these factors potentiate the greater likelihood for female transgender sex workers to be victimized, physically

assaulted, and raped when compared to their non-transgender sex worker counterparts.[59]

Substance Abuse

Substance abuse tends to cluster within social networks and often overlaps with other high risk behaviors such unregulated hormone use and multiple sexual partners.[60] Transgender women often use drugs as a means of coping with the stigma and discrimination associated with their gender status and those involved in sex work, as a means of emotionally escaping during sex acts with their clients.[56,57] Drug use further diminishes their ability to negotiate condom use during sex acts and thereby increases their risk for HIV and other sexually transmitted diseases.[57] HIV sero-positive rates among transgender women engaged in commercial sex work surpass the rates of those who do not exchange sex for survival needs.[56] In addition, they tend to have more casual sex partners and to engage in sex while high on drugs.[56]

Hormone Use

Because of transgender women's desire to achieve congruency between their psychological gender and physical appearance, access to hormones takes priority over other health concerns. Hormones are often accessed without a prescription, may include needle sharing,[51,60-65] and may be associated with other behavioral risks that overlap with drug use. Unmonitored use of female hormones, such as estrogen, pose additional health risks for transgender women such as hypercoagulability, thromboembolism, mood swings, depression, insulin resistance, and abnormal liver enzymes.[63,66,67] Long-term complications such as

scarring, deformity, and infections have also been reported following injection of large quantities of viscous fluids such as silicone and mineral oil into the face, buttocks, hips, thighs, calves, and breasts by unqualified persons.[68,69] Life-threatening complications such as migration of mineral and silicone oil outside of the original injection site to vital organs and other areas of the body, acute pulmonary edema, and chronic inflammation of collagen and connective tissues have been reported.[68-70] Other adverse side effects include breast granulomata, chronic cellulitis, and disfigurement resulting from radical excision of scar tissue.[68-70] Even with the potential for serious complications following illicit hormone injections, the desire to attain rapid feminization takes precedence.[68] Cases of breast and prostate cancers have also been reported among transsexual women taking therapy and risks for acquiring these hormone related malignancies are likely to increase with age.[67,71]

In spite of these harmful health effects, transgender women often use high dose combinations of hormones to accelerate feminization and may not readily accept HIV therapies that interfere with hormone therapy or estrogen levels.[63,64,72] Although this study focuses on transgender women who are HIV-positive, it is important to highlight other potential health consequences associated with hormone therapy as these complications, rather than HIV, may prompt them to seek care within the formal treatment system.

Social Construction of Gender and Sexuality

In Western cultures, the lay public associates transgenderism with homosexuality and social deviance. [35,37,73,74] This is due, in part, to the socially

constructed gender binary categories of male and female (also referred to a

biological sex), the conflation of gender with sexuality, and the dichotomous

social expectations regarding gender roles.[27,38,40,73] The social construction of

sexuality refers to how the society in which we live and culture of which we are a

part, shape our emotions, desires, sexual relationships, and sexual identities.[75]

Interpersonal relationships and social interactions within our social

networks play an integral role in how we define our sexuality, express our sexual

behaviors, and dictate with whom and how we engage in sexual encounters.[75,76]

In addition, social norms, power relations, and geographical location of one's

social network determine how we define and normalize sexual meanings.[77] It is

through the social network that an individual learns the social and sexual

expectations of their ascribed gender role[78] and comes to accept (often without

interrogation) the definitions of normal sexual behaviors and expressions

established by social institutions of power such as religion, medicine, and the

state.[75-77,79]

The term transgender is used to describe one's gender identity and is not

reflective of sexual or romantic practices or preferences. Therefore, it should not

be confused with sexuality or romantic attraction.[19,31-33,80] Despite their assigned

male sex at birth and their psychological female gender, sexual orientation

among transgender women varies. Some may identify as lesbian, others as

bisexual, heterosexual, simply "sexual" or in other diverse ways.[31,46,53] Making

clear distinctions between gender, gender identity, sex, and sexual orientation is

critical to comprehending the disconnect between the internal identity and

physical body experienced by transgender people and the societal confusion that often arises in regards to their gender identity and sexual orientation.[30,81] Gender and sexual identity labels are used to form collective identities[82] which are instrumental in organizing social networks and forming social network ties[83]. Unfortunately they are also used to pathologize and marginalize vulnerable groups such as transgender women.

Transgender Stigma and Discrimination

In general, people living with HIV often conceal their diagnosis due to fear of abandonment from friends, family and HIV related stigma.[84] For multiple marginalized communities such as transgender women, the effects of stigma are more physically and emotionally debilitating. The stress associated with being a sexual minority increases the psychological need for gender affirmation, often resolved through high risk sexual behaviors, drug use, and risky body modifications,[42] and is associated with delayed HIV testing and late stage diagnosis.[2,84] This chronic, psychological stress and anxiety also lead to negative health consequences such as low self-esteem, depression and suicidal ideation.[30,74,85-88] Rates of depression are high among transgender women, and because of their gender identities, they, are often victims of violence and harassment, and often receive inadequate care for their health care needs.[30,50]

The effects of stigma and discrimination on transgender women's health extend well beyond those related to their HIV status. In an effort to avoid discrimination, transgender women are likely to conceal pertinent health information from health care and social service providers and to avoid situations

and environments where they are not accepted.[89-92] This lack of disclosure limits their access to appropriate health screenings for conditions such as breast and prostate cancers and increases their likelihood for other adverse health events.[87] Fear of harassment and discrimination also force transgender women to use emergency rooms for their urgent and primary health care needs, thereby increasing their risk for living with untreated or undertreated chronic health conditions such as hypertension, diabetes, and HIV. [30,87]

Human Immunodeficiency Virus/Acquired Immunodeficiency Virus

Although national HIV data specific to the transgender population is lacking, studies conducted in major metropolitan cites indicate that transgender women are often unaware of their HIV status due to low rates of HIV testing. When they are diagnosed with HIV, these women have low rates of initial and/or follow-up medical appointments.[9,13,33,50,88,93-97] As a result, they are more likely to infect others and experience HIV-related complications and death.
[19,33,50,61,93,96,98-100]

A recent CDC report estimated that 27% of transgender women are HIV-positive.[101] Several other prevalence studies have reported HIV infection rates that range from 11-78% among transgender women; these rates are staggering and exceed those of all gender and sexual minorities.[19,33,61,98,99] Among high risk groups, such as African American transgender women and transgender women who engage in commercial sex work, the HIV disparities widen.[33,34,42,50,55,61,88,102] Worldwide the burden of HIV in transgender women escalates to an astonishing rate, with recent reports showing that transgender women are 49 times more

likely than non-transgender persons to be HIV infected.[103] These rates underscore the urgent need for HIV prevention, treatment, and care that focuses specifically on this population.

Transgender Health Research

HIV has long been thought of as a sexually transmitted disease that is acquired by socially and sexually irresponsible people. While it is true that HIV is transmitted sexually, it is also a complex phenomenon that results, in part, from individual behaviors and decision-making, that is influenced by factors in an individual's social, economic and geographical environment. HIV is also a disease of poverty, low educational and socioeconomic attainment, and disempowerment, that disproportionately impacts vulnerable and minority populations. Risky sexual behaviors such as unprotected sexual intercourse, receptive anal intercourse, and multiple sexual partners, have long since been the primary focus of HIV public health research. The emphasis on these factors has obscured the influence of the social network in the epidemic and has resulted in the pathologization of certain races, sexual acts, gender identities, and sexual orientation.[25,104-108]

Public health research involving the transgender population has been minimal and focused primarily on sexual deviance, homosexuality, mental disorders, and behavioral risk factors involving sex and drug use.[30-32,58,109] The few studies that have examined the unique health needs of the transgender population have done so within the collective group of other sexual minorities.[96,110,111] Although the acronym LGBT is frequently used as an umbrella

term to describe lesbian, gay, bisexual and transgender persons, these populations are very diverse. Therefore, research findings from one group cannot be generalized to others, and combining groups masks differences that exist between them.[110] In the context of HIV/AIDS research, most studies have focused on gay men and lesbians and with health research in general,[111,112] few studies have focused solely on the social processes and factors that influence transgender women's health care utilization.[19,32,50,93,95,100,113,114] This epidemiological and biomedical approach to research has obscured the health and service utilization needs specific to the transgender population.

One such example is the Centers for Disease Control (CDC) and Prevention's HIV/AIDS surveillance system, a national data management system that is used to track the HIV epidemic. Data obtained through this surveillance system is used to identify high risk populations, influence intervention strategies, and to establish priorities for HIV prevention funding.[4] The CDC began conducting population-based AIDS surveillance in 1981; and in 1985 their surveillance efforts were expanded to include HIV.[115] Cases of HIV/AIDS are reported by mode of transmission, race, ethnicity, gender as in male or female, but not transgender. Currently many federal, state, and local agencies do not collect data about individuals' sexual orientation or gender identity, therefore data on individuals who fall outside of the dichotomous margins of male or female, and heterosexual are often not captured.[88,94,109,110,116] For example, public health HIV surveillance categorizes transgender women as men who have sex with men[19,109,110] even though these women do not self-identify as men. This

emphasis on sexual orientation (e.g. being gay or bisexual), rather than sexual behaviors (e.g. receptive anal intercourse regardless of sexual orientation) presents unique challenges for public health workers and medical providers who usually rely on self-report of sexual orientation to screen for HIV risk behaviors.[53,117]

Data obtained from leading health agencies and policy makers are used to establish health priorities, to monitor trends in illness and disability, and to track progress toward achieving national health objectives. These data are essential for the dissemination of reliable and public health information and critical for the development of meaningful prevention programs and care services.[88,94,110,113,116,118,119] Historically, efforts to collect meaningful data on the transgender population have been poorly coordinated.[30,110,113] This lack of meaningful data has contributed to significant and persistent health disparities in the transgender population.[30,74,89-91,97,116,120-123]

Need for the Study

In their 2011 report, *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*, the Institute of Medicine (IOM) advised that in order to build a solid foundation of evidence in transgender health research that the role of social influences and structures on transgender health must be examined. The role of the social network in the HIV epidemic has significant implications for HIV prevention and treatment, yet have been overshadowed by the focus on biomedical determinants.[25] Examination of individual health utilization behaviors without reference to the social network in which they are embedded provides only partial

insight into the complex nature of their sexual practices, health behaviors, and patterns of health care utilization.[124] This is because the interaction that occurs within an individual's social network influences health behaviors and health outcomes.[124] The IOM also recommended that inequities in accessing health care and transgender-specific health needs be examined.[110]

Finally, the IOM suggested that the National Institutes of Health implement a transgender-specific research agenda designed to support research that will advance knowledge and understanding of transgender health and encourage grant applications from investigators who focus on gender minorities as their primary research population.[110] Similarly, the National AIDS Strategy calls for tailored strategies to reduce the rates of new infections among sexual and gender minorities and facilitate their entry into and retention in care.[96] Lastly, the IOM recommends that trans-health research be guided by a social ecological perspective that allows for examination of health issues in various contexts, such as social network ties, social demographics, and environmental factors that affect physical and mental health.[110]

Since the release of this report, funding for transgender health research has flourished and transgender health has become a leading health priority.[101,125-128] Major cities and the District of Columbia have responded by modifying health surveys to include questions that will capture transgender identity data.[129,130] Additionally, national agencies such as the CDC have intensified their efforts to improve the quality of HIV data collected on transgender communities.[101] Department of health officials across various states

have also used the IOM report to guide policy changes and to inform health advocacy initiatives that target the transgender communities. Finally, the number of global transgender and intersex activists groups have also grown significantly since 2011.[131]

Conceptual Framework and Study Aims

The Network Episode Model (NEM) is a sociological, health utilization model that was developed in response to the need to enhance our view of how contexts and social network structures influence health and illness.[52,132] The NEM is based on the premise that the social support system is the primary influence on individual health care utilization and proposes a concept called the ***illness career***, [133-138] which refers to the dynamic social processes that undergird the use of health care services during illness. An illness career starts with an event that triggers a sequence of actions and decisions that are used to cope with a physical or emotional illness. Understanding transgender women's experiences of how they seek, enter, and engage in HIV care is a necessary first step before effective behavioral and public health HIV prevention and care interventions can be developed to facilitate health care utilization for these women.

Using the NEM, this study explored the illness careers of HIV-positive transgender women and the influences of important social relationships in their social support system on the illness career. In addition, this study described the influence of health care encounters within treatment systems on the patterns and pathways through which transgender women are linked to HIV care, and

described how these processes influenced their entry and retention in HIV care.[29,58,88,96,110,111]

Given our limited knowledge of transgender women's experiences with health care utilization and their illness career, it was critical to maintain a discovery-oriented approach of exploratory methods that documented experiences from the perspectives of these women themselves.[139] Therefore, a grounded theory approach was used because it allowed the basic social structural processes and meaning of the phenomenon of interest to emerge naturally.[139,140]

The primary aim of this study was to describe the illness careers of HIV-positive transgender women. The illness career is characterized by all the attempts that an individual uses to cope with an illness episode and maps out the steps (timing, sequencing, and actions) they use throughout the process.[136] Throughout the illness career, an individual makes decisions about whether or not to seek treatment and if so, when, where and how. These decisions are informed by various factors including the cost and benefit of treatment, formal and informal health advisors in their social network, and attitudes that people within their social network have towards healthcare utilization.[136]

The first sub-aim of this study was to describe the influence of important social relationships in the social support system on illness careers. Social support systems, social networks and communities are important for studying health and illness; and provide valuable sources of information about health resources and health promotion efforts.[25] Social networks can also be used to

mobilize interventions[141] and promote health behaviors change such as accessing HIV care.

The second sub-aim of this study was to describe the influence of health care encounters within treatment systems on the illness careers. Healthcare encounters and relationships within treatment systems shape and mold the pathways through which an individual seeks care. These encounters and relationships also affect the level of satisfaction with the care experience, influence acceptance and adherence to treatment, willingness to trust and disclose pertinent health information to the members of the care team, and the decision to remain engaged in care.[31,133,138,142]

The final analytic product of this study is a theoretical, stage model that addresses each of the research aims, describes how transgender women experience the HIV illness career, and that describes how social relationships and health care encounters influences movement throughout each stage. This model is presented is chapter four.

Contribution to the State of Science in Transgender Health

This study is consistent with the national health recommendations outlined by several major policy makers because it focused exclusively on HIV in transgender women. [88,110,112,116,118,143] In addition, it focused on identifying barriers and facilitators to accessing HIV care and provided insight into strategies that can be used to reduce disparities in health care utilization this population. Finally, because this study focused solely on transgender women, it

acknowledges their human right to be recognized as an independent

constituency group and as actors in the national HIV epidemic.

Organization of the Dissertation

Chapter II includes a discussion of the Network Episode Model (NEM), which was used to guide the review of literature and to inform interview guide questions (See Appendix G). This will include a comprehensive review of literature pertaining to the social context of transgender women, the illness career and related concepts, and a discussion of what is known about the influence of social relationships and health care encounters on the illness career.

Chapter III describes the grounded theory methodology that was used to guide this study and also includes a description of the data collection, study procedures, and data analyses used in this study.

Chapter IV will include a description of the sample, the results; and will include a detailed description of the theory *Having the World Change,* a four-stage model that describes the illness careers of HIV-positive transgender women. The stages include: *world come crashing down, shutting out the world, living in a dark world,* and *reconstructing the world.*

Chapter V entails a summary of the complete study, a discussion of the importance of the study, its contribution to the state of the science, and a discussion of how *Having the World Change* can be used to inform strategies for increasing HIV health utilization, reducing delays in care and improving retention; and for improving our understanding of how social networks and health care interactions influence the illness career of HIV-positive transgender women.

Chapter II: Review of Literature

Network Episode Model

The Network Episode Model **(**NEM) starts with the basic premise that illnesses or health problems are social processes that are managed through social networks. It is within the social content of the individual and through their social ties that individuals learn about, begin to understand, and develop strategies to handle life's difficulties.[132,136] Social networks consists of an individual, who is shaped and molded through his/her interactions with others in their network, people or nodes, and network ties links (connections between individuals).[132] The network serves as a framework for describing the relationship structures within a particular population and for describing how behavioral norms, values, and attitudes determine health behaviors and disease risks.[52] [144]

The NEM proposes three important concepts that have been shown to influence health status, health behaviors and care utilization: ***the illness career, the social support system, and the treatment system*** (See Appendix A).**[133-135,137,138]** The NEM has been used to examine lay decision-making for medical care, explore social processes (patterns and pathways) through which individuals access care for medical problems, and as a model for organizing and guiding studies on social epidemiology.[135,137]

This model was selected to guide this study because it provides a useful foundation for examining how social demographics, social networks, and social interactions of HIV-positive transgender women influence their illness careers. These three concepts informed the review of literature, which includes a

definition of the major concepts and a discussion of literature related to transgender identity, HIV as an illness, and HIV care utilization. The review will start with an overview of the social content or episode base for the individual, as it lays the foundation for understanding the social context of the transgender population. A discussion of the three major concepts of the NEM, the illness career, social support system, treatment system, and related literature will follow.

Social Content or Episode Base

Within the *social content or episode base* of the NEM are specific variables such as gender, age, education, work and marital status, income and occupation that form the basis of one's social network, social status, and social support system. Individually these social factors define the social group structure, determine the type social interactions in which an individual engages, and determines the geographical position of their social network members.[145] Prior history of illness, coping style, and access to medical insurance are influenced by the social demographics discussed above and by social network ties. These factors alone (and collectively) influence the nature and quality of an illness. More specifically, they determine the severity, visibility, duration and type (acute or chronic) of illness that one endures. Together, the factors within the social content or episode base of the NEM function as determinants of individual and social network health, health behaviors and access to care. Access to care, the organization of care, and the financing of care are all part of larger organizational constraints, which plays a significant role in how, when, or if an individual accesses the treatment system, and how their illness careers unfold.

Social Content for Transgender Women & HIV

Social and geographical location. For transgender women, gender identity functions as a deterrent to medical care and a barrier to effective discussions regarding sexual orientation and health behaviors that is critical to making informed health and treatment decisions.[64,88,93,95,112,146] Research studies on health care access among transgender women also report that they are at risk for not accessing or delaying health care in part due to competing financial priorities, low educational attainment and unemployment.[147] Compared to the general population, transgender people are four times more likely to live in extreme poverty (<$10,000/year) and because of their gender status, are limited in their income earning capacity, and career advancement.[148,149] Subsequently, they are less likely to occupy formal, paid labor positions that would facilitate access to essential social services such as health insurance, stable housing, and transportation.[150]

In contrast to transgender men (female-to-male), transgender women are more socioeconomically disadvantaged, earn one-third less income, and are subjected to job harassment, termination, and loss of authority.[33,151] As a result of non-accommodating, heterosexist work environments and discrimination, transgender women are often forced into survival sex work, face greater risk for physical exploitation, violence and incarceration, and suffer from adverse health outcomes such as illness, disability and death.[19,33,34,150,152,153]

Personal health background. Within social networks people and health are inter-connected. As a result, whatever is "seated" within a network becomes magnified and anything that is placed within a network will spread.[154] HIV, sexually transmitted infections (STI), health behaviors, health practices, sexual partners, and the like are examples of phenomena that spread throughout networks. In fact, studies have reported that the risk for HIV transmission increases within social networks that have high rates of untreated HIV and other sexually transmitted infections such as genital herpes and syphilis.[49]

Social networks alone do not give rise to phenomenon,[154] however behaviors within the network can spread and sustain disease once it is initiated. To illustrate this point, studies conducted on populations of MSM have shown that co-infection with STIs such as syphilis, gonorrhea, and chlamydia are common among men already known to be infected with HIV.[155] This is indicative of continued engagement in high-risk sexual behaviors following an HIV diagnosis. Concomitant STI present additional health threats, such as re-infection and super-infection to people living with HIV and increases the likelihood of spreading the virus through oral and rectal mucosal shedding.[155] Further, studies on spatial clustering of HIV have shown large clusters of HIV are often situated in geographical areas that are largely impoverished and have large populations of MSM and intravenous drug users.[156,157]

Transgender women are more likely to experience chronic psychological and emotional stress because of their gender status or sexual orientation. The minority stress model is helpful in understanding how stigma and discrimination

create negative health consequences such as low self-esteem, depression and suicidal ideation.[89,90] Transgender stigma and discrimination produces chronic psychological stress and anxiety. As a result, transgender women are prone to avoidant coping, which forces them to conceal their transgender bodies and avoid situations and environments not accepting of their gender identities.[89-91]

Avoidance coping is common among socioeconomically disadvantaged minorities, drug users, and women and is correlated with higher levels of depressive symptoms or psychological distress.[30,158-160] While stigma and discrimination are not new actors in the HIV epidemic, when partnered with a transgender identity, their interaction can be devastating, resulting in avoidance of medically necessary care, suboptimal adherence to HIV medication, and poorer health outcomes.[30,61,161-163]

Compared to the general population transgender women are less likely to have medical insurance and those who do are more likely to have public[33] or state insurances such as Medicaid and Medicare.[158] Among racial and ethnic groups, Black transgender persons have the lowest rates of insurance coverage of all.[158] Lack of medical insurance directly restricts access to medically necessary and preventive medical care and worsens long-term health outcomes.[164]

Nature of the event and illness characteristics. Service utilization rates tend to be higher among individuals with a diagnosis of AIDS than among those diagnosed with HIV only. When controlling for race and gender, Blacks report more frequent hospital admissions and longer lengths of stays. Illness severity

and functional limitations due to illness and pain often motivate individuals to seek care.[165]

Engagement in HIV care is often described as a spectrum that ranges from not being aware of one's HIV infection with high HIV viral loads to being fully engaged in care with optimal viral load suppression, defined as less than 200 copies of HIV virus per milliliter of blood.[166] Despite the benefits of early treatment and engagement in care, nearly half of the individuals who are HIV-positive delay care for up to one year or more and enter care with advanced disease progression or AIDS.[10,16,167-171] Blacks and black MSM, for example, are more likely to be diagnosed with AIDS at first diagnosis when compared to other racial and ethnic groups and are less likely to have virologic suppression within one year of starting antiretroviral therapy (ARV).[166,171] ARV therapy plays a critical role in HIV viral load suppression, improving health outcomes, and minimizing the spread of HIV infection,[72,171] yet transgender women are less likely to adhere to prescribed antiretroviral therapies (ART).[72] This suggests that something other than access to recommended therapies is constraining their utilization of health services.

Organizational constraints. The pathways through which an individual must travel to enter HIV care are complex and can discourage care utilization.[167,168,172] For example, following an initial diagnosis of HIV, an individual is referred to an HIV care coordinator and HIV medical specialist for a psychosocial needs assessment, medical exam, and if needed, initiation of HIV medication therapy.[167,173] Once in care, continued engagement (adherence) in

care is necessary to achieve and sustain optimal health outcomes, yet many people with HIV drop out of care. Comorbidities, competing financial priorities, lack of transportation, substance abuse, ability to cope with an HIV diagnosis, presence of symptoms, and quality of relationships with health care providers are factors that have been shown to influence an individual's decision to remain in HIV care.[170,172,174,175]

For transgender people accessing the treatment system is problematic.[92,123] That is because erasure, or exclusion from the institutional world, of the transgender population within the treatment system is inherent and social and institutional stigma towards the transgender population has created a systemic avoidance,[123] or erasure of trans-health and social issues.[92,123] One such example is the exclusion of transgender health care content from medical and nursing school curricula.[92,123,176,177] Because transgender health care is not part of standard medical or nursing school education, physicians and nurses are, by default, not prepared to provide competent care to transgender patients.[92,178] This lack of preparation threatens the quality of patient-provider communication and reinforces a treatment system that is intrinsically designed to be unresponsive to the health needs of the transgender population.[92,179]

With such oversight at the institutional level, transgender women encounter a number of barriers to care,[9,180] have many unmet needs,[66] and report having fewer positive encounters with their health care providers.[31,42,72] The organization and accessibility of care for transgender women may look very different from that of their non-transgender counterparts. Specifically, because of

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their gender status, transgender women may have two to three different health care providers--one to manage their hormones for gender transition, another to manage their general health care issues, and in the case of HIV-positive transgender women, a third to manage their HIV disease.[30] Adding to the organizational constraints and complexities of care utilization is a general lack of knowledge among physicians, nurses, and other health care providers about how to manage the complex health needs of transgender women.[63,66,72,88,112,114,123,181] Insensitive and insulting comments and lack of trans-friendly health care environments[123] further inhibit their access to healthcare.[31,72,92]

The variables which form the social content or episode base for the individual give rise to the type and quality of one's social support system, act as antecedents or predisposing factors to illness, and can determine the level and types of care to which one has access within the treatment system.

The Illness Career

The illness career refers to the dynamic social processes that undergird the use of health care services during illness. An illness career starts with an event that triggers a sequence of actions and decisions that are used to cope with a physical or emotional illness.[132] Throughout the illness career, an individual is faced with having to make decisions about whether or not to seek treatment and if so, when, where and how. These decisions are informed by various factors including the cost and benefit of treatment, the combination of formal and informal health advisors in their social network, and the attitudes that people within their social network have towards healthcare utilization.[132,136]

The illness career is composed of pathways (key entrances and exits) through which an individual enters and exits healthcare, as well as patterns (timing and sequencing) of treatment events that an individual uses to cope with an illness episode.[133,135-138] See Appendix A, Network Episode Model (NEM).

The illness career of HIV-positive transgender women has not been thoroughly described; therefore, much of what is known about healthcare utilization throughout an illness episode has been derived from studies on non-transgender persons who do not have the added stressors associated with being a gender minority. Since it is not uncommon for individuals to have multiple illnesses at once and because one illness episode can trigger the onset of a new illness or worsen an existing one, the illness career within the NEM is ideal for studying individuals who have concurrent illness episodes. More specifically, it is ideal for describing the illness careers of HIV-positive transgender women who, in essence, have two overarching illness careers: Gender dysphoria and HIV. I surmise that while the illness careers of being transgender and HIV positive may start at different time points in a woman's life, there are likely times when the two illness careers intersect thereby altering their illness perceptions, health utilization patterns, and nature of their healthcare encounters.

In the next section, gender dysphoria will be discussed within the concept of illness. Recognizing illness, asking for guidance and referrals, and a description of key concepts in the illness career and related literature will follow.

Gender Dysphoria

The belief that transgenderism is an illness is pervasive in general society

and among institutions such as medicine and other regulatory bodies that define

social norms and determine insurance eligibility for, and access to, healthcare

services.[40] Yet being transgender in and of itself does not constitute illness.

Rather it is the emotional and psychological discomfort, or gender dysphoria

(GD) that ensues as a result of the conflict between the biological sex and the

psychological gender that qualifies it as a psychiatric illness treatable through

psychotherapy and medication.[35,40,41,80]

Since GD is not experienced by all transgender people it could be argued

that not all experience illness because of their transgender identity.[41] At the same

time, transgender people who desire hormone therapy and other surgeries such

as chest reconstruction or breast augmentation to achieve secondary female sex

characteristics, must assume the patient role and subscribe to the illness label in

order to access the necessary medical care and treatment.[41,60] Along with

accepting the illness label, there are other pre-requisites to accessing these

services through the treatment system. For example, in order to access

hormones, one must have real life experience in their preferred gender role,

exhibit progress towards resolving other life problems that contributed to their

mental duress and demonstrate their ability to adhere to hormonal therapy as

prescribed.[46] Individuals desiring sex reassignment surgery must live in their

preferred gender role, under supervision of a medical professional, for a

minimum of 12 months.[46,48] These "requirements" function as organizational

constraints for some transgender women who, due to accessibility and affordability of care and other organizational policies, resort to obtaining unmonitored hormones and obtaining surgical enhancements underground or outside of the formal treatment system.[42,92]

The distinguishing characteristic of GD is discomfort or distress that prompts a transgender person to seek treatment from medical professionals in hopes of alleviating this distress and finding comfort with their preferred gender role and expression.[41,80,182] Treatment for GD varies from person to person and may include feminization or masculinization through hormones and/or sexual reassignment surgeries, psychotherapy, voice and communication therapy, and name and gender change on legal documents.[36,41] Interventions such as these are medically and psychosocially necessary to alleviate the discomfort associated with GD and are critically important to helping transgender people achieve comfort with their self and identity.[41]

Recognizing illness

The illness career begins with the onset of an illness or related symptoms and with an acknowledgement by an individual that they are ill.[183] Acknowledgement of illness alone is not enough to prompt health care seeking. In order for this to happen, an individual must think that the problem is serious enough to seek professional care, accept or admit that they are ill, and trust the health care provider enough to consult with them for treatment.[183]

The definition (meaning) of illness and the ability to recognize, acknowledge, and to know when to seek care varies according to race and

ethnicity, culture, gender, social class, and educational level.[183] As a result, health status, quality and timing of onset for treatment, and health outcomes may also vary by these same variables. The social meaning ascribed to an illness also influences one's decision to enter care. For instance, illnesses that are deemed serious may illicit a societal reaction that prompts an individual to seek professional medical care.[183] On the contrary, highly stigmatized diseases such as HIV may be concealed and care seeking delayed until the manifestation of symptoms, which typically occurs in the later stages of disease.[123,184]

Asking for Guidance and Referrals

Once an illness is acknowledged on a personal level, an individual will typically seek guidance and referrals, but not formally. In most instances, this process of seeking guidance starts within the individual's social network. In his study on the lay construction of illness, Freidson discusses how the process of asking friends for help, guidance or referrals distinguishes friends from others (or non-friends).[183] He further describes how the process of asking for help, particularly for stigmatizing illnesses such as psychiatric disorders, is not easy. The same then is true for stigmatizing illnesses such as HIV. Friedson holds that when an individual suffers from common illnesses such as a cold, the process of asking for help, even from a stranger, occurs without hesitation.

The process of asking for help and the characteristics of the helper are important in studying health and illness. This is because an individual is more likely to have the courage to share with a friend that they are ill, and admit that they need help, but is not likely to disclose to others (non-friends) such

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information.[183] Disclosure of one's HIV or transgender status may result in a variety of responses that range from support and acceptance to physical abuse, discrimination, and abandonment.[185] Fear and anticipation of how friends and non-friends may respond to disclosure of an HIV-positive status,[184,185] or transgender identity, may discourage any level of disclosure and therefore limit access to potentially helpful guidance or treatment.

This underscores the importance of friends within social networks in not only helping guide an individual into care, but also keeping them in care, and perhaps determining when care is sought. This further emphasizes how the social support system, more specifically; the community network functions influence the illness trajectory.

Key entrances. Key entrances in the illness career are preceded by events that trigger an individual to seek care.[138] These events or cues prompt an individual to take action and vary according to the severity of illness, signs and symptoms of disease, visibility of illness, and duration of signs and symptoms. A significant number of individuals who test HIV-positive wait longer than one year to enter medical treatment.[186,187] Because of this, a substantial number of people have advanced HIV disease once they enter care they often begin their illness careers when they are dying.[186].[184]

In a study to examine acceptance of HIV testing among women, the presence of illness symptoms or the illness of a family member or partner, were reported as cues for seeking HIV testing or treatment.[185] By comparison, the absence of symptoms are known to reinforce denial about illness and delay entry

into care.[186] In a study to examine health-related beliefs and decisions about accessing HIV medical care, participants indicated that not having symptoms of HIV meant that it was not necessary to seek care.[188] Presence of symptoms in someone who is HIV infected is a late indicator of illness and is associated with poorer health outcomes.[186,189]

Mistrust of medical providers, fear of discrimination in health care settings, shock of receiving an initial HIV diagnosis, and poor social support have also been cited as reasons for avoidance or delay of entry into care.[6,15,16,164,170,190] Despite the nature of their illness, individuals, who lack trust in medical providers delay or avoid care until their illness symptoms worsen. Conversely, a person who trusts medical providers may enter their illness career at an earlier stage in illness and have greater options for treatment. Similarly, an individual who believes in the efficacy or benefit of a specified treatment may be more inclined to seek care sooner and more frequently.[191] This illustrates how health care encounters, trusting relationships with medical providers, and welcoming environments of care can affect the pathways through which people enter care and alter the trajectory of the illness career.

Key exits. Key exits refer to events that result in discharge of an individual from the illness career. It refers to the period of time when care ends (termination of care) or when illness ends (recovery from illness or death). According to the NEM individuals exit care when they are no longer sick, meaning that the disease has been cured or they have started to feel better, when care has been terminated, when they have recovered from an illness, or once they have died.[138]

Avoidance and disbelief of HIV status are two major reasons why people delay or drop out of care.[188,192] Attending medical appointments, adhering to complex medication regimens, and discussing their disease with medical providers are constant reminders that one has HIV.[188] In addition, receiving routine HIV lab tests, such as CD4 counts and HIV viral loads, become constant sources of anxiety as they are indicators of disease progression and yet another reminder of poor health.[188] In this respect, exiting care is used as a means of coping (through avoidance) with a disease that is mentally and emotionally difficult for many people living with HIV to accept.[188]

Previous studies on drop-out rates show that factors such as being tended to by more than one practitioner, being male, younger, living alone, having limited knowledge of one's illness, and having a history of psychiatric disorder are associated with higher risk of discontinuing care.[193,194] Other factors contributing to breaks or termination of care includes lack of therapeutic alliance between the individual and health care provider,[188] lack of helpfulness within the health care facility, and long delays between initial appointment and referrals to specialist.[194] These factors will be discussed in greater detail under the ***treatment system.***

Key timing/sequencing. Key timing/sequencing refers to events that affect the timing and sequencing of entry and navigation through care. These include factors such as having multiple health care providers, the medical team composition, ordering of consultations, delay and spacing of consultations, and the degree and length of compliance.[132]

Delay or failure to initiate ARV, lack of consistency (stopping and starting) with therapy, poor adherence and viral resistance are four main barriers to successful and timely treatment with ARV.[195] Early HIV detection and treatment improves prognosis, but is challenging because acute HIV infection resembles common viral infections and may be dismissed as such. Of all new HIV cases, 30-40% of all cases are diagnosed late, meaning that the person has AIDS at initial diagnosis. Therefore, the timing and sequencing of events within the illness career and the stage of illness once a person enters care will be affected. Lack of illness symptoms or clinical indicators may result in missed illness cues and therefore result in entrance into care at more advanced stage and a prolonged or impossible recovery altogether.[196] Similarly, some people may present with symptoms such as weight loss, thrush and pneumonia that are indicative of AIDS, but are misinterpreted as complications of diabetes.[197] Men, blacks and Hispanics, people 25 years and older, individuals who earn less than $10,000 per year, and those on state-based insurance programs such as Medicaid and Medicare are more likely to delay, or not access, HIV care.[197,198]

In a study of delayed entry into health care for women with HIV disease, Ickovics and colleagues found that women who knew their HIV status prior to becoming pregnant were four times more likely to delay entry into care.[199] In addition, once the women presented for care, more than 64% were symptomatic. Similar findings were reported by Samet, et al. who concluded that, on average, most individuals who are aware of their risk for HIV delay recommended HIV testing for up to 2.5 years.[187]

These findings suggest that a diagnosis of HIV alone or the awareness of one's risk for HIV, are enough to prompt the search for adequate and timely care. On the other hand, it appears that the onset of symptoms may trigger healthcare seeking. Albeit, the diagnosis itself and the time that it takes for an individual to develop symptoms may alter the key timing and sequence of activities that occur within the illness career and limit treatment options.

Difficulty recognizing illness, acknowledging the existence of illness and following medical advice also influence the key timing and sequencing within the illnesses career. Mitchell & Selmes offer a framework for helping us understand the various reasons that care may be interrupted, delayed or avoided altogether. These reasons are both biomedical and health-care system related in nature and include factors such as being asymptomatic and therefore not being screened for illness or disease and denial, type of illness, and reluctance to accept diagnosis once informed of disease.[194] The denial or reluctance to accept a diagnosis then triggers a series of other events that change the course of the illness career such as hesitance to start treatment if offered and lack of adherence and follow-up to medical appointments and prescribed treatment.[194] These studies illustrate the complexity of factors that determine the course of the illness career.

So what does this mean for the illness career? For starters it means that in comparison to individuals with higher educational attainment and from higher socioeconomic levels, people from lower socio-economic classes are less likely to use traditional medical care and more likely to seek lay care and rely on home remedies.[183] Next it may also mean individuals with less social, economic and

financial means may enter the illness career at a later stage, for example when they are terminally ill or dying, as opposed to at an earlier stage of illness when they are acutely or chronically ill. Third it suggests that the illness career is shorter lived for poorer persons and therefore, their options for treatment fewer and that individuals who are socially isolated, or who do not have friends with whom they can share information about their health, may endure worse health outcomes. Taken together, this means that in order to understand the factors that propel an individual into treatment, the meaning of illness and the methods used to gauge the severity of symptoms must be defined from the perspective of the social network of which the individual. Describing the illness careers of HIV-positive transgender women will yield insight into what may prompt or cue transgender women to utilization health care and how their transgender status influences the illness career and impacts their ability to navigate the treatment system.

Social Support System

Sociodemographic, behavioral, intrapersonal, and structural characteristics form the basis of membership in certain groups and people with similar characteristics tend to connect and interact with those whom they share the most similarities.[200] Sexual minorities, who tend to construct their social networks around their sexual identities, practices, and values, are one good example.[83] This principle, known as homophily structures network ties within marriages, friendships, work place relationships; and influences the type of information that is transferred and exchanged within the network. Homophily in

race and ethnicity form the deepest divides within social networks, with age, religion, education, occupation and gender following, respectively.[200] Homophily has implications for the type of information that is received, attitudes and beliefs that are formed, and the type of interactions that are experienced.[200] Social networks function as sources of social support, can impact health outcomes for populations and groups, and can be a springboard for social capital and political action.[82,83]

Social support may play a particularly important role in the lives of HIV positive transgender women who are coping with an HIV diagnosis and may assist them in managing the challenges associated with the illness.[201] As such, it is essential to understand the role that a transgender woman's social support system plays in her decision making, rationale for utilizing care, the means by which they access care, and the mechanisms that they use to cope with illness.[83]

Social networks vary in terms of the types and levels of social support provided, and have been shown to influence psychological health, physical well-being, coping response to stress, access to health information, and receipt of health care.[135,141,202,203] Likewise, beliefs and attitudes derived from the social network influence attitudes toward health and professional medical care,[138] impact the relationship between the patient and provider, shape the medical encounter, and impact health care utilization.[138,191]

Prior research on social support systems has emphasized the relationships among social support, quality of life and well-being for those living with HIV/AIDS and other chronic illnesses.[63,142,173,204,205] Within the social support

system, family members, friends, and religious organizations serve as sources of informal and formal social support. Social networks can influence health norms and behaviors and can be used to mobilize interventions[141] and promote healthier behaviors such as HIV care utilization. Contrastingly, HIV-related stigma and discrimination within the social support system, social isolation, and poor social relationships have been linked to lower rates of medication adherence[206] and can prevent utilization of healthcare altogether.[142] This is especially true of transgender women who may forego healthcare in order to avoid transgender stigma and discrimination during a healthcare encounter.

Since transgender women are at greater risk for social isolation, their social support systems may vary greatly from the general population and from other sexual minorities. As a result, they may be more likely to seek and receive social support from transgender friends, trans-friendly people,[83] and through non-traditional venues such as the ballroom community.[66,207,208] Ballroom communities are social networks that are composed of homes that are led by "house" mothers and fathers.[207,208] These homes provide a family-like structure for marginalized members of the LBGT community, particularly transgender women from racial minority groups, and may be instrumental in facilitating their healthcare utilization.[207,208]

Support offered throughout the course of the HIV illness career can influence how efficaciously one manages the HIV disease, adheres to medical treatment, perceives illness, and copes with illness.[63,142,173,204,205] For instance, studies on HIV-positive transgender women have shown that social support

systems are helpful in managing complex social issues, such as violence and

drug use; obtaining access to highly coveted medical goods such as hormones

and silicone, and feeling more in control of their lives and capable of managing

their illness.[83] Moreover, social support systems provide protection from social

isolation and a safe place for sharing survival strategies such as obtaining cash,

accessing social services, and maintaining a feminine appearance.[32,64,83,201,204]

On the contrary, people who do not perceive any social support and who fear

that they will be abandoned and stigmatized by their friends and family, often

conceal their HIV diagnosis to avoid being abandoned.[204] Likewise, lack of social

support is more debilitating for multiply marginalized communities such as

transgender women and minority racial groups, and often results in delayed HIV

testing, late stage diagnosis, and underutilization of care.[204]

These examples underscore the wealth of resources offered through the

social support system and demonstrate how the network structure and function

interact with cultural factors, to influence the illness career, health care decision

making, basic survival, access to relevant health information, and health

outcomes.[52,209] These studies further accentuate the importance of engaging the

social network of transgender women in the development of methods to increase

their healthcare utilization and the need to design interventions in such a way

that can be owned and implemented by the social network itself.

Treatment system. Prior to entering the treatment system, an individual

must manage organizational constraints such as accessibility and affordability of

care.[191] Their ability to do so greatly depends on their social resources such as

education, work status, income, occupation, and access to medical insurance. These constraints can delay or prevent health care utilization and can directly influence illness severity and health outcomes.

Within the treatment system, variables such as the provider-patient relationship, organizational culture and climate, financing options or affordability of care, and coordination of care within and across the system influence the illness trajectory. Social networks within treatment systems determine the culture of care within an organization (e.g. attitudes towards gender minorities and involvement of family members and same sex partners in care), determine a health care provider's scope of practice, influence the quality of care available within the system, and determine an individual's level and type of access to care.[133,138,170,210 138]

In particular, healthcare encounters and relationships within treatment systems influence satisfaction with the care experience, acceptance and adherence to treatment, willingness to trust and disclose pertinent health information, and the decision to remain engaged in care.[31,133,138,142] Stigmatization of homosexuality and transgenderism are examples of social responses within treatment systems that cause gender and sexual minorities to delay HIV testing and screening for other sexually transmitted infections and delay of initiation of antiretroviral therapy.[2]

Organizational culture, organizational climate, service integration, and coordination also affect how health care providers respond to patients and impact an individual's ability to navigate through the treatment system.[133,138,164] The

effects of such have been reported on marginalized populations such as socioeconomically disadvantaged people of color who are less likely to access primary medical care and more likely to use emergency room departments for their primary care providers.[142] And again in studies on referrals, specifically those that have reported a relationship between difficulties in accessing and navigating the HIV health care when HIV specialists, case managers, and social workers are geographically located in separate facilities.[6,164,170,173,211,212]

The effect of the treatment system on health utilization and health outcomes were reported in a national U.S. survey of over 7,000 transgender persons. In this survey respondents reported that they postponed medically necessary care and experienced significant barriers to accessing health care because of stigma and discrimination, inability to afford care, refusal of care due to their gender status, harassment and violence in the medical setting, and lack of provider knowledge about TG care. [30,33,50,88,91,113,132,213] Collectively, these factors cause transgender women to withhold pertinent information regarding their sexual orientation, illness, and health behaviors from their medical provider.[64,88,95,112,132,146] Non-disclosure hinders effective treatment and care discussions, as well as informed decision-making, results in poorer health outcomes and alters the timing and sequencing of events within the illness career.[64,88,95,112,132,146]

By comparison, treatment systems that are trans-friendly or welcoming are more likely to engage transgender women in care. In a study to examine HIV prevention and primary care for transgender women in a community-based clinic,

participants indicated that clinics that did not identify itself as "gay or transgender-friendly" eliminated the need for the women to identify as "trans" and instead gave them the flexibility to identify themselves simply as women.[214] Transgender women's need to identify as "women" cannot be understated, as it is this distinction that affirms their psychological gender identity and affirms their femininity. It is for this same reason that hormone therapy is so critically important to transgender women and why it often takes priority over HIV medication and related care because it represents the first step in solidifying their gender identities.[83]

In sum, the literature suggests several gaps in knowledge. The first is how the intersection of a transgender identity combined with a diagnosis of HIV shapes the illness career. The second and third are how important social relationships in the social networks and healthcare encounter within the treatment system influence the illness trajectory of HIV-positive transgender women.

Because social networks play an integral role in dissemination health information and influencing behavior change, it is imperative to identify how important social relationships and health encounters influence illness trajectories and care utilization among transgender women. In doing so, researchers are more likely to be successful in designing interventions that will be owned by and sustained through their social support systems.[215]

Chapter III: Methods

This chapter provides a description of the grounded theory methodology, recruitment strategies, data collection, and data analysis procedures that were used to guide this study.

Research Design

Effective strategies for HIV prevention and treatment require understanding the experiences of what it is like to be a transgender woman living with HIV and trying to navigate the complex systems of care. This perspective can only be obtained by eliciting stories from the women themselves and is best achieved through qualitative research methods.[51] Grounded theory methods were selected because this approach allows for exploration of shared social processes, experiences, and symbolic interactions.[139,140]

Background and Philosophy of Grounded Theory

Grounded theory (GT) methods are best described as a "systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories "grounded" in the data themselves" (Charmaz, p. 2).[139] This methodological approach is based on the assertion that people who share common circumstances, have similar life experiences and maintain common beliefs and behaviors.[139] GT methods emerged from the collaborative work of sociologists Barney G. Glaser and Anselm L. Strauss[139] and originates from symbolic interactionism. Symbolic interactionism is a sociological, theoretical perspective that is based on the assumption people construct themselves, society and reality through social interaction.[139] There are three core premises of

symbolic interaction. The first is that people act towards other objects and people in their social environment according to the meanings that they have for those objects and people.[216] The second is that "meanings" arise from social interactions among individuals.[216] The third is that meanings are established and modified through an interpretive process undertaken by individuals.[216]

Distinguishing characteristics. The hallmark features of GT include simultaneous data collection and analysis, theoretical sampling, constant comparison, coding and memo-writing, and theory, usually mid-range, development.[139,217] GT focuses on process and trajectory, uses gerunds to indicate action and change, detect processes, and stick to the data, and has a core category or variable that ties stages and phases of the emerging theory together.[139]

Justification for grounded theory methods

GT uses an inductive, discovery-oriented approach to guide development of substantive theories which can be used to describe the complexities of people undergoing change, explain the influence of social interactions on outcomes, and describe the ways in which the social environment influences their human experience.[139,218] Since little is known about how the social network and social processes influence HIV-positive transgender women's decisions to seek, enter, and be retained in care and how these factors affect their illness experiences, GT was felt to be the ideal method for this study.[139,140,219] Basic assumptions of GT is that individual behavior, experiences, and the meanings ascribed to them by the individual are best understood from their perspective and most influenced by

their sociocultural environment.[139,140,218] Therefore obtaining understanding of the phenomenon under study requires face-to-face interaction during which participants are given the opportunity to describe their experiences in their own words.[220-223]

Research Team and Reflexivity

The PI conducted all 18 interviews as part of her doctoral dissertation. She is an African-American, non-transgender woman and transgender ally. For several years prior to, and during the course of this study, she served as the quality improvement nurse for a Ryan White HIV/AIDS services program at the county health department and attended the Ryan White Consumer Planning Council meetings, which were regularly attended by members of the LGBT community. This investigator has an interest in health equity and equitable access to care for gender and sexual minorities. She had a collegial relationship with one of the community advisory board members, a transgender woman, who also served as one of the study's participants. As part of her role as a quality improvement nurse, the PI participated in cultural events such as the annual AIDS walk, Indy Gay Pride, and attended a House Ball, which consists of various forms of artistic performance (e.g. drag, dance, vogueing, and runway walks) by members from the LGBT community.

Sampling and Recruitment Strategies

Multiple recruitment tools and sampling strategies were used to recruit a sample of transgender women with diverse health care experiences and illness careers. These strategies included use of a Community Advisory Board (CAB), direct phone calls from collaborating agencies, and informational meetings with

collaborating agencies. Recruitment flyers, introductory study letters, and recruitment palm cards were used to advertise the study. See Appendix J.

Recruitment and Sampling Strategies

Snowball, convenience sampling, and venue-based sampling were used throughout the study. Recruitment for the study occurred in two stages. During Stage 1 and the first phase of data collection, introductory letters and study flyers were mailed to HIV-positive transgender women by the Indiana State Department of Health's HIV/AIDS services program and the Marion County Public Health Department's HIV/AIDS services program. Recruitment materials were mailed only to those transgender women who had given consent to receive HIV-related mail and who had accessed HIV-related care in the previous 12 months. The letters emphasized the voluntary nature of the study and the PI's contact information; see Appendix D. The study flyer included a picture of the PI, the PI's contact information, estimated length of the interview, inclusion criteria. See Appendix J. The flyer indicated that a gift card would be provided as a "thank you" for the participants' time and information, but the amount of the incentive was not included on the recruitment flyers during this stage.

In addition to mailing introductory letters and flyers to eligible participants, one collaborating HIV clinic opted to contact eligible transgender women by making direct phone calls to inform them about the study. During these calls, care providers introduced the study to the women and asked if they were interested in participating. Participants who were interested in participating in the study were given the option to contact the PI directly to schedule the interview or

to give permission for the PI to contact them and schedule the interview. The PI screened participants over the phone and scheduled a time to conduct the interview. Direct phone calls continued throughout the duration of study recruitment. See *Procedure for Direct Call from Health Care Provider to Prospective Participants* in Appendix C.

During Stage 2 and the second round of data collection, the PI implemented use of a Community Advisory Board (CAB) that consisted of five members and held informational meetings with collaborating agencies.

The CAB was used to ground the study in the needs of the community, to further establish trustworthiness of the PI, and to enhance recruitment efforts. The first CAB member was a transgender woman that the investigator met through her associations with the local health department. The PI met with this community member, provided her an overview of the study, and invited her to serve as a CAB member. This community member agreed to join the CAB and to assist the PI in recruiting other key people for the CAB.

CAB members were recruited from community-based organizations that were known to provide care to transgender women and from other venues identified by the first community member. There were a total of five CAB members: two African American transgender women, one black Hispanic transgender woman, one African American community-based street outreach worker, and one African American gay male who worked closely with the transgender community. All CAB members verbally agreed to assist with recruitment. The PI met with the full CAB once before starting the second round

of data collection and continued to meet with select members periodically throughout data collection. CAB members provided substantial input into the design of recruitment materials and selection of recruitment venues. Each CAB member was given a $50 gift card for each meeting they attended as a thank you for their time and contributions to the study.

The CAB assisted in the design of two separate recruitment flyers; see Appendix J. Both flyers contained a picture of the investigator, a brief description of the study, a description of the social benefits of participation, a description of the potential personal benefit to the participants, and the incentive amount. One flyer was general and contained no language specific to HIV. CAB members felt that prospective participants would be reluctant to remove a pull-tab from a recruitment flyer that made references to HIV, especially if these flyers were in general social venues. The second flyer contained language specific to HIV. CAB members felt that potentially eligible participants would not hesitate to stop and read or remove a pull-tab from these flyers as long as they were in places known to provide HIV care such as HIV clinics, AIDS Service Organizations, and Community-Based Organizations.

CAB members also suggested use of business card sized palm cards that they would use to directly approach eligible participants, see Appendix J. At the suggestion of the CAB, the term "HIV" was not used on the palm cards. CAB members advised that this would allow participants to place the cards in their pockets or purses without having to worry if someone found the card and thus

found out the participants' HIV status. CAB members distributed these cards only to transgender women they knew to be HIV-positive.

To further enhance recruitment efforts, the PI held informational meetings with staff at collaborating agencies within the treatment system and at community venues identified by the CAB. During these meetings the aims and expected benefits of the study were described, and staff, community members were encouraged to share information about the study with their transgender female clients or friends and were given study fliers to distribute throughout their agency or community venues. Table 1 shows the total number of participants recruited by strategy.

Table 1 *Participants by Recruitment Method*

Recruitment strategy	Number of participants
Recruitment flyers	N=4
Referred by recruitment/collaborating agency	N=7
Community advisory board member	N=7
Total number of participants enrolled	N= 18

Institutional Review Board

The Institutional Review Board (IRB) at Indiana University Purdue University Indianapolis provided ethical approval for this study. To maximize confidentiality of participants, a waiver of written informed consent was obtained from the IRB. Prior to enrollment, all participants were asked to read a written information sheet and encouraged to ask questions before providing verbal consent for participation.

Inclusion Criteria and Data Collection

Inclusion criteria for study participants included being 18 years of age or older, identifying as a transgender woman, self-identifying as HIV-positive, and being able to participate in an interview in English. Each prospective participant was screened over the telephone; three were screened face-to-face. Participants meeting the inclusion criteria were scheduled for an interview at a site and time that was mutually agreeable to the participant and PI.

The PI conducted individual, semi-structured interviews with 18 HIV-positive transgender women. Interviews were digitally recorded and transcribed verbatim by a professional transcriptionist. As social network map (See Appendix H) was also used to elicit the names of the important people in the participant's social network and to generate a discussion of how each individual supported the participants and influenced their health care utilization following their initial HIV diagnosis. This methodological approach has been used in mental health studies to design social network interventions to facilitate mental health treatment.[224]

Prior to the start of each interview participants were asked to complete a demographic data collection sheet (See Appendix F). The demographic data collection sheet contained19 questions, 10 fill in the blank and nine multiple choice and included questions about age, race/ethnicity, current gender and gender at birth, sexual orientation, relationship status, employment status, educational attainment, insurance status, and health history. The verbal interview began immediately after participants completed the demographic data collection sheet. Interviews lasted between 60 minutes and three hours, with average of

two 90 minutes, and were conducted in quiet, private settings, such as the participants' homes, study rooms in public libraries, and counseling rooms at participating sites. The interviews elicited detailed narratives about the women's experiences with testing HIV-positive and accessing health care (See Interview Guide, Appendix G). Specifically, participants were asked about the role of important relationships in their social network and the role of their health care encounters on their utilization of HIV care. Participants were also asked questions about their gender identity, their experiences of coming out as transgender, and their experiences as a transgender woman. Participants were given a $50 gift card in appreciation for their time at completion of their interview.

Sample Size Justification

In grounded theory, an exact determination of sample size cannot be established a priori. Initially a sample size of 20-25 HIV-positive transgender women was anticipated. This number was selected because qualitative research studies typically rely on 20-25 participants to achieve informational redundancy. The final sample size for this study was 18, as it was at this point that data obtained from interviews began to replicate.

Data Analysis

The illness career refers to the dynamic social processes that undergird the use of health care services during illness. It starts with an event that triggers a sequence of actions and decisions that are used to cope with a physical or emotional illness. Throughout the illness career, an individual is faced with having to make decisions about treatment-whether or not to seek it and, if so,

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when, where and how. These decisions are informed by many factors- the cost and benefit of treatment, health advisors in their social network, and their social network's attitudes towards healthcare utilization. The primary aim of this study was to describe the illness careers of HIV-positive transgender women. The sub-aims of this study were to describe how important social relationships, health care encounters, and social support influence the illness career.

Data were analyzed with procedures outlined by Charmaz.[139] According to Charmaz, grounded theory coding forms the framework of the analysis. Coding is the link between data collection and the emerging theory. Coding allows the researcher to describe what is happening in the data and is used to generate initial thoughts about its meaning.

Initial coding is first used to separate data into categories and to identify processes. During initial coding the researcher reads the data closely and begins to code each line. Initial codes are provisional and may be reworded to improve the degree to which they capture what is taking place in the data. Line-by-line codes are then used to identify analytic ideas to pursue in subsequent data collection and analysis.[139,225]

In this study initial coding began after the first three interviews. The investigator read each transcript multiple times in their entirety, highlighted passages that reflected salient ideas and themes, and wrote line-by-line codes in the margins. As data collection and analysis progressed, questions in subsequent interviews were modified for in order to explore important areas that emerged during the first three interviews in more depth and to verify findings and

relationships that emerged between the concepts. This process was repeated for the 15 subsequent interviews. After completing initial coding of the transcripts, line-by-line codes were compared for similarities and differences and for commonalities and exceptions, and organized the codes into five broad categories. Throughout this process the investigator consulted with select members of my committee for validation of the initial codes and categories.

According to Charmaz, axial coding is used to sort, synthesize, and organize large amounts of data and reconstruct them in new ways. During this process, the broad categories are broken down into subcategories and the concepts linking the categories together are described through memo writing. Memos are used to capture the researcher's thoughts, comparisons and connections made between the data, to illustrate how they have made sense of the data, and to inform subsequent analysis.[139]

For this study, axial coding was used to organize data into various tables. The investigator started with five tables, one for each broad category, and inserted the corresponding line-by-line codes within each the table. For example, the first column included the participant number, the second column included the line numbers for the corresponding code, and the third column included the codes, which were written as actions. Within each broad category subcategories were developed. For instance, the category of *Testing Positive for HIV*, was divided into subcategories of: *Getting the Results, Feeling Scared and Anxious, Getting Caught Up in Thoughts and Feelings, Thinking I Would Die, Shutting Down and Shutting Others Out*, and so on. After development of the

subcategories, the focus shifted to creating linkages between the data. The investigator used memos to document her thoughts on how the codes fit together, to round out the categories, and to document the analytic process. Finally, the investigator discussed the emerging ideas with select committee members. This phase of data analysis continued until all emerging categories and subcategories were placed into a theoretical framework that described the connections between the categories.

According to Charmaz's criteria, selective or theoretical coding is used towards the end of the study. These codes specify possible relationships between categories and help the researcher tell a coherent analytic story.[139,225]

In this study, selective coding was used to identify the core categories in the model. The investigator constantly compared, revised, and expanded categories until theoretical "saturation," the point when gathering new data did not spawn new theoretical insights or reveal any new properties of the core theoretical categories,[139] was achieved. The theoretical relationships among the categories formed the basis of the theoretical framework, and were determined by iterative movement between the evolving theoretical framework and the data, theoretical sampling (obtaining additional data through modifications in the interview questions as data collection progressed and analytic memo writing).

The core theoretical constructs formed the basis of the theoretical narrative that is presented in the discussion. The final analytic product of this study, a theoretical model that contains narrative summaries that addresses the research aims and provided in-depth descriptions of important aspects of the

framework, is presented is chapter four. The model was the result of an iterative process of rereading the transcripts (data) several times, to review the line-by-line codes and categories to confirm or modify the emerging stages in the model. The framework is presented in a schematic drawing and depicts the psychosocial stages through which the participants experienced the illness career following their diagnosis of HIV. Factors that enabled movement one from one phase to the next are depicted in a table format.

Descriptive Validity/Qualitative Rigor

Charmaz's criteria of credibility, originality, resonance, and usefulness was used to maintain validity and rigor.[139] A discussion of Charmaz's criteria and a description of how each was addressed in this study are presented in the following section.

Credibility. According to Charmaz, credibility in GT research is demonstrated through several criteria. First, the researcher has exhibited an intimate knowledge, or familiarity, of the research topic and setting. Second, there is evidence that systematic comparisons between observations and categories, which cover a wide range of empirical observations, were conducted. Third strong logical links between data, the argument being presented and analysis is evident. The last criteria that Charmaz suggests must be met to establish credibility is that the researcher provide enough evidence to support their claims and that be able to withstand an independent assessment of those claims.[139]

In this study, the researcher used several measures to clarify her stance in relation to the participants and subject matter. First, interviews were audio-recorded and transcribed to ensure that the participants' experiences and perspectives were accurately recorded and quotations will be used to truthfully convey their lived experiences.[226] Second, the researcher used open-ended questions to allow participants to speak in their own voice about their experiences. Third, the researcher reviewed all transcripts against interview recordings to enhance accuracy.

Originality. According to Charmaz, originality is demonstrated through new insights brought forth by the researcher. Studies that produce new concepts, challenge, expand, or clarify current ideas, concepts and practices are said to exhibit originality.[139]

This study is original because it focused on a concept of which little is known and generated new knowledge.[139] In particular this study presented a four stage theoretical model that described the illness careers of HIV-positive transgender women and offered new insights into how these women manage their HIV over time. In addition, it provided insight into how relationships with their social network and network of health care providers formed the context of the participant's illness careers. Finally, this study identified pivotal moments that marked movement from one phase of the process to the next.

Resonance. According to the criteria outlined by Charmaz, resonance is demonstrated in GT studies through several qualities. First, through categories that depict the richness of studied experience.[139] Second, when categories reveal

both luminal (ambiguous) and taken-for granted meanings.[139] Third, when the researcher uses data to make connections between larger collectivities or institutions and individual lives. Last, when the final theoretical product makes sense to the study participants and offers substantive insight about the participant's lives and their world.[139]

To ensure resonance of the final theoretical model in this study, the investigator, used line-by-line coding to ensure that the initial analyses accurately uncovered what participants said and ensured that important nuances and salient ideas in the data were not overlooked.[139] Self-reflexivity was used to clarify and reflect on the investigator's personal biases throughout the duration of the study[139,227,228] and analytic memos were kept as an audit trail. The investigator also held bi-weekly meetings with the qualitative methods advisor and dissertation chair to discuss the interviews, analyses, interpretations, and conclusions.[229] These steps ensured that the research process was clearly documented and the methods of data collection and analyses were clearly detailed.[229]

Usefulness. Charmaz states that usefulness in GT research means that the analysis offers interpretations that are useful to people in their daily lives. GT studies are said to be useful when they inspire further research in other robust areas.[139] Implications for future research are discussed in chapter 5.

Chapter IV Results

The purpose of this study was to describe the illness careers of HIV-positive transgender women. The illness career includes all the attempts that an individual uses to cope with an illness episode and the steps (timing, sequencing, and actions) they use throughout the process.[136] Throughout the illness career, an individual makes decisions about whether or not to seek treatment and if so, when, where and how to do so. These decisions are informed by various factors including the cost and benefit of treatment, formal and informal health advisors in individuals' social network, and attitudes that people within their social network have towards healthcare utilization.[136]

A sub-aim of this study was to describe the influence of important social relationships on illness careers of HIV transgender women. Social relationships can influence health beliefs and behaviors, and have either a harmful or beneficial effect on one's health outcomes. It is through important social relationships that individuals learn about, begin to understand, and develop strategies to handle life's difficulties.[132,136,144]

A second sub-aim of this study was to describe the influence of health care encounters on the illness careers on HIV transgender women. Healthcare encounters influence how individuals seek care and experience their healthcare. The quality of health care encounters influences individuals' acceptance and adherence to treatment, willingness to trust and disclose pertinent health information to the members of the care team, and decide to remain engaged in care.[31,133,138,142]

Description of Sample

The sample consisted of 18 urban-dwelling, transgender women. As shown in Table 2, the racial/ethnic makeup of the sample was as follows: 10 African Americans (55% of sample), four Whites (22%), one Hispanic-Black (6%), one Native American Pacific Islander (6%), and two multi-racial (11%).

At the time of the interview, 12 participants (66%) had been living with HIV between 1-5 years; three (16%) between 21-25 years; one (6%) between 6-10 years, one (6%) between 11-15 years; and one (6%) for more than 25 years. Eight participants (45% of the sample) were diagnosed with HIV between the ages of 20-29, five (28%) were diagnosed between the ages of 18-19, four (22%) were diagnosed between the ages of 30-39, and one (5%) was diagnosed between the ages of 40-49. Participants received their initial HIV-positive test results in a variety of settings: Hospital (n=4, 22%), HIV counseling, testing, and referral (CTR) center (n=4, 22%), in a prison/jail (n=4, 22%), in a physician's office (n=4, 22%), and at a commercial plasma center (n=2, 11%). This information was not collected on the demographic data collection sheet, but was provided during the interview.

Ten (56%) reported their sexual orientation as heterosexual, three (17%) as gay, two (10%) as bisexual, one (6%) as "sexual," one (6%) as "asexual," and one (6%) as "transgender." Asexual and transgender were not listed as options on the demographic data collection sheet, but were hand written on the form by the participants themselves. Asexuality is defined as the lack of interest in or

desire for sex. Sixteen (89%) participants reported their relationship status single and two participants (11%) reported being in a relationship.

Eight participants (44%) reported the 12th grade as their highest level of education completed. Five (28%) reported having some college education, two (11%) reporting having completed college, two (11%) reported never completing high school, and one (6%) reported having a GED.

Most participants in this study (n=10, 56%) were unemployed. The remaining participants (n=8, 44%) were employed in various settings such as the entertainment industry, retail, health care, and warehousing.

The majority of the participants (n=17, 94%) were insured. The most common type of insurance reported was Medicaid, followed by state-funded insurance programs such as Healthy Indiana Plan, MD Wise, and federal programs such as Ryan White Parts A and C, and private insurance.

The data collection sheet (Appendix G) did not contain questions about adverse life events. During the verbal interview, however, participants reported experiences such as substance abuse (n=11, 61%), sex work (n=9, 50%), forms of violence such as physical assault and harassment, rape, and intimate partner violence (n=7, 39%), incarceration (n=7, 39%), and childhood sexual assault (n=3, 17%).

Table 2 *Participant Demographics*

Race/Ethnicity	Number of participants
African American	10 (55%)
White	4 (22%)
Hispanic/Latino	1 (6%)
Native American/Pacific Islander	1 (6%)
Multi-racial	2 (11%)
Number of years living with HIV at the time of interview	Number of participants
1-5 years	12 (66%)
6-10 years	1 (6%)
11-15 years	1 (6%)
21-25 years	3 (16%)
>25 years	1 (6%)
HIV counseling and testing center	HIV counseling and testing center
18-19 years	5 (28%)
20-29 years	8 (45%)
30-39 years	4 (22%)
40-49 years	1 (5%)
Sexual orientation	Number of participants
Heterosexual	10 (56%)
Gay	3 (17%)
Bisexual	2 (10%)
Sexual	1 (6%)
"Transgender"	Age at time of HIV diagnosis
"Asexual"	18-19 years
Relationship status	Number of participants
Single	16 (89%)
In a relationship	2 (11%)
Highest completed level of education	Number of participants
High school	9 (50%)
Some college	5 (28%)
College graduate	2 (11%)
Never completed high school	2 (11%)
Employment status	Number of participants
Unemployed	10 (56%)
Employed	8 (44%)
Insurance status	Number of participants
Insured	17 (94%)
Uninsured	1 (6%)

Description of Interviews

The interviews lasted between one to three hours with the average interview lasting 1.5 hours. Interviews were conducted in quiet, private settings, such as the participants' homes, private study rooms in public libraries, and private offices at care coordination (recruitment) sites.

Some women were slightly apprehensive about the interview at first. One woman scheduled an interview then cancelled it because she felt nervous about telling her story. After talking it over with her friends, she called back and rescheduled her interview. Another woman said, "I wasn't open at first…[but] it's getting easier to be more open to talk about it."

The women showed a range of emotions throughout the interviews. Many became tearful when they talked about their gender identity confusion as children and when they discussed coming out to their families for the first time as transgender. Several were also tearful when they discussed their experiences of testing HIV-positive and telling their families about HIV for the first time. Although the interviews focused on experiences as transgender women and HIV (Refer to Interview Guide, Appendix F), the women commonly described other adverse life events such as childhood sexual abuse. Yet while much of the interviews focused on hardship, the women also shared positive aspects of their lives. For example, a few laughed and smiled when discussing the first time they dressed up as girls and wore make-up.

The women were eager to share their stories and indicated that they felt good about participating in the interview. Some stated the interview "was a relief"

and that it allowed them to "get a lot of stuff of their chest." Other women were happy to see that someone was genuinely interested in their experiences as transgender women and their experiences with health care. One participant said, "You could be doing your doctorate work on anything in the whole world, but you have chosen to do your doctorate study on transgender issues, and that means a great deal to me. So thank you." Another participant said, "It feels good to do something like this. It should be done more often, on a regular basis, because I think a lot of us would have a lot to talk about, and a lot of us have a lot [that we need] to get out and deal with…"

Throughout each stage of the model, supporting quotes are provided as evidence to support the claims in the study. The participants' demographics and pseudonyms are included in Table 3 *Participant Pseudonyms and Demographics*.

Table 3 *Participant Pseudonyms and Demographics*

Participant	Age	Race	Pseudonym	Testing Site
1	31	Black	Elise	*Doctor's office*
2	49	White	Gretchen	HIV counseling & testing site
3	36	Black	Stephanie	Hospital
4	30	Hispanic-Black	'Drea	HIV counseling & testing site
5	43	Black	Maxine	Jail/prison
6	*60*	*White*	*Jessica*	*Doctor's office*
7	58	White	Brenda	HIV counseling & testing site
8	22	Black	Cheron	Commercial plasma center
9	21	Asian/Pacific Islander	Monique	Jail/prison
10	29	Black	Erin	Commercial plasma center
11	*32*	*White*	*Rachel*	*Doctor's office*
12	*31*	*Black*	*Denise*	*Doctor's office*
13	49	Black	Chantel	Jail/prison
14	21	Black	Tiffany	Hospital
15	51	Black	Crystal	Hospital
16	26	Black	Porsha	Hospital
17	35	Black	Kim	Jail/prison
18	34	Black	Star	HIV counseling & testing site

Conceptual Model/Framework

Results indicated that the participants found their illness careers to be complex and full of emotional "ups and downs." They described frequent health care appointments for HIV and, for some, appointments and treatment for substance abuse and mental health problems. Many indicated that other life adversities such poverty and homelessness and conflicting family dynamics surrounding their transgender and HIV-positive status complicated their healthcare. Many began their illness careers with feelings of fear and anger, as well as denial, but over time they gained a sense of acceptance, resilience, and renewal. Interactions with family, friends, and romantic partners as well as a variety of health care providers influenced the participants' illness trajectories.

Data analysis revealed that the illness trajectory for transgender women is best described by a core process we have labeled *Having the World Change*. The analysis yielded four stages that constitute this process: *having the world come crashing down, shutting out the world, living in a dark world,* and *reconstructing the world*. I will first present the core process and then describe each of the four stages. For each stage, I will also discuss how the women's healthcare encounters and interactions with important others influenced that stage.

While the findings are presented as a model of a common process with four stages, the model is best understood as a conceptual rendering of the common ways in which transgender women experience the HIV illness career. The stages were actually fluid and iterative; not all of the participants moved

through all of the stages in the same order, some experienced the stages

simultaneously, some lingered in one stage longer than others, and some

reverted to earlier stages when they encountered new challenges.   The model is

presented in Figure 1.
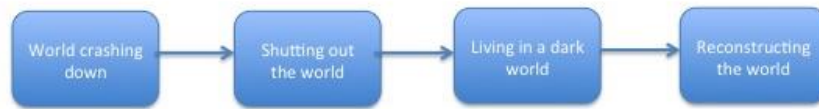
Figure 1. Having the world change model. This figure illustrates the four

psychosocial stages in the illness career of HIV-positive transgender women.

Having the World Change

The participants claimed that being diagnosed with HIV altered their entire life and fundamental changed their perceptions of themselves. The metaphor "Having the World Change" is used to describe how having HIV was not just having a chronic disease for the participants, but rather a life experience that disrupted their sense of self, their connection to others, and most aspects of their daily lives In her book, *Trauma and Recovery,* Herman (1997) writes that traumatic events "breach the attachments of family, friendship, love, and community" and "shatter the construction of the self that is formed and sustained in relation to others" (p. 51). Many parallels exist between Herman's descriptions of life after trauma and the participants' description of how their lives changed after HIV. The participants described HIV as a traumatic event that abruptly altered their lives and caused much chaos and confusion. Before their diagnosis, the participants identified as women or transgender women, but after they thought of themselves as "HIV-positive" first and women or transgender women second. Relationships with important others such as family, friends, and romantic partners changed in essential ways after participants were diagnosed with HIV. Herman writes that, in coming to terms with a traumatic event, the survivor must mourn the loss of their "old self that the trauma destroyed" and "develop a new self." (p. 196). The metaphor of "Having the World Change" therefore captures the pervasiveness of the changes faced by the participants and the degree of transformation that they experienced as they managed the illness in the context of their identity as transgender women.

Having the World Come Crashing Down

The first stage of *Having the World Change* occurred when participants were initially diagnosed with HIV. We labeled this first stage, *Having the world come crashing down.* This phrase is commonly used to denote an unpleasant or traumatic life event that occurs and suddenly leaves one feeling confused or upset.[230] The term "crashing down" refers to the structural collapse of something and thus resonates with the women's sense that their lives as they knew them had been destroyed.[230] One woman, for example, claimed that her "whole world just shattered" when she found out she had HIV. Though a few women believed that acquiring HIV was an inevitable outcome of being transgender and were not surprised by their diagnosis, most were shocked to learn their HIV status. Upon learning the diagnosis, they experienced disbelief, fear, confusion, anxiety, devastation, rage, and doom. Women described the moments when hearing the news that they were HIV-positive as "crushing" and "devastating." The way in which their worlds came crashing down was influenced by nature of the health care setting in which they were informed of their diagnosis and the dynamics of their encounters with health care providers.

Health Care Encounters

All the women were tested for HIV and received their results within the context of a healthcare setting. The healthcare settings included jails or prisons, hospitals, HIV counseling and testing sites, healthcare providers offices, and commercial plasma centers. The setting had a significant impact on how the women experienced *the world come crashing down*, as the type of support

received in the immediate moments following the diagnosis varied considerable according to setting.

In jail or prison. Several women were tested for HIV as part of a jail or prison intake health-screening exam or as part of a plea agreement for criminal charges. During intake, jail and prison staff advised the women that they would be "called back" to the medical office by a member of the health care staff if their HIV test results were positive. Because several women were jailed on charges of prostitution and drug use, they were "shocked" but not "surprised" about their diagnosis. Monique said, "I felt shocked, but it wasn't [shocking] because of the actions [that I was taking]. I knew that I was putting my life at risk and my health at risk for doing what I was doing. The money was not good for it, but it was good at that time." Chantel described similar feelings of being surprised, but not shocked to learn that her test results were HIV-positive. She said,

> I had been [testing] regularly since like 1989 when my best friend died of AIDS. I had been doing it regularly because I was kind of scared…It was due to my own mistake because I took the condom off while I was having sex, but had been STD free for all that time, [from] 1989 to '92. [Still when I tested HIV-positive] it just kind of threw me off, so I stayed in denial a long time.

Kim also felt surprised with her diagnosis, even though she expressed feeling that she would eventually test HIV-positive one day. She said,

I was [lost] for words. But in the same breath, I knew somewhere in the back of my mind [that] it was [only] a matter of time before I actually got it [HIV]. But how was I going to deal with it? I was in denial because you don't really want to say to yourself "You've got HIV". You know what I'm saying? Society has already scorned it as the killer gay disease. So you're thinking, "Damn". [I] knew

the lifestyle [that I] was leading, the unprotected sex [that I] was having, [that] it was just going to be a matter of time before it crept up through [my] blood stream. [I] just didn't know when. For at least one participant, being diagnosed with HIV was completely shocking. For Maxine, who was diagnosed in the pre-Highly Active Antiretroviral Therapy (HAART) era, the time period from 1981-1996 when there were no effective treatments for HIV, and when she 19 years old, the news was completely shocking. Prior to testing positive, she had "never heard about HIV." She explained,

> I had caught a charge for prostitution. One of the things that was part of the condition of the plea agreement…was that I had an HIV test going into the diagnostic center…I went to the center and they drew blood. I don't even remember, prior to that, hearing anything about HIV really. I didn't think it was ever a conversation about HIV that I ever remember having [when I was] younger, or prior to testing positive…My first introduction to HIV was when I tested positive, and I still didn't really understand it.

Kim shared a similar story. She said,

> I was called down after I did all of my little initial…blood work and counseling, and all of that. I didn't know I was HIV-positive. I didn't know that. They called me down to the doctor's office, and the doctor told me, "Did you know you were HIV-positive?" And it seemed like my whole world just shattered. I was lost for words.

In addition to the emotional stress of receiving an HIV diagnosis and other fears associated with being incarcerated, most women worried about issues specific to being HIV-positive while incarcerated. The fears included being "labeled in DOC [Department of Corrections] as getting meds," being thought of as a bad person, and being shunned by other inmates. Lack of privacy was also a major concern. Chantel described the difficulties of keeping her HIV diagnosis a secret in prison. She said,

> They called us down, and if it comes back positive, they come back
> and come get us and take us down, and tell us. But it's kind of like
> putting your business out there too because most people know that
> once you done went through the orientation part, and if they call
> you back down there like that after the doctor did, you know, the
> blood work, then something's not right. So it kind of puts a label on
> you, like oh you must be positive because it seem like the people in
> there look for that call back. You know oh, is this gay person going
> to get called back? And then when you get called back down there,
> it's embarrassing and you come back and you're trying to deny it,
> and you don't want it to be true and you don't want the people to
> start spreading rumors and gossip.

Maxine described similar difficulties with maintaining her privacy in prison. She

said,

> It was a horrible experience because the particular facility that I was
> in put these Plexiglas, sheets of Plexiglas up against our cells that
> had holes in it, moved our roommates out, we couldn't eat in the
> chow hall, we couldn't go to rec unless we went with each other.
> And this security panel where they open up all the bars, they had
> these huge, red things that said medical deadlock on them and
> everybody knew that [we were] HIV positive.

The type of support the women received in prison or jail after receiving the

diagnosis varied considerably. Maxine, for example, was given educational

pamphlets to read about HIV transmission, Chantel was offered post-test

counseling but refused because she was "too angry to talk to anyone" and was in

"denial", and Kim was offered, but declined post-test counseling because she

was also in "denial."

In a hospital. Several women learned of their HIV status while

hospitalized for treatment of other health conditions such as pneumonia,

seizures, and infections. These women therefore had to manage the stress

associated with those ailments along with the mental and emotional stress of

being newly diagnosed with HIV. A couple of the women felt shocked, confused,

and distressed by news of their diagnosis. When Porsha learned that she was HIV-positive she was shocked. She said, "My heart was breaking because I know how careful I am with my sex life. I use a condom with doing everything. So it was like a real shocker. Like how did I get it? I had to really sit back and think." By comparison, a couple of the women had suspected they were HIV-positive. Crystal, who was diagnosed when she was 47-years-old shared, "I think I had HIV for a long time and didn't feel that I needed to get checked, and so that's how I got to the point I was at with the pneumonia and stuff." Similarly, Tiffany, who was 18 years old when she was diagnosed, expressed, "I was kind of in shock, but I was kind of relieved because I kind of knew."

The women who were diagnosed in the hospital had unique challenges that were not shared by women who tested positive in other settings. Most were given their test results right away and immediately experienced the *world come crashing down*. A couple of the women were intubated and unconscious when they first tested positive for HIV, and *having the world come crashing down* was delayed for them until they regained consciousness. Women who were critically ill sometimes learned of their diagnosis after a family member had already been informed. Crystal described how once she arose from her coma that her mother already knew about her HIV. She said, "My mother and my brother were there [and] when I woke up they already knew." Most women learned of their HIV status from their health care provider, but one woman learned from her mother, that she was HIV-positive. When she admitted to the hospital after having a seizure, Porsha's mother asked the doctor to "run all of the tests" to determine

why Porsha was having seizures. The doctor told the Porsha's mother that the HIV test results were positive. When Porsha awoke from her coma her mother told her that she was HIV-positive. She said,

> My mom told me that I had HIV. [When] I woke up she made sure I was okay and everything. My brothers were there and then she was like, "Do you want them to know or do you want them to step out?" And I'm like know what? Because I'm lost, I just woke up out of a coma so I was like it don't matter because they're my brothers. So she told me, "Well I had some tests ran on you and we found out that you have HIV."

Unlike the health care providers who informed the women's family about the women's HIV-positive status first, Stephanie's doctor asked her family to leave the room so that he could deliver the test results. She said, "They [the doctor] told everybody to leave the room, but I told him that my mom could stay."

Of all the women who tested HIV-positive in the hospital, Tiffany was the only one who received post-diagnosis counseling. She shared what happened in the moments after learning that her screening test came back reactive. A couple of women had little follow-up. Porsha, for example, said that the doctors talked to her about her high blood pressure and diabetes, but not her newly diagnosed HIV. Similarly, Crystal said, "Actually nobody said anything [about her diagnosis]." By comparison, Stephanie received only a referral upon discharge. She said, "I got discharged from the hospital and what they did was refer me to a primary care doctor and [then] he referred me to one of his colleagues in the building who was an infectious disease doctor."

In a HIV counseling and testing site. Several women learned of their HIV status at HIV counseling and testing site. This experience differed from

learning the diagnosis in prison or other settings because these women came to site specifically to find out if they were HIV-positive. Though most sought testing on their own, some were advised to seek testing. For these women *the world come crashing down* occurred the moment they were advised to seek testing and then again after learning their results. Star described how her "heart dropped" and she had "an out of body experience" when the health department contacted her to come in for testing. She stated, "A cold went over me and my heart was beating fast." When a former romantic partner of Gretchen suggested that she get tested, she felt devastated. She stated, "In my heart I knew something's going on. I think I knew I had it [HIV] before I even got it [the results]." Having the *world come crashing down* occurred multiple times over a several weeks for Gretchen: when it was first suggested that she get tested, when the rapid salivary test results were positive, when she received an inconclusive confirmatory blood test result, and when she was finally confirmed positive. She shared,

> I was kind of leery cause they did a swab thing and I thought no. The first one was reactive. She took a second one and sent it out to get a confirmatory result and it came back inconclusive. They wanted me to come back the following week to do a blood test. I had to wait three weeks just to get the results back on the second one and I'm dying over here to know. I wanted to know what was going on.

Unlike most of the participants who learned their diagnosis in prison or jail or in the hospital, those who were tested at HIV counseling and testing center often felt supported by the staff after learning their HIV status. Brenda was diagnosed in 1990 (pre-HAART era) described her testing experience. She said, "It was very crushing, because I had a lot of friends that had passed away early

on. So when I found out it just devastated me…But the staff handled me with kid gloves, I couldn't ask for better." Star also felt supported by the HIV counseling and testing center staff. She said, "[They were] "real nice and sweet to me." Despite her multiple experiences with repeat testing and inconsistent test results, Gretchen also indicated that the counseling and testing staff was supportive and helped her get the care she needed. 'Drea, on the other hand, declined an offer for support because she was so angry about her diagnosis. She said, "They told me about counseling and things that I could get to help me cope with it [HIV], but I didn't want to hear that. I was in so much rage. I was just in rage."

In a health care provider's office. Other women learned of their HIV status in the office of a primary health care provider. The responses of the healthcare providers varied considerably and influenced how these women experienced their world crashing down. Elise felt supported by her doctor in the moments that followed her testing HIV-positive. She said,

> When I first found out about me having HIV I was on the verge of getting ready to give up. The doctor called me in and he got to talking to me and he was just telling me that just because I have HIV don't mean that I'm going to die this soon.

A couple of women, however, were not well supported by their health care providers. For example, Rachel's doctor just gave her the news that she was positive. Unlike Elise, Rachel's doctor did not provide additional verbal support. Rachel said, "She [the doctor] just told me, 'You're positive.' Then [she] gave me a list of papers, numbers to call. I didn't call for a long time. I just ran from it…you know." Though these women were usually given test results face-to-face in the health care provider's office, one woman received her test results from the doctor

over the phone and thus, received very little emotional or informational support.

Denise described how she learned that she was HIV-positive. She said, "She [the doctor] called me. She called my home and told me, and I was ready to go then. I almost ended it all then."

Again women who tested HIV-positive in the pre-HAART era had especially difficult experiences throughout. Jessica, who was diagnosed in the late 80's and was living as a gay man at the time, shared that she did not feel supported by her health care provider. She recalled:

> He talked me into getting tested and I was taken aback. I was afraid to get tested. I didn't have any symptoms and this was 1987. I got tested and when I came back he gave me the news that I was HIV-positive. I was hysterical. The only thing I remember him telling me is, "Well you probably don't want to live to be old, do you?" I thought here is a gay man in his 60s telling me that I don't want to live to be old. That was such a different time then too. There was only AZT.

In a commercial plasma center. A couple of women were told of their HIV status while donating plasma to earn cash. Because commercial plasma centers did not have health care as their primary mission, the response of the staff to these women's diagnosis of HIV could be matter-of-fact. Erica recalled the day that she learned that she was HIV-positive. She said, "I came in one day and was about to donate and they told me that I had become positive for HIV. So I went to an HIV clinic and I had them test me [again] and I came back positive." Yet because staff in some centers knew the women, they could be quite supportive when the women learned of their HIV. For example, Cheron felt greatly supported by the plasma center staff in the immediate moments following her diagnosis. She said, "The people gathered around me, talked to me, and

things like that. I knew I could never go back there, but before I left [the plasma center] that day, I had a lot of support. I really did."

Interactions with Important Others

Most participants interacted with important other people in their lives immediately following receiving a diagnosis of HIV. The responses of the others strongly influenced the participants' experiences of *the world come crashing down.* These important others typically included family, friends, and romantic partners.

Family members. Telling family members was difficult for some of the women because it required them to be vulnerable, trusting, and courageous during a time of emotional uncertainty. Some women found telling to be freeing because they were no longer burdened with keeping HIV a secret from their families, whereas others found it to be frightening because they realized it could lead to rejection and disgrace.

Many women delayed telling their families about HIV, but some shared the news of their HIV status with their families without hesitation. These women felt safe immediately sharing the news with their loved ones because they were close to their family members and never worried that their families would reject them. Families of these women supported them through affirming messages and assurances. Tiffany, who was living as a gay male at the time she was diagnosed, and who tested positive while being treated in the emergency room for a tooth abscess, asked her physician to inform her mother of the diagnosis.

She said,

> The doctor told her, 'I'm sorry, [but] your son did come back
> reactive for the HIV test. We would like to start him on meds and
> I'm going to link him up to a care coordinator.' From there it went
> on. And my mother was like, 'It's going to be okay and from [then]
> on my mother [has been] very supportive. She was calm. I mean
> she cried…but other than that [was supportive.]

Some families supported the women by listening, empathizing, and providing physical comfort. Rachel tested HIV-positive when she was 19-years-old. She described how her family supported her in the immediate moments that followed her diagnosis:

> I [went] back [to the doctor's office] and they told me I had it [HIV]
> and then I went to my grandpa's house and laid in his lap and cried,
> [then] seen my uncle and cried. I was just a kid. I didn't have
> [anybody]. My mom was a drug addict.

For other women, not knowing how their families would respond made them apprehensive about telling about their HIV diagnosis. Women who had strained relationships with their families were especially unsure about sharing their news, and some avoided discussing their HIV status with family members from the onset. For some women, this apprehension was tied to their family's previous reactions to news of their transgender identities. As a result, these women delayed telling their families about their HIV-positive status for many years. Drea', for example, grew up in a very religious family and hid her transgender identity from her mom for many years said, "I kept it a secret for years that I was positive to friends and family. I didn't want nobody to know." Kim, who was rejected after coming out to her family as transgender when she was just 15, also feared how her family would respond to the news. She said, "If I

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went to my family [about being HIV-positive], it probably would have been some negativity here and there, and it might have pulled me back to a place in my life that I didn't want to go. So that's why I haven't told them yet." Chantel, who kept her transgender identity from her family for years, also delayed telling her family about her HIV. She said, "It took me 17 years to tell my family because my family had just found out that I was transgender…And I didn't think that my mother's understanding would allow me to still be around my family."

Women who were hospitalized and critically ill when they were diagnosed and thought that they were going to die were forced to engage in the discussion about their HIV with their families. These interactions usually occurred before the women could process the news of their own diagnosis and even when they knew that their families would not be supportive. Crystal shared how unsettling it was to talk about HIV with her mom before she was ready. She said, "When I woke up they [mother and brother] already knew [that I was HIV-positive]. My mother was the type there was never any communication or discussion behind things…I didn't like everybody knowing [about HIV] before I could really grasp what was going on."

Some families reacted to the news of the women testing positive for HIV with blaming responses. These family members were devastated by the news of the participants' HIV, were angry with the participants for contracting it, and shut the participants out of the family members' lives. The relationship between these women and their family members changed permanently and the quality of the relationship "went downhill" afterward the disclosure. Erin's whose mom passed

away when Erin was just 14 and who was raised by her older sister, described

how her sister reacted to her news that she was HIV-positive. She said,

> I told my sister [first] and she was devastated. I didn't want to hide it from them [my family]. …When I told [her] she [said], "Okay, leave me alone right now. I have to be alone." To be honest, [my] relationship [with my] sister went downhill [afterwards]. I'm pretty sure she was mad at me for contracting it [HIV]. She even told me that. She [said], "You should have known better!" She said, "I'm mad at you. I still love you, but I'm mad at you because momma raised us better than that.

Rejection by family members added to the emotional trauma that

participants experienced during this stage.

Friends. A few participants initially kept their HIV status a secret from their

families but shared the news with friends. The participants found that telling

friends was often less challenging than tell family members, especially when the

participants confided in a friend who was also HIV-positive. These friends were

able to be empathic and responded to the participants' news with compassion.

Star described how her friend helped her through this stage. She said, "I told him

[my friend] and he just talked to me. He [said], "Girl, I've been living with it [HIV]

for this long and you see how I live? You see that I'm fine. You see that, you

know?" And I was like, "You're right. You are fine."

Because the fear of dying was heightened for women at this stage, their

friends shared their own stories of living with HIV as a testimony of their survival

to encourage and assure the women that "everything would be okay." These

women generally felt comforted by such survival stories and encouraged that

they could successfully manage living with HIV as well.

Many of the women relied on their HIV-positive friends for help in getting connected to HIV care. Brenda, who worked as an entertainer, turned to a friend for help after her diagnosis. She said, "I went to work [that day], and I talked with another girl (transgender) that worked there in show. I told her and she guided me along because she was HIV-positive as well." Similarly, Drea' also turned to another transgender woman, who was also HIV-positive, for help. These friends "guided" these women to services providing care coordination where they learned the "ins and outs" of getting a "good doctor" and staying healthy. Receiving assistance from friends with navigating HIV care minimized the angst that women felt during this stage.

Romantic partners. Women had an especially difficult time telling their current and past romantic partners about their HIV status. The implications of the HIV diagnosis for women and their partners were far-reaching and had the potential to adversely affect multiple others, including the partners of the women's' partners. Telling partners was also worrisome because the women knew that a diagnosis of HIV could threaten the stability and quality of their romantic relationship and in some cases end their relationships permanently.

The women found telling a current romantic partner of the HIV diagnosis was particularly challenging because of the implication that they may have been infected by their partner or that their partner may have infected them. The women and their romantic partners sometimes had to confront the possibility that one, the other, or both had been unfaithful during the course of their relationship. In some cases, disclosure of the HIV diagnosis brought to light that a partner

previously knew of his or her HIV status and intentionally withheld the information from the women. In other cases, a partner accused the women of infecting him or her. In many cases, a disclosure was followed by arguments and discord in the relationship. Gretchen, who was diagnosed when she was 48 and infected by a much younger partner, described how her partner reacted to her when she became upset to learn that he tested HIV-positive. She said, "[He said], 'Well, I don't know what the fuck you're upset about. I've got my whole life ahead of me.' And I just sat there and said, "You have your whole life ahead of you and I don't?" Cheron, whose partner initially concealed his HIV-positive status from her, described how they argued after she tested positive and when she found out that her partner was previously aware of his own HIV-positive status. She said, "I was hurt. I was upset. I cried. I went back to him. At the time we were living in a hotel room. We got into it a couple of times and we'd argue [and] cry. I was devastated for a while."

Some partners initially scoffed at the women's suggestion to get tested but eventually agreed to testing to assuage the women's fears. Gretchen's partner, for example, initially refused to get tested. She said,

> I made him get checked. I told him that he had to. [I told him], 'You don't have a choice.' He said, 'No, I ain't got this shit. I know me, I know what's going on with my body.' I [was] like 'You need to go get checked, please.' So he did and he was totally negative. I had never had such a huge burden lifted off my shoulders.

Women who feared that they might have infected their partners described feeling tormented by thoughts and fears of infecting a former partner and waiting

in agony for his or her HIV test results. This was particularly difficult for the women who were still dealing with the initial shock of their own diagnosis.

Sometimes women notified a former partner in hopes that they would come to understand how they became infected. This was an especially delicate situation because it implied that the women's former partners had infected them.

Former partners responded to the women's news of their HIV diagnosis in a variety of ways. Some former partners, who had maintained amicable friendships with the women after the romantic relationship ended, responded to the women in a non-threatening and positive manner. These partners provided emotional support and reassurance to the women. Gretchen described how her former partner supported her. She said, "What [are] you crying for? They got medicine for this shit." I didn't know what to say. He kept telling me that he was very sorry it happened and that even though we [didn't] live together [anymore] [that he was here for me]." These women were relieved by these supportive responses because they had feared that the former partners would be angry and lash out.

Other former partners responded in a negative manner. Some "blocked" the women from social media sites in order to permanently sever all communication with the women, and some denied knowing anything about HIV and ignored the women's concerns. Porsha said that her former partner "just blocked her" after she told him that she tested positive for HIV. She said,

> I called him and told him that I had HIV and that [he] was the last
> person I had sex with without a condom. [Then I asked him if he
> had HIV]. I knew he had it [because] he just hung up on me. He
> blocked me from Facebook, Urban Chat, all of the websites.

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Erin described how her former partners responded when she contacted him about her new HIV diagnosis. Erin said that her first partner, "Acted like he didn't know," and that he second partner told her that at his last check-up his doctors told him that he "didn't have anything." Such negative responses exacerbated the feelings of chaos that women felt during this stage and prevented them from getting the closure they sought.

Finally because confronting a current or former partner about HIV was potentially volatile, a couple of women avoided discussing their HIV status with former partners entirely. When talking about her former partner 'Drea said,

> He [was] the only person that I [had] been with. I didn't understand [how I was infected]. Well, I found out he [had] been cheating on me for the last six months, and that was the last time since we got tested…So I wanted to kill him. It was like so much rage in my life.

Tiffany encountered similar challenges about confronting the person who she believed infected her. She explained,

> You can never say [for certain] who just gave it to [you] because that's a hard case to prove. But the person [who] I believe gave it to me…when I saw him, we talked and he [told me] that he was positive. I just never told him that he infected me. I had so many questions. I didn't really want to get physical with him because it was just like he could have not known…[When I saw him] he looked bad. He didn't look how he use to look.

The inability to pinpoint by whom and when they were infected, or to talk to former or current partners about their new diagnosis magnified these women's sense of their world crashing down and impacted their ability to move on from this stage.

Shutting the World Out

The second stage of *Having the World Change* occurred after the initial shock of the women's diagnoses subsided. We labeled this stage *Shutting the world out*. The phrase "shutting out" is used to describe the action of confining oneself to a closed space, excluding oneself from something, or isolating oneself from a situation.[231] This phrase was selected because it resonates with how the women dealt with the shock of their HIV diagnosis by withdrawing from family and close friends, keeping their HIV a secret, denying the reality of their HIV diagnosis, and avoiding HIV care. One woman, for example, claimed that her "mind just shut down" and that she did not want to do anything after she was diagnosed with HIV. Although the women did not want to "face" their diagnosis, this stage was nonetheless marked by a good deal of inner turmoil as they felt anxious, helpless, and confused.

Health Care Encounters

The women typically experienced a three or four week lag between their initial HIV diagnosis and their first visit with a care coordinator and their health care provider. Much of the stage of *shutting out the world* occurred outside the context of a healthcare setting and without interactions with health care providers. Once women connected to a care provider, the nature of their encounters with health care providers, the characteristics of the health care providers, and the health care setting influenced how they experienced the stage of *shutting the world out*.

Care coordinators. Because women were shutting out the world in this stage, encounters with care coordinators that enabled them to confront the realities of their illness and connect with on-going HIV care were most helpful. The care coordination visit was typically the women's first healthcare encounter following their initial diagnosis; therefore, many felt scared and "uneasy" about receiving help. Encounters with the care coordinators were also the first time that many women had discussed their HIV with anyone. Care coordinators who could act as "sounding boards," and did not act judgmental, were able to establish trust and get the women, who were otherwise shutting out the world, to talk about their experiences and feelings about HIV.

Kim described importance of her care coordinator in helping her cease to deny her illness:

> I connected with her quickly [even though] I was still in denial and was also taking meds. I can't help but to get teary-eyed. So she made me realize that even though I have this disease I can still live a life and outlive most people that don't have it. [She told me that it was] all about taking care of [myself]. It was the major turning point in my life that made me realize [I had to get] out of denial. [After talking to her] it was like the weight [was] off my shoulders." Even though [she] was a stranger I felt relaxed and comfortable with her.

Care coordinators also played a critical role with women who were shutting out the world by connecting them to healthcare providers, preparing them for their HIV medical visits, and helping them with the anxiety they felt about seeing the health HIV care provider for the first time. Care coordinators accompanied some women to their first appointments and helped them understand information given by the health HIV care provider. Chantel described her first visit to the HIV care provider. She said,

[My] care coordinator went with me on my first doctor's appointment because I was really scared and didn't know [what to expect]. She made time to go with me to sit in there and listen and help me get [to the point of being] okay…That made the transition [to see the doctor] so much easier.

Although most care coordinators were supportive when women were shutting out the world, some were not. For example, woman felt disheartened when they perceived their care coordinators to be aloof. Star said,

I left the [care coordination] center altogether because I didn't like their treatment. It wasn't personable at all. [The care coordinator] was just kind of doing her job. You know what I'm saying? And my life is more to me than someone's job. My care is more important to me than someone's job. Not only do I deal with being HIV [positive] I also deal with being transgender, which is another life struggle that I've been dealing with forever too. So I take it very seriously.

Women who perceived their care coordinators to be uninterested in their care were hesitant to return for services, and this prolonged the time they did not receive care.

Health care providers (HCPs). Because women were shutting out the world, engaging with HCPs was often challenging as it meant facing the HIV diagnosis the women had received. During this stage, some women avoided all contact with their health care providers and "just ran from it [HIV]." They delayed care in order to "shut out" the HIV. Some women were reluctant to access care because they feared going to a clinic would expose that they were HIV-positive. As a result, many women did not receive consistent care and were thus at risk for adverse health outcomes.

For women who did receive care from a HCP during this stage, the first visit was particularly unsettling as it was their first introduction to formal medical

care. Some women felt exposed when they began care and perceived that the world was "staring at them." Even those women who sought care at clinics known specifically for HIV care wanted a more "discreet" way to access care.

Because women were shutting out the world, HCPs who educated women about the realities of HIV, alleviated their fears about HIV, presented the grave consequences of avoiding treatment, and initiated HAART were most helpful. Such encounters helped women acknowledge their HIV disease, encouraged them to start treatment, and allowed them "come to terms with the fact" that they were truly HIV-positive. For example, HCPs who warned participants that "coming off and on" medications could cause medication resistance and limit their future treatment options helped women accept treatment. The HCP of one woman, for example, told her that if she delayed starting medication, her HIV was "going to turn into AIDS." This woman started medication because she did not want to die. Kim described the moment when she had to make a decision about starting medication. She said, "She [her HCP] gave me a choice of three pills or one combined pill. So, [it] stuck in my head, death, or live your life…"

In some instances, however, encounters with HCPs exacerbated the women's withdrawal and denial. For example, women "shut down" when they felt "rushed" during their visit with the HCP, when they were not given time to ask questions or discuss their concerns, and when HCPs did not involve them in their treatment decisions. Porsha stated, "He [the doctor] talked about a lot of stuff that day. He moved so fast…We ran through everything; the medicine and all that. I'll ask questions and it's like they just rush through it…"

Some women felt that their HCP was uncomfortable providing care to them because they were transgender, and this experience particularly contributed to women's avoidance of care and withdrawal from their care providers. Denise said,

> He [the doctor] did everything, but not like usually a doctor would do it. You know how the doctor will put the thing [stethoscope] on you and listen and all this and that? He wouldn't touch right here (indicating her breast/chest area). You know what I'm saying? It was like really weird. But then after that, I never go to see the doctor again. I got a new doctor.

Women also shut down and avoided care when their HCP referred to them as men. Maxine explained the inconsistencies in how HCP referred to her during her health care encounters contributed to her shutting down. She said, "I even hear people after the appointments, they [the HCP] might have said "she" in the meeting, but then when they're talking among themselves, it's "him" and "he." Brenda also described the significant impact that being referred to as a male by her HCP had on her engagement in care:

> The nurse practitioner had a student in one day with me. She explained to the student in front of me, that even though I had the surgery I was still considered male. I said, don't tell her that…I said, you know what, [just] because I have this chromosome or that chromosome doesn't make me male. What makes you female or male is totally inside and out. I [told her] that there are women born every day without a reproductive system, which is terrible, but that doesn't make them any less of a woman than I am now. I [then told] her don't you sit there and tell that girl who's trying to learn something that it's that cut and dry. So I walked away from her and I've never been back.

The lack of gender affirmation was, embarrassing, made some women reluctant remain in care, and interrupted their care experience. Porsha said,

It's the most embarrassing part [being called by male name] because people will be sitting there next to me talking and thinking I'm a girl and everything. Then the next thing you hear [is] my first [male] name. So I have to get up and go up there and everybody is looking at me like, 'Are you for real?'…[Once] the doctor walked in and walked right back out of the room. I heard him say, 'Well, where is [referring to me by my male name]? They were like, 'That's her.' [The doctor responded], 'That's her? The door was open. He came back in and was like 'I'm so sorry.'

In jail or prison. For women who were shutting out the world and in jail or prison, interacting with health care providers was especially problematic. The women's reluctance to acknowledge their disease or obtain treatment was exacerbated by the lack of privacy and confidentiality experienced while incarcerated.

Prison health care providers often attempted to engage the women in care by repeatedly prodding them to attend their clinic visits and start treatment. Some women were irritated by these attempts because entering care would force them to confront the realities of their diagnosis and because going to clinic appointments would signal to other inmates that they were sick. Chantel said, "I [wanted them] to leave me alone, [to] just [let] me live my life, and make my own decision, my own choice. I didn't want medication. I wasn't ready for that decision. Especially not in prison." Other women wanted to be "left alone" and refused treatment because they still felt healthy and were still able to do all the things that they did prior to their diagnosis. Kim, who was incarcerated multiple times and continued to deny the realities of her illness said,

I went through a series of phases in my life where [after] I found out I had it [HIV], to see if my body, my immune system was really out of whack or still working. So when I realized that it was still working, I just automatically assumed that I didn't have it. I didn't lose

weight, and that's another thing I looked at myself too. I said [to myself], 'You're not losing any weight, you're still the same size, your appetite is still there.' [I would] get a cold [and I would] get over it. [I would get] a cut [and it would] heal [in] the same [amount of] time [as before].

Even after being released from jail or prison a couple of women did not seek care until years after their initial diagnoses. A few women, however, received care only when they were incarcerated. Maxine explained, "I was never on the streets long enough to go the doctor. And if I was out on the streets long enough to go to the doctor I don't like when I was out of prison it [HIV] was ever a concern."

In a hospital. Some women were hospitalized for treatment of other health conditions during their shutting down stage. The family members of these women learned of the participants' HIV status from the participants' HCP by chance. Star, who was avoiding telling her family about HIV, said,

My family found out…because I broke both of my heels. I was in the hospital and the doctor came in. My sister-in-law was sitting there, and the doctor came in and said something [like], 'Is it okay for her to be here?' I was like yes, [it's] fine. [Then] the doctor said something about [me] being HIV-positive. I just had to respond normally. I looked over at her and she was crying…she had to leave the room because, you know, she had just found out that I was HIV-positive…And I said, 'Don't tell anybody."

Stephanie shared a similar experience. She said,

"My step-dad found out from my doctor. The doctor came in and said, 'Oh, you're HIV-positive.' And my step-father was sitting there and I just looked real alarmed. He [step-father] was so calm and he never reacted. So that's how he found out.

While this manner of revelation was upsetting to the women and their family members, it did help these women move from the shutting out stage.

Women felt "relieved" and no longer felt "pressured" to initiate the discussion with their family members when their health care providers shared the news. These women felt more comfortable sharing their HIV status with other family members after their health care providers made the initial disclosure. Stephanie explained how after her step-father found out, she "eventually told her aunts because she was real close to them." Star also shared the news of her status with her mom after her sister-in-law unintentionally learned of Star's HIV status. She said, [Afterwards] I told my mother. My mother didn't cry, but my sister was still crying…They didn't treat me any different."

Mental health professionals. Some participants received care from mental health professionals including psychiatrists and licensed mental health social workers. Though these professionals were often tasked with helping participants come to terms with their new HIV diagnosis, the participants often shut down more as a result of these encounters. Denise described how she withdrew from mental health care after an encounter with her psychiatrist:

> The [psychiatrist] said, "I've never dealt with anybody like this [transgender] before." I looked at him and said, "Well, honey is there some kind of paperwork I need to sign for you to release your duties or something? Because this ain't going to work." He said, "No, but I will put you back in the system so you can find a new doctor."

In addition to wanting support and guidance on managing life's challenges, women also wanted guidance and support on how to move forward as women and disclose their transgender identity to others, but often felt they could not talk to their psychiatrist about this. Crystal described why she avoided talking about her transgender identity with her therapist:

I deal with the HIV better than I deal with anything. The only things we [she and the psychiatrist] talk about [are] stress [and] things that release stress because I deal with a lot of things. So we don't just talk about the HIV. I don't have a problem with HIV. I can deal [and] live with that…The transgender, no. I actually don't have anybody to really talk to about that. [Nobody] I really trust about the transsexual stuff. Not that I can't talk to my psychiatrist, but I haven't. There [are] other things that made me feel [more anxious].

Having a mental health provider who did not understand the women's needs as transgender women caused them to shut down further. A couple of women were referred to a licensed mental health social worker for support in dealing with HIV and other life stressors. While these professionals were perceived as more helpful than psychiatrists, the therapists' approaches could also be off-putting and thus cause the participants to withdrawal even further. Gretchen described how the therapist asked her questions: "Sometimes [the way that] therapists act [when they say], "Oh really, and what did you do then?" and how they act makes me want to look at them and say, "God, do you have to act like that?!"

Auxiliary staff. Encounters with auxiliary staff such as front office administrators, receptionists, and medical assistants could also influence participants' experiences of shutting out the world. Because these care providers were often the first point of contact for participants prior to their visit with a care coordinator or HCP, they played a critical role in setting the tone for the entire visit. Prior to their care coordination or medical visit, women would check-in with a front office receptionist or medical assistant. During this encounter women would sign their names and then provide copies of their driver's license or other photo identification and their insurance information. Because most women had

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not completed sexual reassignment surgery, their legal documentation still contained their male names. As a result, front office staff would refer to the women by their legal male name, or other pronouns such as "sir," "he," and "Mister" instead of their preferred name. Women were especially embarrassed when these staff referred to them as men even though they were dressed as women and when these interactions occurred while others were also in the waiting room. These experiences often discouraged the participants from following through with their care appointment and thus exacerbated their process of shutting out the world. Jessica said,

> Just the whole thing in waiting rooms and everything, of people [calling me] Mister. Or they wouldn't, until I got my drivers licensed and everything changed, wouldn't [call me by my preferred name]. They wouldn't put it on my chart…I had to remind people. Because they wouldn't look up, they don't look up. They don't look at you. They just look at a chart and then start calling you sir and all of that, and Mister. There were times when I got pretty heated with some of them. And, [if] I [was] sitting in the waiting room, I wouldn't even answer.

Chantel described how upsetting it was to interact with auxiliary staff. She explained,

> The woman at the desk continues to call me he. I asked her more than once to quite calling me he…I mean I have breasts. I've had work done. I mean whatever her thoughts are, [she] should be keeping them to herself. If I go off [on her] I'd be wrong. I mean just every time I go in there and she says he. I'm just like screw it! That shows how much [she] respects me. That just makes me not want to go.

In other instances, however, front office staff would protect the women's identities by using removable sign-in stickers that would not allow other clinic attendees to see their names on the list. Because some women felt uneasy

about sitting in the waiting room of an HIV clinic, some front office staff gave

them the option to wait in a more private room until they were ready to be seen

by the HCP. Women also felt more welcomed and were less inclined to

disengage from care with auxiliary staff referred to them by their "girl name," and

when staff used pronouns such as "she" and "her" when referring to them.

Support groups. A few women were referred to support groups to help

them manage the psychosocial stress of their new diagnosis and to meet other

people who were living with the disease. Women attended these groups, but

seldom felt included. In some cases, support group sessions made women feel

more ostracized. Gretchen said,

> They [care coordinator centers] have support groups, but they
> really don't have any support groups for girls like me…Most of the
> help available out there for HIV, especially at the [care coordinator
> centers] is geared towards the gay community…In my heart it was
> very wrong [to include] transsexual women into the [Lesbian, gay,
> and bisexual (LGB)] umbrella.

Interactions with Important Others

During the *Shutting Out the World* stage women often avoided activities

and interactions with important others or interacted infrequently with them to

keep their HIV a secret for a longer period of time. Avoiding encounters with

others however led to social isolation that in turn often worsened the women's

emotional distress and fear and reinforced their denial of their illness. How

important others reacted to the women avoiding them and or to the women's

revelation of their HIV strongly influenced how the women experienced this

stage.

Family members. Women were especially likely to avoid family members whom the women feared would reject or judge them because of their HIV status. Telling a parent was the "biggest obstacle" for some participants because of the negative stereotypes associated with HIV and because of the shame women felt about their HIV status. Not disclosing their HIV protected some women from negative responses but also shut them off from potential sources of support. Many women felt frustrated because they wanted their families to know about their HIV but did not know how to tell them about their diagnosis.

The pressures of keeping their HIV a secret from their families eventually began to "eat [away]" at these women and created additional emotional distress. Some eventually shared the news with their families because they were so emotionally distraught that they would "break down at the drop of a hat." In some cases, the women's emotional breakdowns prompted family members to ask questions and encourage the participant to "open up." For example, 'Drea's mother asked questions to determine why the 'Drea was always so tearful. She said,

> My mother is just a wonderful person. She knows everything, I feel like, sometimes. She [kept] saying, 'Something's not right about you.' She kept saying it for years, [that] something was not right. She knew that I wasn't dating [any] more. She knew he [boyfriend] had cheated on me. But she didn't know everything. And, I told her [about HIV]. I just broke down in tears. I cried. I boo-hooed. She said, 'You should have told me. You should [not] have fought this alone. We're here for you.' [Since] then my sister, and my brother, and [the rest of] my family [have] been there. That's when things actually picked up for me.

Parents' acceptance of the women lessened their sense of shame and subsequently their avoidance and withdrawal. In addition, positive messages

such as, "I still love you" and "I still accept you for whatever the circumstances" gave the women the courage to reconnect with other family members. Star described how she felt after telling her family that she was HIV:

> I felt like a burden was lifted off of me. When I told my family, I felt like I could tell the world. I feel like that was what mattered, was my family knowing. I was relieved of that pressure of hiding a deep secret.

Family members who were knowledgeable about HIV were able to help women understand the course of the disease and the realities of treatment.

Women diagnosed during the pre-HAART era were especially fearful of being rejected by their families and kept their HIV a secret to prevent their families from "shying away." During the pre-HAART era people believed that HIV was spread through casual contact and thus pre-HAART women especially struggled with telling they were HIV-positive because they could lose all ties with their families.

These families responded in varying ways. Brenda's mother, for example, learned through "soap operas" that she watched how HIV was spread and thus did not fear being infected by touching or hugging Brenda. Physical support such as hugging or touching was very affirming and instrumental in moving these women from the shutting out stage. Families who were not aware of how HIV was spread, however, responded in a way that made participants feel unaccepted. Jessica, who was diagnosed with HIV during the 1980's said,

> The only thing that was weird was that I was at a family dinner, like a Thanksgiving or something. I had a drink, like a pop, or something with ice, and my little niece went to grab for it. I was the first one that said no, and everybody else was like, 'No!' and ran towards [her]. People didn't know really know a lot.

Some family members never questioned the women about their withdrawal and avoidance of family contact. These women resented this because they felt that their families should have known that they were going through a difficult time even without them "saying anything." Chantel explained,

> I was depressed. I stayed depressed for a longtime. I started having anxiety attacks. I felt like people didn't understand what I was going through, even though they [didn't know]. I didn't know how to tell them; [and], I didn't tell them, but I felt like they should still understand that I'm going through something. Whatever it [was] didn't matter, [they should have] just understood that I was not feeling [well].

Some women disclosed their HIV status to their families but family members were either silent or responded negatively to the women, and this further exacerbated their isolation and withdrawal. Many women had previously strained relationships with their families because they were transgender. Some of these family members further shamed the participants because of their HIV status. Monique explained, "My dad thinks that if you're a homosexual the consequences of your sins [is that] you will get HIV." These negative responses from family members created additional tension between the women and their families and resulted in some women permanently severing ties with their family members. For other women, the negative reactions from their families pushed them further into drug use and other self-destructive behaviors.

Friends. Some women also shut out their friends, not wanting to disappoint them because of the newly diagnosed HIV. Porsha for example, claimed that she was reluctant to tell her friends that she was HIV-positive because she had previously advised them to be careful and protect themselves

from HIV and therefore feared she would her look like a "hypocrite." Other women were selective in which friends they told of their HIV status. For instance, some women disclosed their status mainly to their HIV-positive friends, close friends, and friends who were health care workers.

Women felt less isolated when they had friends who were HIV-positive. Crystal, for example, said, "Because I had friends [that were HIV positive], I was aware of the situation [and] knew what to expect." HIV-positive friends also helped women engage in care by advising them on which agencies were "good," dealt best with transgender women, and were most discreet. Drea, for instance, sought a friend's advice on where to go for care. She said, "A friend told me [about a clinic that] could help me over all the other agencies [and] get me everything [that I needed]." This information was especially helpful to women who had delayed entry into care because they feared others finding out about their HIV status.

For some women being part of the "entertainment industry" and knowing other transgender women who were entertainers and HIV-positive lessened their fears about living with HIV and helped them come to terms with their HIV. Brenda described how being in the "majority," meaning being an HIV-positive entertainer, helped her accept her HIV:

> A lot of the entertainers are in the same boat that I am. So we break the ice, especially in the back rooms and stuff where the real show goes on, with levity about the situation. We know it's serious. But we handle it better than most people because we're entertainers and we've got to.

By comparison, women who did not interact with other transgender women were more like to deny their illness, avoid care, and have a difficult time coming to terms with their illness. Denise, for example, avoided telling her family and friends about HIV for a "long time" said that she "really [didn't] deal with any of my kind [transgender women]. Elise, who also struggled with moving out of this stage, said that she did not "fool with" other transgender women. Some women who were diagnosed during the pre-HAART era came to terms with their HIV much faster and initiated HIV treatment early because they had witnessed the devastating health effects of HIV on their friends who "did not take care of themselves or get healthcare." Remembering how their friends suffered motivated them to remain engaged in care.

Some women lingered in the shutting out stage for some time because they found it hard to trust their friends enough to be open with them. Rachel described the people that she knew as "very shady," and explained how not having friends that she could trust, influenced her shutting down. She said,

> I didn't have no brothers, no sisters. I didn't have no family. Everybody that was around me was around me for hustling, and I just felt horrible…I was really depressed because I was pretty much alone out there…A lot of everybody [was] going through the same shit.

Gretchen also lingered in the shutting out stage because she did not have any friends to talk to. She said, "I'm in a situation where I don't really have anybody to talk to about this stuff. So I just started talking to a therapist because I was having a lot of anxiety about it [HIV] and not being able to sleep." Stephanie's shutting out stage was also prolonged because

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she did not have anyone to talk to. She said, "I couldn't share the news with anybody, so I just started dealing with it [by] myself."

Romantic partners. Many women avoided romantic partners during the shutting out stage as the women blamed their partners for infecting them, felt guilty that they infected their partners, or wanted to avoid infecting their partners. Porsha described why she avoided intimate relationships: "I don't want no [HIV] slip-ups, I don't want no accidents, I don't want nothing. Because a lot of men want to have sex with you without condoms." For some women, withdrawal from romantic partners worsened the isolation that participants endured at this stage, and some feared that no one would ever want to be with them again. Stephanie, for example, said "Who's gonna want to be with me? Who's gonna want to be with a pretty sick girl?" For these women, having to tell others that they were HIV-positive was "worse than telling someone [that they were] transgender." By avoiding dating, they could avoid disclosing their HIV status, could avoid risking their privacy, and could avoid rejection.

Some women struggled with whether or not to tell their romantic partners that they were HIV-positive. Chantel described this dilemma:

> I [had] to get it in my mind that if I take a chance and have sex or if I felt like I could trust [someone] enough not to harm me. Because words are very deadly [and] dangerous. I was scared to let people know that I [was] positive...I'm a lonely individual and I like people, but over the years I've learned [that] I don't have to tell them if I'm [not] going to have sex. Then, I need to let them know.

Some women did begin dating during this period without disclosing their HIV status. These women initially delayed telling partners about their HIV because they feared rejection. If partners rejected the women when their HIV

status was revealed, the women were more likely to avoid future relationships which then exacerbated their loneliness. Other women disclosed their HIV status to partners to fulfill to their legal and moral obligations. Prospective partners responded in a variety of ways. Some ended the relationship immediately, which hurt the women and discouraged them from pursuing subsequent relationships. These women grieved the loss of current and future relationships and further withdrew from others. Denise explained, "My goal was to be in a relationship, have children, and even a career. But who would want to be in a relationship [with me]? I could barely even get a man to understand me being a woman and respecting me as one [before HIV]."

Partners who were HIV-positive helped women who were shutting out the world come to terms with the realities of their diagnosis by helping them deal with the fear and uncertainty they felt about having HIV. They also encouraged the women to engage in care by attending their appointments with them and reminding them to take their HIV medication. HIV-positive partners also lessened the social isolation and fear of rejection that the women experienced during the shutting out stage.

No one. Several women kept the news of their HIV diagnosis to themselves for a lengthy period of time following their initial diagnosis and therefore received little support in this stage. These women did not tell family, friends, or current or former partners because of embarrassment or fear of rejection, and struggled with keeping the news from their families for years. Kim never told her family because she did not know how to start the discussion.

To this day [five years after being diagnosed] I still haven't told my family. They don't know. I haven't really found the courage or strength to tell them. I don't really know how to, that's the thing about it. I don't know how to get them all together in a room and tell them that I'm HIV-positive. But I'm not letting it be a weight on my shoulders.

Living in a Dark World

The third stage of *Having the World Change* occurred when participants engaged in health- and life-threatening behaviors and descended into a dangerous world. We labeled this stage *Living in a dark world* to capture the hazards and devastation that pervaded the women's lives at this point. The term "dark world" refers to a dismal, bleak, and dark place of existence[232] and thus best captures the sense of despair that the women experienced during this stage. One woman, for example, believed that she was stuck in a "continuous cycle" of destruction. Drug use and sex work presented particular dangers for the women.

Some women began to "binge drink," smoke marijuana, and "self-medicate" with other drugs in an attempt to deal with their HIV, whereas other women who already had a long history of drug abuse increased their use during this period, leading to other high-risk behaviors. For example, some women engaged in unprotected sex work encounters to procure drugs, thereby increasing their risk of reinfection and their clients' risk of infection. A few women also engaged in illegal activities such as fraudulent check writing and "boosting" (stealing merchandise for the purpose of reselling) as a way to earn more money for drugs.

The stress of the HIV diagnosis in conjunction with other life struggles such as homelessness, unemployment, lack of family support, and being transgender caused some participants to initiate sex work and others to increase their involvement in the sex work they had engaged in before the diagnosis.

Women were often pushed into sex work because they could not get jobs as transgender women. Despite the risks associated with sex work, many participants felt "stuck" because they had no other options for employment. As Tiffany said, "If I don't do this anymore, how am I going to live? I can't get a job as a transgender [and] I'm not happy as a male. So what do I do?" Women who engaged in sex work often used drugs that "put them in the mindset" for sex work and helped them "get into character."

Some women were "on the verge of giving up" during this stage and became suicidal. Women who had a history of depression were especially prone to becoming suicidal during this time. A few women made overt suicide attempts, and others "overdosed" on drugs in an attempt to end their lives. Rachel, for example, increased their use of "hard drugs" such as methamphetamine, heroin, and crack and used them in quantities large enough to cause death. A few women made suicide gestures such as sliding a razor over their wrists and "staring down" the barrel of a loaded gun. Denise said, "Sometimes I think about hurting myself because it really…it really is hard, it's hard…It's hurtful. I wanted to slit my wrists. I didn't want to live no more."

During this stage, sex work, drug use, and life has a transgender woman occurred in the context of a dangerous milieu of the "streets." Because of their transgender status, many women feared being attacked "on the streets." They were often in danger of being killed or injured, rape, or robbed. Women described constantly living in fear for their lives and always worrying if someone would kill them just because they were transgender. Porsha, for example, said, "Life is

really hard for us transgender women out here." Women had been harassed and brutalized by police, assaulted and raped by men, and verbally threatened, harassed, and called names such as "he-she-freak" by those they encountered on the street. The world of sex work was especially precarious. These women were also at risk for being killed or raped when refusing to perform certain sex acts.

Health Care Encounters

The most common pattern of health care encounters that occurred during the stage of *living in a dark world* was inconsistent or no care. Women interacted only sporadically with care coordinators, primary HIV care providers, providers at drug rehabilitation centers, and providers at homeless shelters. These encounters, however, influenced how the women experienced life in a dark world.

Care coordinators. Women's encounters with care coordinators during this stage often focused on the participants' unstable life patterns, unsafe environments, and risky behaviors. As well as refer participants to HIV care, care coordinators also helped them secure housing, obtain food vouchers, and complete applications for insurance.

Some participants sought help from care coordinators for their self-destructive behaviors. Care coordinators advised participants on how to manage these behaviors and avoid behavioral triggers, such as friends who used drugs and parties were drugs were available, as well as encouraged them to consider substance abuse treatment. Care coordinators who were supportive but not

authoritarian were most helpful. Chantel said, "They would give me their opinion, [but said] that [it] was up to me to make a decision [about] whether I wanted to do it or not. They were not forcing [me]. They [were] just suggesting that maybe it was not good for [me]."

Despite the chaos that consumed their lives during this dark stage, some women attempted to "stay in touch" with their care coordinator. Chantel explains, "During my usage I was missing a lot of my appointments. I stayed in touch with my care coordinator and tried to stay up [with my appointments]. But my using and alcohol wouldn't let me." During times when the participants' self-destructive behaviors and unstable lifestyles interrupted their care, care coordinators often made repeated attempts to reengage participants in care.

The women's functioning during the stage of *living in a dark world* was improved if they maintained even intermittent contact with their care coordinators by "drifting in and out of care." Even brief encounters allowed care coordinators to reconnect with participants and discuss the risks inherent in their behaviors. Care coordinators continued to encourage participants to receive services regularly despite the chaos in their lives. The care coordinator of one participant told one woman, "When you're ready [to get help], you let me know. The in and out, in and out, it's too much."

On the other hand, women who avoided all contact with their care coordinators did not have access to HIV care for extended periods of time and did not take advantage of the help and resources available through care

coordination programs. Tiffany, who was homeless, used drugs, and worked as a

sex worker never showed for her initial intake:

> He [care coordinator] kept trying [and trying] to get in touch with
> me. [He would call and say], "We have to get in touch with you
> [and] start your first intake." [I would say], "Yes, I'll meet you, I'll
> meet you. [But] would never go. At that point I guess the symptoms
> went away…and I [didn't] have time to worry about meds and stuff
> like that. I needed to get housing and stuff.

Health care providers (HCPs). Encounters with HCPs at this stage

centered on the adverse health consequences associated with the participants'

risk behaviors. Women who dwelled in this stage were preoccupied by their life

struggles at the expense of attending to their HIV. For these participants, HIV

was not an "immediate" health care need and many missed HIV care

appointments and delayed starting medication because they were "getting high."

Participants who were taking HIV medication also experienced multiple treatment

interruptions because of their illicit drug use. Some of these participants would

discontinue their medication therapy altogether, and others would medications

irregularly. Chantel said,

> I would stay disconnected [from care] for like three to four months.
> But it didn't stop me from going to get my medication. I didn't stop
> my medication. I just would have big days that I would miss. Two or
> three days I'd miss; [and] then, I'd take them again. I always tried to
> make sure that I kept my medication around regardless.

The lack of consistent HIV care created additional health challenges and

further exacerbated their health damaging behaviors. For instance, some women

who went on and off of their medication experienced HIV drug resistance,

progression to AIDS, and higher "numbers [HIV viral loads]."

Similar to care coordinators, staff at the HCPs office often contacted women who missed their appointments by phone to find out why they did not show for their appointments and to reschedule their visits. Some women felt "bad" about missing their visits, but "made [up] excuses" about why they did "not show," and continued to skip their visits.

However, the few women who did attend appointments regularly had an opportunity to talk about their drug use and other life-threatening behaviors with their HCPs. Many of the women who used drugs were aware of their dangers, and thus these participants informed their HCPs about their drug use. Chantel, for example, stated, "I [had] to let them [HCP] know [about the drug use] so they [would] know what they [had to] do on their end to keep me okay."

Some HCPs used the health care encounter as their opportunity to challenge women about their drug use. These providers were firm in their recommendations that participants stop using drugs and warned them of the adverse health consequences. Elise told her doctor that she was "getting high" stated, "My doctor was like, 'Make a choice. Either you keep getting high or get the treatment and take the medications so that [you] can live longer.' And I chose the medicine." Other providers were more supportive than challenging but still instrumental in helping women move beyond the dark world.

Rachel said,

I had a nervous breakdown. I was doing drugs real bad and went to
the doctor and just broke down. [I told] the doctor that the reason
why I do this stuff is because I'm depressed, I have low self-
esteem, I felt alone. I was messing with heroin, [and] I OD'd a
couple of times. It was depression [and I was] self-medicating with
drugs…She hugged me, and of course, [asked me] if I wanted to go
to rehab, and comforted me in the best way she could.

Inconsistent or no care was also common among women who

experienced other adversities beyond those of drug use. For example, having

multiple chronic health problems, living in poverty, and not having transportation

could disrupt care. Women who moved around frequently due to homelessness

had a difficult time remaining consistent with care, which added to their emotional

stress and caused them to be physically ill. Several women only sought care

after acquiring pneumonia. For these women, the onset of illness or other

physical symptoms of HIV prompted them to connect to HIV care.

Jails or prison. Several women were arrested and jailed for their

involvement in sex work. These women often delayed or dismissed HIV care

altogether because they did not want other inmates to know that they were HIV-

positive. Some women were incarcerated numerous times and had a more

difficult time staying "consistent" with their HIV care. For example, some women

would adhere to their HIV care when they were not in prison and would stop

treatment when they were re-incarcerated. These periodic lapses in care resulted

in irreversible health consequences for these participants. Maxine said,

The most important thing for me at that particular time was to not
have to deal with that [HIV]. Nobody dealt with it in prison. [I would]
go to the doctor and they'd take my blood. It wasn't about
medication…I was still on drugs and couldn't stay consistent to [my]

HIV [treatment]. At this point in my life I'm on the last choices [of HIV medication] until they make more.

Mental health professionals. Some women were referred for mental health care to for help in dealing with their life struggles but declined. For these women, HCPs recommendations that they receive a "psychological, psychiatric evaluation" were not welcomed. Tiffany said,

> They thought I needed a psychological, psychiatric evaluation because I explained to them everything [the drug use, prostitution, homelessness that I had gone through]. I [told them] "I'm fine. Trust me." She said, "We do this all the time." She was trying to give me her professional viewpoint. I [was] like, "No, I'm alright. Trust me. I've been going this long. I don't need to sit in a room to have somebody tell me what they think I should do because they're going home to their three-bedroom house, their wife and kids, and dog. I'm not. So…you can't tell me how to live [in] my shoes based off a book you were trained in in college until you live it. So we had that battle, and of course I never went to see [the psychiatrist].

The women were especially offended when they perceived that they were recommended for mental health care because they were transgender.

Drug rehabilitation providers. Some women were referred to drug rehabilitation programs to help with their addictions. They received treatment in residential programs, inpatient treatment programs, or support groups. These treatments were not often helpful. Often the participants felt threatened in treatment because of they were transgender or because they were not ready to commit to recovery. Rachel said,

> I went to rehab twice and rehab just isn't for me. Being a transgender woman and going into these rehabs, they expect you to use a men's restroom, [and] you have a bunch of catty women that are making comments and stuff…I only stayed in rehab a week. Not having structure in my life and then going into this place and having structure, I felt like I don't need to be here. I can [just]

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leave. Which was stupid. I should have stayed the course. But the mentality that I was in, [I just said], let's go.

Although most staff members at drug rehab centers were inexperienced in caring for transgender persons, some women attributed their successful completion of drug treatment to the drug center staff. Drug center staff were most helpful to the women when they normalized their interactions with the women, treated the women with "respect," and who ensured that the women had a welcoming environment.

As part of their treatment for substance abuse, some women were referred to group therapy for help with managing their addictions. Only those groups that used a personalized approach, however, proved to be helpful. Chantel said, "I don't like a big crowds of people…I can deal with it, but I need to talk to somebody about something more personal, more intimate. I know [that] I keep using, [but] what is my problem? I don't understand." The lack of one-on-one interactions prevented women from exploring the deeper issues related to their substance abuse and prolonged their recovery.

Staff in homeless shelters. Several women in this stage were homeless and sought housing at shelters or boarding homes. The environment in the homeless shelter could cause further distress. Some negative encounters with staff in the homeless shelters intensified the instability of their lives. Cheron, for example said, "It's nasty [and] not fit for nobody, period."

As a condition of receiving temporary shelter, women were expected to present as men and they found this highly distressing. Cheron said, "They put

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you in there with all of the men. They make you take off your hair, your makeup, all of that. You have to because you have to blend in."

Participants who stayed in homeless shelters also worried about their belongings being stolen by others and feared for their safety. Tiffany, who was sick with pneumonia and who had recently been "kicked out" of a friend's house said,

> I went to the drop-in [and] my fear was tuberculosis. The people [were] dirty [and] trying to hit on me… It was hard. I mean having to take showers with other guys, you know? Getting talked to [like I was] crazy. I had to go in with the guys [and] dress up like [a guy]/ I couldn't be on the female side because they said females might have an issue…[Then] my suitcase [was stolen]. I [tried] to get my stuff back, but it was to the point that I'm like, you know what? Fuck it. I don' even care no more. I just took what I could get [back] and left from there to start over. So it's like I kept backpedaling. It was horrible.

Some women sought temporary refuge in a boarding home. While the purpose of the boarding home stay was to give women time to reestablish themselves, it usually exacerbated their troubles. Crystal, for example, said, "It was like a drug haven…I ran away with the drugs."

Interactions with Important Others

Like with the prior stages, women's interactions with important people in their lives at during the stage of *living in a dark world* influenced how they experienced this time. These important others included family members, friends, and romantic partners.

Families. Most women interacted only intermittently with their families during this stage. For most women, these occasional encounters with family members helped minimize the chaos in their lives. Rachel, who was

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"prostituting," using drugs, and living in hotels, described her dark world stage, "I took a break from all the road and stuff, and went and stayed with some family, and just got myself together. Got on some right medication that didn't make me depressed, and then went back out on the road again."

Some women, however, were driven to heavier drug use because of family tragedies. Family tragedies could also trigger depression and suicidal thoughts. Chantel said,

> My nephew was in a school bus crash. He was only six years old and he lost his leg…He was in a coma for a month and I went [to be with] him for two weeks straight…I started using [real]…I was at that point where I really didn't care. I kept taking my medication, but just didn't care about anything else in life…I was drinking heavy, I just didn't care. I was suicidal [and] didn't want to be bothered.

Women who were incarcerated and heavily involved in drug use during this stage often had no contact with their families. Others were isolated from their families because of abuse within the family. Family estrangement could worsen the women's experiences of living in a dark world.

Friends. Some women were drawn deeper into the dark stage as a result of their interactions with friends who were also living in a dark world. For example, some women reverted to using drugs again or started using harsher drugs when they were around friends who were actively using. Women involved in sex work were often friends with other sex workers, most of whom also used drugs. For these women, drugs were easily accessible at parties, clubs, and other social venues that they frequented as part of their sex work. As a result, they were constantly immersed in drug-ridden, dangerous environments that threatened their physical safety.

Women, whose friends who were "in recovery," were most helpful in moving women beyond the dark world. Women found support in friends who had similar life challenges. These friends connected participants to recovery services and provided them housing so that they could get "off the street." Because many of these friends were also HIV-positive, they assisted participants with getting into care where they could receive more formal help for their addiction and other social needs. Maxine, who felt supported by her friends said,

> When I finally got out [of prison I] met some people that helped me to understand what HIV care was. [One friend] was working at [an AIDS service organization] and he was in recovery too. I can honestly say that I'm alive because of him. I don't think that I would have ever made it this far [if] it had not been for him and [a couple of other friends] because [they] did not judge me. They loved me until I learned to love myself. [They] were there between the prison trips and [gave me] a place to live, [even though] I was a crack head, [and] never put me out [on the street] because I was HIV-positive.

Women often entered into sex work through their associations with other transgender sex workers. These friends "showed women the way" and "taught them how to get money." While sex work afforded participants a way out of the homeless shelters and provided a means of greater financial stability, it also prolonged their existence in the dark world. Tiffany said, "I became wrapped up in that lifestyle. And once you get wrapped up in that lifestyle, you forget about being human. Everything is about money, you become greedy."

Romantic partners. The women's romantic relationships were tentative and often volatile at this stage. The instability of the women's lives made them vulnerable to partner abuse and other forms of violence. Women who were in

relationships during this stage were living "double lives" because they did not

want their partners to know what they were going through.

Reconstructing the World

The fourth stage of *Having the World Change* occurred when the women

emerged from the stage of *living in the dark world*. We labeled this stage

reconstructing the world. This phrase is commonly used to describe the process

of rebuilding one's life after a devastating event.[233] This phrase was selected

because it resonates with the women's sense that they were rebuilding their lives

that had been previously shattered by their HIV. One woman, for example, felt

like she "had the world again." During this stage the women focused on restoring

their sense of self, regaining control over their lives, and planning for the future.

The women felt "driven to live," to take better care of themselves, to live healthier

lives, and to pursue life-long goals. Denise, for example, claimed, "As long as I

can control what is going to happen, I'm going to live a long, long life."

For many women reconstructing their world was closely tied to their being

transgender. During this stage some women decided to live "full time" as women,

and they experienced this as freeing and empowering. Brenda, who underwent

sexual reassignment surgery after her HIV diagnosis, claimed that it helped her

to "pursue what I really felt inside."

As the women focused on restructuring their worlds, their feelings of

hopelessness and desperation began to diminish and they worried less about the

"image" associated with being HIV-positive. Many no longer defined themselves

by their HIV or obsessed about being HIV-positive and became comfortable

discussing their illness experiences openly with others. Elise said, "At first I was

[scared] to go out into the world. But then I [realized that] HIV [was] really nothing

and [that] a lot of people can't really tell [that] I'm HIV-positive." The women gained the courage to reestablish themselves and to move forward with their lives in the wake of HIV.

At this stage, some women who had previously thought of HIV as a fatal illness now viewed it as just "another" disease. Jessica, for example, described it as "the new diabetes." Adopting this illness perspective minimized the shame and fear that participants previously had about being HIV-positive. Maxine said, "I've learned to live with, or [rather] forced HIV to live with me so it doesn't become one of those things, like being a transwoman, that overshadows me." By reframing how they viewed their diagnosis, women experienced the negative emotions previously tied to HIV less frequently and had the sense that they regained control of their lives.

Some women experienced their HIV diagnosis as a "turning point" that forced them to confront other negative aspects of their lives. These women withdrew from relationships that were harmful to them and some abandoned dangerous or risky behaviors such as sex work and drug use. Women who were successful in *reconstructing the world* were empowered and motivated "to get better…to get stronger, to rebuild [themselves], and to become better people." Cheron said, "HIV is a big thing. But at the same time, it's not so bad [and it's not] going to stop me from living."

Many women relied on their spiritual beliefs that "God is a loving [and forgiving] god" and that "God doesn't make mistakes;" and their religious practices such as "fasting" and "praying" to "come to grips" with their HIV.

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Monique said, "I was fasting to cleanse my body from [what I felt were] the evil spirits that I had inside [of] me." A few women attributed their emotional healing to their beliefs in a "higher power." Some women's religious beliefs helped them to realize that they were not "bad people" and as a result they became less concerned about what other people thought about them being HIV-positive.

During this stage, some women regained control over their lives by using their personal experiences with HIV to help others. Brenda, for example, claimed that "Ever since [being diagnosed] I've just been on a mission to help give back." Publicly disclosing their HIV status to others gave participants a greater sense of esteem and made them feel accomplished. In giving back participants felt that they were "helping the world in some sort of way." Some participants gave back to the larger community by serving as spokespersons for various HIV programs, serving as "gay activists," and publicly educating others about HIV. Others gave back on a smaller scale by educating other transgender women about HIV and helping those that were HIV-positive get into care. Star said,

> I'm to the point where I don't care if people know I have it. I haven't made a billboard saying, 'Hey, I'm HIV-positive,' but I'm not denying it. I can speak on it to help people be more aware of what their status is, and I can be used as a symbol of hope maybe.

Women who had previously struggled with addiction and other life challenges reconstructed their worlds through sobriety. Some who were previously involved in sex work and other crimes "came off prostitution," found alternative ways of earning income, and rebuilt a stable life. Some participants who were repeatedly incarcerated rediscovered the world outside of prison. Kim said, "I want[ed] to do better and bigger things with my life. I haven't been back to

the penitentiary in three years. [I am] drug free and working my ass off. I have [had] two promotions at my job now."

Health Care Encounters

Women who progressed to the stage of *reconstructing the world* interacted regularly with their care providers, remained engaged in care, and played an active role in their health care decisions. Positive health care encounters enabled participants to reconstruct their worlds.

Care coordinators. Strong and consistent relationships with the care coordinators were especially helpful to participants as they reconstructed their worlds. These relationships were particularly important to participants who were estranged from their families or who had not been able to tell their families about their HIV diagnosis. Women in these situations indicated that their relationships with these care coordinators, especially those who were "more personal than client-based," were a "god-send." Talking to care coordinators about HIV and family concerns gave these women "peace of mind" and allowed them to "get things off their chest." Care coordinators also encouraged participants to reevaluate relationships that were not healthy or supportive of their new way of living and existing. Care coordinators "listened and gave" participants' advice on dealing with destructive family dynamics and other negative relationships.

Care coordinators helped women reconstruct their worlds by providing active assistance in practical matters. For example, some care coordinators helped women find regular, steady jobs so that would not have to "hustle" anymore. Care coordinators also helped women in establishing their new

transgender identities by assisting them with getting their names legally changed and constantly referring to them by their female names.

Health care providers (HCPs). On-going stable relationships with HCPs to whom women felt strongly connected helped them reconstruct their worlds. Women felt especially strong connections to their care providers when they shared things in common. For example, some women felt more of a "connection" to care providers who were also HIV-positive, who were gay, or who were experienced in providing care to members of the LGBT community. Maxine said, "[My doctor] was HIV-positive…He convinced me to share that I was positive in order to get better…He helped me to understand that I was a powerful individual."

Because embracing their transgender identity was important for some women in reconnecting to their world, HCPs also helped these women by facilitating feminization by prescribing hormone therapies. Maxine described how her doctor, who was gay and HIV-positive, helped her achieve feminization:

> He was the first doctor that asked me if I was on hormones. I never understood why he asked me if I was on hormones. But he knew [that I was transgender]. He talked to me about hormones and told me that these things [becoming a woman] were really possible.

HCP also played a critical role in helping women reconstruct their worlds by helping them reframe their perspectives about living with HIV and assuring them that they were not dying from "something," but rather "living" with a disease. Such encounters helped women "feel alive again" and gave them hope.

Mental health professionals. During the reconstruction stage some women received care from psychiatrists. Psychiatrist played a key role in helping

women address dysfunctional family issues that threatened their emotional and

mental health and overall state of happiness. Crystal said,

> [He] helped me deal with going [back home] and dealing with other
> people in my family that affected me during that time. So I went
> back and I faced it. I figured that if you face something and you go
> on, don't hate anyone, but just go on, [then] you will look better and
> peaceful.

Mental health professionals also helped women with "mental health

issues" reconstruct their worlds by exercising "lots of patience" during their

encounters and helping them to avoid incarceration and other criminalization by

helping them manage their legal issues. Psychiatrists helped women find closure

about strained relationships with their families, which facilitated their healing and

boosted their progress towards reconstructing their worlds.

Interaction with Important Others

During the stage of *reconstructing the world,* women established new

relationships with important others who could support them in reconnecting to

and rebuilding their worlds. As with the earlier stages, how important others

engaged with women strongly influenced how they experienced this stage.

Family members. During the stage *reconstructing the world*, many

women reconnected to their families or connected with them in new ways. Some

women who had been estranged from their family reestablished a relationship

with them. These women felt "joy" and were "ecstatic" when this occurred. Kim

said, "It was like the hole my heart had been finally sealed." Often, this

reconnection was related to the new transgender identity some of the women

had assumed. Family members who accepted their new identities, such as by

referring to the women by their female names, helped women reestablish

themselves in the world. Brenda described how her mother helped with her

gender transition:

> She refinanced her car to get the money, which was $13,500 for
> the surgery. I have since paid her back, but if it hadn't been for her
> [I would not have been able to afford the surgery]. She was there
> and helped [me after] the surgery and everything.

Reconstructing relationships with family members sometimes occurred

many years after the women were diagnosed with HIV or came out to their

families as transgender. Some relationships were repaired when family members

came to understand what the women had endured, and, in these instances, the

participants felt vindicated related to past grievances. Maxine said,

> My brother never realized until he got older and went to counseling
> that my father had abused me the entire time we were growing up.
> And for my brother to finally say 'I understand what happened. I
> understand what you went through.' It was all I ever wanted.

Some women who reconstructed their lives had on-going family support,

and these families played a significant role in this stage by "loving [the women no

matter what" and providing on-going emotional and physical support. These

women felt empowered by having their family "in their corner" as they moved

forward with their lives.

Friends. Some women reconstructed their worlds by forming new

friendships and creating new family structures with friends who were gay,

lesbian, and transgender. These new families resembled traditional, nuclear

families and were led by "gay" or "house fathers," and they were comprised of

"gay" sons, daughters, and siblings. Women that belonged to these families had

been invited by the "gay father" to join his house as "gay children." Gay fathers

provided the women with oversight, support, and guidance during the stage of

reconstructing the world and helped them to establish a meaningful family

connection. These new families were especially important for women who

remained estranged from their birth families. Tiffany was homeless before joining

the "house" and whose her mother was unaware of her transgender identity. She

explained,

> We're [friends and I] like a house basically. We go places [together]
> and it makes me feel like I have that family that I really don't have. I
> mean I do have [family], but it's a different support because [they]
> are more of a peer to me than a parent…It's great having support,
> knowing that [I] can come in and do anything and say anything, and
> [that] they will guide me in the right direction because they've been
> through it [HIV].

Other women reconstructed their worlds by adopting "gay children."

Women adopted "gay children" in order to assemble a more complete family, to

make up for the family they never had, and to have a more meaningful life. Star

said,

> My children love me. They call me mommy, or mother. They come
> to me for guidance, and care, and I give it to them. I do the best
> that I can. I love my children. They're the closet that I [will ever]
> have to having my own children. They love me back and I'm very
> real with them…I keep it real [with them] because this is the real
> world that we live in. I've got about 17. Some of them are near and
> far. They idolize me, they love me, and they love being an
> extension of me. I've had a moment of being hands-on with them,
> teaching them, and nurturing them to what they should try to be.

These new family structures thus provided the foundation on which these

women reconstructed their world and their lives and offered them the chance to

reinvest in and mentor similar others.

Some women reestablished themselves in the world through performance. Women found new meaning, purpose, and value in their lives as entertainers. Star said, "It's [performing] the only thing in this world that belongs to me…when I'm out on stage and I'm under the spotlight, and I am who I am." Other women reconstructed their worlds by establishing kinships with other entertainers. Tiffany described how her relationship with other entertainers helped her restructure her world and reestablish her identity:

> When I'm dancing, I have my whole house or other people cheering me on so it feels really good. It makes me feel good about my other life that I did live [before HIV]…Dancing makes [me forget about HIV]. It's kind of like a relief. Just expressing how I feel [through dance]. It's kind of hard to explain, but it's like you [are] vogeuing how you feel. If I feel pretty, I'm going to come out and I'm going to swing my hair. [When I'm dancing] I don't even think about [HIV]. I just think about me [and] the way I want to live.

Connecting with friends or similar others that were gay, transgender, or HIV-positive gave some women drive and confidence to reconstruct their worlds and overcome the stigma and shame associated with being HIV-positive. One woman shared, "It's like we're all going through the same thing, but it feels good." Friends helped rebuild the women's self-esteem and influence their new identities. Maxine claimed, "[My friends] gave me the ability to have a voice…they taught me how to ask for exactly what I wanted and how to advocate for myself."

Romantic partners. Some women reconstructed their worlds by pursuing new romantic relationships. Women whose partners supported them after learning the news of their HIV were instrumental in helping the women rebuild their world. Other women had partners who, despite their HIV-negative status,

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were also accepting and willing to initiate a relationship. These partners were especially encouraging as many participants felt that having HIV severely limited their chances of establishing future meaningful relationships. Gretchen who met her partner through and online dating site and disclosed her status to him over the phone said,

> [I told him], there's something I gotta tell you, I didn't tell you in the beginning cause I didn't think that I would ever meet you…But I have to tell you this. So I told him the whole story about how it happened and everything. His response to me was, 'Oh my god. You're worried about that? What do you think they make condoms for?" I just sat there and was like, 'Oh god, so you're not made at me?" He said, 'No.' And I said, 'Yay, I'm so glad!"

Some women did not develop new romantic relationship at this stage, but were optimistic about "falling in love" again and finding someone who would accept them being transgender and HIV-positive. 'Drea said, "I [have] two barriers against me. I'm a transgendered woman, plus I'm positive. But I'm willing to find men who are willing to accept it [and], hopefully just fall in love with me."

Summary

The findings of this study are presented in a model that is organized by a core concept of *Having the World Change* and is comprised of four stages: the *world crashing down, shutting out the world, living in a dark world,* and *reconstructing the world.* Having HIV changed the women's identities, relationships, and daily lives in ways that were profound and ubiquitous. The women described a process that began with experiencing the devastation of learning that were infected with HIV followed by a period in which they denied the realities of the disease, avoided care, and withdrew from others. For some, this

period was followed by a time in which they engaged in risky behaviors and found themselves in dangerous situations. Some women then experienced a period in which they reestablished a sense of identity, reconnected with important others, and developed a lifestyle that was satisfying and health-affirming.

While the model is presented as a linear process with well-defined stages, in actuality there was great deal of variability in terms of how women traveled through those stages. For example, while all of the women experienced the first stage, they experienced the second stage in varying degrees; some experienced much avoidance and withdrawal for long periods of time, whereas others moved through this stage fairly quickly and faced the realities of the illness and engaged in consistent care fairly soon after diagnosis. Not all the women experienced the third stage as some reported few, if any, destructive behaviors. Not all of the women had "reached" stage four and many were still in one of the earlier stages when they were interviewed.

In addition, women did not always go through the stages in a linear fashion. Some "recycled" through the stages. For example, some women began to reconstruct their lives and then encountered other life challenges such as major illnesses, disruptions in a relationship, or assaults that returned them to an earlier stage. Others experienced some aspects of two stages simultaneously. For example, some women continued to experience the destructive behaviors that characterized stage three while beginning to engage in some of the healing behaviors that characterized stage four. As examples of non-linear courses, Figure 2 represents the trajectory of a woman who did not experience stage

three because she received a good deal of support during stage two, *shutting out*
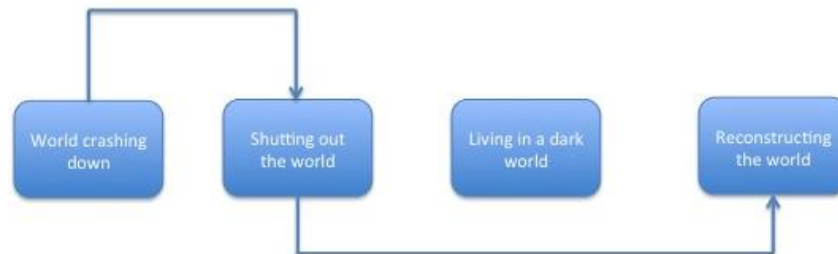
the world.

Figure 2. This figure illustrates the illness career or trajectory of an HIV-positive

transgender woman who received support.

In contrast, Figure 3 represents the trajectory of a woman who recycled

through stage two and three after reaching stage four, *reconstructing the world*

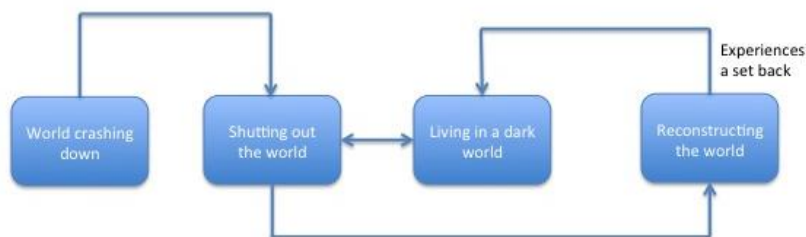because she experienced a significant loss that served as a "set back."

Figure 3. This figure illustrates the illness career or trajectory of an HIV-positive

transgender woman who experienced a set-back.

The findings confirm that healthcare settings and healthcare encounters,

regardless of stage, influence the women's experience with HIV. Healthcare

encounters that helped the women understand their illness, feel understood as

transgender women, confront their self-destructive behaviors, and engage in

appropriate and consistent care helped participants fare well. Staff at HIV

counseling and testing sites that routinely provided HIV testing and care

coordinators who worked primarily with HIV clients tended to be most helpful as

they were knowledgeable about the illness, more supportive of the women, and

better positioned to provide more pragmatic help such direct referrals and help

with housing, insurance, and transportation. By comparison, healthcare

encounters in hospitals, jails, and commercial plasma centers tended to be more

problematic due to lack privacy and having staff that were less knowledgeable

about HIV and HIV treatment.

Care coordinators in particular played a significant role in helping women

navigate the treatment system and obtain social services. Care coordinators

facilitated women's early initiation of and retention in care by providing direct

referrals to a health care provider, escorting women to HIV care, and using a

non-judgmental approach. HCPs who allayed the women's fears about dying by

educating them about HIV and who were able to engage them in consistent care,

including medication therapy, were also particularly helpful.

In contrast, healthcare encounters in which the women were ignored,

judged, or disrespected, especially as transgender women, impeded their care

and hampered their healing. Encounters with mental health professionals were

often not experienced positively by the women. Several structural factors within

the treatment system also served as barriers. These factors included long lag

times between the HIV diagnosis and the initial intake appointment with a care coordinator, delays in insurance approvals, frequent changes of HCPs, HIV only clinics (as opposed to comprehensive care), lack of integrated care (e.g. HIV care, primary care, and hormone therapy) services, and a lack of transgender-friendly care settings.

Similarly the findings confirm that relationships with important others strongly influenced how participants experienced the HIV illness career. Relationships with family were very important and throughout all the stages family members were most helpful if they were understanding and nonjudgmental - not only of the women's HIV, but also of their lives as transgender women. Family members who were rejecting of the women or who were estranged from them exacerbated the women's distress. Friends, especially those who were also HIV positive and transgender, often provided alternative family structures for the women; offered housing, food, and other basic essentials of living; and helped them to initiate HIV and substance abuse care. In contrast, interactions with romantic partners were often complex and challenging especially if the partners had infected the women or conversely if the women had infected the partner. Yet some partners, especially those who were also HIV-positive, were very accepting and supportive of the women.

The experiences of the women as both transgender and HIV-infected women were often closely intertwined. In several instances, the women's healthcare was impeded because they encountered providers were who not tolerant of, knowledgeable about, or sensitive to transgender persons. Some

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women were rejected or mistreated by important others both because they were

transgender and HIV positive, and some of their destructive behaviors were tied

to both their gender identity and to their illness. Conversely, the women often

received the most support for their HIV course from other women who were

transgendered.

Chapter V. Discussion

Summary and Conclusion

The primary goals of this dissertation were to describe the illness careers of HIV-positive transgender women and to discuss how interactions with important others in the social network, and health care providers in the treatment network influenced their illness careers. This final chapter includes a brief overview of the major findings, limitations, implications for practice and future research, and conclusions.

Significance of the Study

This study is unique in that it is, to our knowledge, the only study that has examined the illness career from the perspective of transgender women living with HIV. This study adds to the state of the science by presenting a stage model that describes the psychosocial process that ensues following an HIV diagnosis among a group of HIV-positive transgender women. What is unique about this model is that it offers a theoretical explanation of how the illness career is influenced by the health care setting, interactions with health care providers, and interactions with important others. Because this model is grounded in the experiences of the transgender women, it also offers an explanation of how a transgender gender identity influences health. This model further adds to the state of the knowledge by identifying the stages following an HIV diagnosis where transgender women are most: vulnerable, at risk for self-harm, violence, and death; and at risk for not engaging in or falling out of care. As a result, this model can be used to help inform interventions that will target these critical

stages and thus improve the care experiences and illness trajectories for this

population.

Major Findings and Consistency with Existing Research

The findings of this study are presented in a stage model that is organized

by a core concept of *Having the World Change* and is comprised of four stages:

the world crashing down, shutting out the world, living in a dark world, and

reconstructing the world The stages included in this model parallel the stages

that have been reported in previous studies on coping with HIV and other serious

illnesses.[234-239] In addition, the model incorporates many overlapping principles of

the theory of stress and coping (world crashing down, shutting out, living in a

dark world), the theory of resilience (world crashing down and reconstructing),

the stages of grief (all four stages) the theory of uncertainty (shutting out), and

trauma and recovery (all four stages).[234,239-242] These findings also add further

validity to the claims of the Network Episode Model (NEM), which proposes that

relationships and interactions with health care providers in the treatment system

and with important others in the social network influence the illness

trajectory.[132,134,136,243]

The findings reveal that the illness career for participants in this study was

influenced by the health care setting and four key groups of people: health care

providers (which include care coordinators, primary HIV care providers, and

mental health professionals) and family members, friends, and romantic partners.

Results also confirm that transgender identity influences the illness trajectory and

the nature of interactions with health care providers and important others in the social network.

In this study the role of the care coordinator must be recognized as the most fundamental factor that enabled participants' movement from one stage to the next. Care coordinators who could: 1) establish trust or "connect" with participants: 2) were "sounding boards" 3) assisted participants with obtaining insurance, food, housing, and other essentials; 4) educated participants about HIV; and 5) escorted participants to HIV care appointments, were most influential in moving the participants out of the most vulnerable stages (world crashing down, shutting out the world, living in a dark world). In particular, the "sounding board" effect that care coordinators provided enabled participants to articulate their uncertainties and problems in ways that helps them rectify and resolve their troubles[244] throughout the illness career and that facilitated their movement towards the final stage *reconstructing the world*. This study further validates the care coordinators' vital role in coordinating and optimizing engagement in care for people living with HIV.[10,14,245,246]

The role of HCPs in this study must also be recognized in getting participants to acknowledge their disease and start HIV treatment when they educated them about the benefits of starting treatment and the consequences of delaying or consistently interrupting treatment. Interactions with HCPs sometimes hindered participants' attempts to manage their illness career. Participants' movement across the stages was hampered when HCPs did not involve them in decision-making regarding their care, did not answer participants' questions or

concerns, "rushed" through their encounters, and were not affirming of the participants' transgender identity.

Relationships with family and friends were very important throughout all stages of the model and influenced the illness careers in different, but equally important ways. Family members who gave participants positive, and affirming messages, who were knowledgeable about HIV, including how HIV is transmitted, and who knew other people that were HIV-positive were particularly helpful in supporting participants along the illness career. Parental acceptance (especially from mothers) of the participants' transgender identity and non-judgmental attitude about HIV, enabled participants to move from the stage of the *world crashing down* to the stage of *reconstructing the world*.

By comparison, if family members (especially parents),were not accepting of the participants' transgender identity, blamed the participants' HIV diagnosis on their gender identity, lacked knowledge about HIV, and gave negative and degrading messages, often hampered participants' movement to the final stage of *reconstructing the world*. Participants who were not supported by their families often lingered in the stages of *shutting out the world* and *living in a dark world,* had significant challenges pulling their lives back together after their HIV diagnosis, and many never reached the final stage of *reconstructing the world*.

Friends who were HIV-positive provided support throughout each stage. Positive and affirming messages from family and friends were helpful throughout the illness career. But friends who were HIV-positive (especially friends who were gay or transgender) were especially helpful in moving participants out of the most

traumatic and vulnerable stages of *world crashing down* and *shutting out the world.* The shared identity of being HIV positive created an instant connection between participants and these friends, and therefore lessened the fear, isolation and shame that participants felt during the early phases of their illness career. Specifically, friends who were HIV-positive helped participants move on to the subsequent stages, by answering the participants' questions about living with HIV, by helping them get connected with HIV care, and by assuaging their fears about dying.

During the stage of *living in a dark world*, most participants withdrew from family and avoided encounters with health care providers, but maintained intermittent contact with friends who shared similar life challenges, such as a history of drug use or homelessness. Friends who were in recovery helped participants move out of this stage by offering housing, food, other basic living essentials, and by helping them to initiate treatment for substance abuse and HIV. Friends who were gay or transgender also helped participants move out of this stage by providing alternate family structures and permanent housing. By comparison friends who were actively using drugs, who were engaging in sex work, and who were committing crimes to support their drug habits, hampered participants' movement out of this stage.

In terms of disclosure, the participants in this study grappled less with telling their friends that they were HIV-positive than they did with telling their families. These findings corroborate other studies that have suggested that

disclosing one's HIV-positive status to a friend is often easier than disclosing to a relative.[247]

Relationships with romantic partners were also very important throughout all stages of the model, but were often tenuous and complex. Throughout the illness career participants experienced stress and anxiety about disclosing their HIV status to others. Disclosure in the context of a romantic relationship, however, often caused participants, who may have progressed to the stage of *reconstructing the world* to cycle back to earlier stages. Participants who were rejected, shunned, or blamed for infecting or exposing their partner often returned to the stage of *shutting out the world*.

Findings from the present study suggest that disclosure is a constant source of stress that occurs throughout the illness career, resurfaces with new romantic relationships, and causes participants to recycle through previous stages of the model. These findings are consistent with previous studies that represents disclosure as a lingering source of acute and chronic stress, yet legally required for avoiding criminalization.[248] Two key factors enabled or helped ease the distress of disclosure to a romantic partner. The first was being in a romantic relationship with someone else who was HIV-positive. The second was non-disclosure. Prior research has suggested that non-disclosure is a coping mechanism used as a means to protect oneself from the negative responses of others.[248,249]

Results from this study further substantiate how unstable life patterns such as homelessness, sex work, and drug use, and negatively affects the illness

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career. Participants in this study who had unstable life patterns often lingered in the stage of *living in a dark world* and received inconsistent to no care. These findings are consistent with prior research that on the relationship between HIV risk, substance abuse, unstable housing, mental illness, and incarceration.[250-255] Results suggest that these unstable life patterns were exacerbated in certain care settings that were intended alleviate the instability. For instance, participants who sought temporary housing in homeless shelters and boarding homes experienced many set-backs. These participants felt threatened in homeless shelters because they were housed with men, because they were verbally attacked for being transgender, and because their belongings were stolen. The environment in boarding homes also worsened the instability because they were drug-ridden. Participants who sought temporary housing in these settings were often pressured to, and often did, resume their drug use.

Mental illnesses such as bipolar disorder, schizophrenia, depression, and suicidality were common among the participants in this study. Findings indicate that these participants often traveled back and forth between *shutting out the world* and *living in a dark world* and received inconsistent to no care. Participants who sought care at inpatient drug rehabilitation centers and substance abuse support groups often fared worse in those settings. The inpatient drug rehabilitation centers were not inclusive of transgender women and substance abuse support groups did not allow for individualized care and counseling. As stated earlier, participants who received support from friends who were former addicts, and housing support from chosen kin, fared better during this stage.

Findings in the current study also support prior research that the formal treatment (health care) system influences the illness trajectory.[132,136-138,243,256] In this study, there were general systems of care issues that could not be tied to a particular health care provider or interaction, but still influenced the participants' illness careers. These were nuances such as lack of privacy in health care settings, changes to health care providers, which led to inconsistent or no care for some participants in this study, delays in getting insurance, and the lag time between when participants first tested HIV-positive and when they first were seen by a care coordinator or primary HIV care provider.

In this study, the lack of privacy (e.g. "call-backs" to get test results and "calls" to the clinic") in the jail and prison setting negatively influenced the participants' illness trajectory and health care experiences by discouraging participants from initiating or adhering to HIV care. These findings are consistent with prior research on the impact of incarceration and prison release on adherence to HIV treatment outcomes.[257-260] The lack of privacy and confidentiality in jails and prisons is evidenced in a recent study conducted in North Carolina on jail personnel's perception of privacy and confidentiality. Most of the participants agreed with the statement that, "if an inmate is taking medications in jail, other inmates will know about it." Also, in this same study, 64 (81%) of the correctional facilities indicated that detention officers openly distributed medications in view of other inmates.[261]

Findings in the current study suggest that frequent changes to care providers disrupt continuity of care. These results are consistent with findings

from other studies that have demonstrated a link between frequent changes in health care providers and underutilization of care.[123] "Passing off" transgender clients to other care providers due to inexperience or discomfort in providing care to transgender women also emerged as a major finding that disrupted care. "Passing off" clients is also a form of institutional erasure that discourages care utilization, adds to the difficulties of tracking this population's service utilization, and creates an illusion of population scarcity.[123]

Inherent in these general systems issues were problems such as non-inclusive environments of care. This study did not allow full exploration of ways that the health care environment influenced the illness careers of the participants in this study. However, tentative findings suggest that several strategies could be used to improve engagement in care and health outcomes: 1)Employing other transgender people in the various treatment system settings (HIV CTS, HIV clinics, and primary care clinics); 2) providing cultural competency training for front line staff such as receptionists, and auxiliary staff; educating HCP about transgender people and their health needs; 4) adapting intake and other transgender health-related forms to reflect transgender identities would facilitate engagement in care and subsequently improve health outcomes.[123]

Limitations

The findings must be understood in the context of several study limitations. The sample included18 transgender women living with HIV, many of whom had experienced major life challenges such as substance abuse, incarceration, physical violence and assault, and were involved in sex work

throughout the course of their illness career. Thus, this model may not be generalizable to transgender women who do not share similar experiences. In addition, this model was informed by the experiences of HIV-positive transgender women who had some level of interactions with health care providers and who had received some type of formal HIV care. Therefore, this model may not represent the illness trajectories of HIV-positive transgender women who have never entered formal care.

There were several limitations related to the socio-demographic makeup of the sample. Most of the participants (n=10, 56%) were unemployed, a small number (n=2, 11%) had a college degree, and some (n=2, 11%) never completed high school. Therefore the model may not reflect the illness careers of transgender women who are insured, who are employed, and who have higher educational attainment.

In addition, because participants' narratives were retrospective, their memories of past events may have been distorted or diminished. Even with this limitation, we believe that the narratives shared by the 18 participants in this study provided rich data that will help increase our knowledge of their illness careers and increase our understanding of how interactions with important others in their social network and interactions with HCPs in the treatment network influence their illness trajectories.

The *Having the World Change* model is a stage model that suggests that the illness careers of HIV-positive transgender women is a dynamic and progressive trajectory that involves four stages. We do not, however, wish to

imply that all of the participants moved through the stages in a sequential or predictable manner. Some participants instead passed over stages, some lingered in stages, and some recycled to earlier stages. While we identified factors that enabled participants to move from one stage to the next, we acknowledge that are likely other factors facilitated or restricted participants' progress towards *reconstructing the world,* for example, that we did not identify. Thus the model serves as a theoretical depiction of how the illness career unfolded in our group of participants.

There were also some limitations related to recruitment. Respondents were recruited in an urban, Midwestern city, mostly at sites serving low-income, minority clients. Other transgender women in the study's setting and in other parts of the county may experience the HIV illness career differently and may have different experiences during their encounters with health care providers, family members, and romantic partners.

Face-to-face interviews may have also biased respondents to give responses that were more positive than their actual experiences. In addition, the investigator's role as a nurse with the local health department and her relationship with care providers in the community may have also biased respondents to give responses they felt to be more socially acceptable. Nevertheless, these data were obtained from various care settings and shed light on the understudied issues health care access and the psychosocial needs of transgender women following their initial diagnosis.

More research is needed to determine if the findings in this study are applicable to the larger population of transgender persons living with HIV. It is important to note, however, that the grounded theory methods used in this study allow for in-depth exploration of transgender women's experiences through their own words and from their perspectives. As such, this approach provides a more grounded description of the problems and possible solutions.

Practice Implications

The *Having the World Change* model has utility for health care providers who work with HIV-positive transgender women. By determining an individual's current stage in the model, a care coordinator, health care provider, mental health professional, would be alerted the types of help and support that might facilitate movement to the next stage. The findings indicate, for example, that a transgender woman who is in the *world crashing down* stage needs emotional and informational support, active referrals to HIV care, a private setting in which they can discuss their questions and concerns with a care provider, and physical and emotional support and affirming messages from a family member or friend to move on. Whereas the transgender woman who is in the *shutting out the world* phase needs to feel a sense of connection and trust towards their care coordinator, education about HIV and the benefits of treatment from their HCP, to feel safe and respected, and acceptance from important others to begin to deal with the realities of their illness and to emerge from their state of isolation and withdrawal.

The model might also broaden health care providers' perspectives with regard to the stages through which transgender women progress after an initial HIV diagnosis, the variety of ways in which they attempt to cope with their illness, and the life challenges that disrupt their attempts to cope and access care. This model, therefore, can give HCPs insight into how they can best facilitate progress along the various stages and best facilitate positive coping and engagement in care. The factors that caused participants to shut down, avoid care, and deny their HIV for example, suggest that HCPs should consider how the health care setting (privacy and inclusiveness) and interactions with various health care providers and auxiliary staff attribute to shutting down.

Because being accepted and respected as women was also very important to establishing trust with participants, gender affirmation and support for outwardly embracing and disclosing one's transgender identity to others should routinely be addressed during health care interactions and adopted as a supportive and therapeutic measure. This is true for interactions throughout the illness career, but is particularly relevant to transgender women who are in the *shutting out the world* stage. Finally because the lack of privacy in the care setting routinely emerged as an issue of great concern for participants in the *shutting out the world* stage and discouraged them from acknowledging their illness and engaging in care, confidentiality should continually be addressed as a therapeutic issue for transgender women who are in *shutting out the world* stage.

The model also suggests that there is a great deal of variability in how transgender women move through the various stages. For example, there were

several participants who did not experience a *shutting out the world* stage, but instead progressed on to the stage of *reconstructing their world*. By comparison there were several participants who lingered in the stage of *shutting out the world* and then progressed to and remained in the stage of *living in a dark world* when they did not receive adequate support. HCPs should have an understanding of these dynamic and nuanced processes by which HIV- transgender women experience their illness career and tailor the nature of their encounters to address the variation in needs that present throughout the illness trajectory.

Care coordinators primarily managed the psychosocial needs of participants in this study. This model, therefore, could help this group of care providers identify the psychosocial needs of transgender women (based on stage) and then assist them by tailoring their interactions accordingly. For example, a care coordinator that encounters a transgender woman who is *living in a dark world*, interactions and interventions should address unstable life patterns such as homelessness, adverse behaviors such as substance use, dangerous environments such as "life on street" and the world of commercial sex work; and should address the basic essentials of living such as food and access to insurance. In contrast, care coordinators' interactions with a transgender woman in the *reconstructing the world* stage should focus on supporting her new way of living and existing and identifying strategies to sustain the new way of living over time. Examples include finding stable employment that would allow for permanent housing, transitioning out of sex work, and developing other life skills that will encourage independence and self-efficacy, and build self-esteem.

The model suggests relationships with important others also strongly influenced how participants experienced the illness career. As such, HCP may consider strategies for including supportive family members and friends, especially friends who are also HIV-positive or transgender, in the early stage (*world come crashing down and shutting out the world*) health care encounters with transgender women. When possible, HCP may also consider scenarios that would engage supportive family members and friends in strategies to help HIV-positive transgender women to better cope with their illness acknowledge their disease, and remain engaged in HIV care. Findings suggest that transgender women's family structure may deviate from the definition of a traditional family and instead be composed of chosen family members or fictive kin. HCPs should be aware of these variations in family structure and support the involvement of chosen or fictive kin throughout all stages of the illness career.

Families were most helpful if they understood about the participants' HIV and their lives as transgender women, therefore, including select family members in health care encounters that focus on HIV education and transgender identity can optimize family members' capacity to support transgender women throughout the illness career. Participants also fared relatively well during the stage of the *world come crashing down* when they received emotional and physical support from their family. Therefore, providers in HIV counseling and testing settings should encourage individuals to have a supportive and trusted family member or friend with them when they receive their HIV test results and during the post-test counseling session.

The presence of these supportive important others will benefit the individual in several ways. First, the presence of a supportive person when receiving an HIV-positive result can soften the initial shock and trauma that ensues during the stage of the *world crashing down.* Second, because participants expressed feeling a great deal of confusion and anxiety during this stage, a supportive family member or friend can interact with the care provider in this setting to ensure that all of the appropriate information regarding follow-up care is provided, to communicate concerns, and ask other questions that might help engage the individual in HIV care. Third because participants struggled with disclosing their HIV status to important others, especially family members, throughout the course of their illness career, having a family member present during the *world crashing down* phase would help alleviate the burden that participants felt from wanting to, but not being able to tell their family about their HIV. Family members or trusted friends who are involved in this stage could then also support and help participants in future disclosures to important others.

HCPs should also be aware that while disclosing one's HIV status to family and friends is challenging, that disclosing one's HIV status to a romantic partner is particularly distressing. HCPs need to have an awareness that individuals who receive negative responses from important others in their social network are at risk of repeat trauma and may cycle back to earlier stages or engage in adverse behaviors in an effort to deal with the trauma. Therefore, disclosure (guidance on how, when, and to whom) must be routinely addressed as a therapeutic issue. HCPs can use the model to determine an individual's

position along the illness career and then advise them on the best approach and strategies for disclosure. Since participants fared pretty well through the disclosure stage when their HCPs made the initial disclosure to their families, HCPs may consider routinely supporting individuals with disclosure.

It is also important to note that many participants in this study received their initial HIV diagnosis in jail or prison. Jail and prison-based providers need to be alerted to the severe emotional trauma, fear, isolation, and denial that occurs during the stages that follow an initial diagnosis and be proactive in providing emotional support and opportunities for transgender women to discuss their diagnosis with a HCP in a safe and confidential setting.[262]

The jail and prison setting complicated every stage of the illness career for participants in this study. One process that helped these participants to acknowledge their illness, initiate treatment, and reconnect with others was pre-release case management. Previous research suggest that pre-release case management facilitates engagement in HIV after release, however, transgender women who are not nearing release have educational and psychosocial needs that are not being addressed during incarceration.[262,263] Therefore, another recommendation would be to integrate the case management approach to care throughout the cycle of incarcerate for HIV-positive transgender women, not just prior to release. In a study on the prevention needs of HIV-positive men and women awaiting release from prison, Catz and colleagues reported that education for HIV-infected inmates should focus how viral load impacts transmission, ways to protect oneself (from reinfection) and others from being

newly infected, and should focus on enhancing behavioral skills.[262] The findings

in the current study corroborate the need for this type of education for

transgender women also throughout their incarceration.

Finally, the *Having the World Change* model has implications for public

health practitioners and can be used to help optimize engagement in the HIV

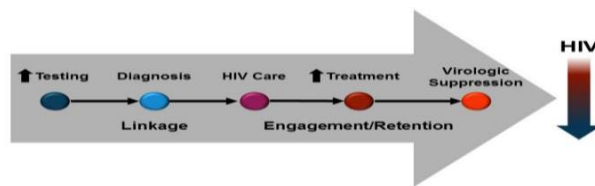Care Continuum (also known as the Treatment Cascade). See Figure 4.

Figure 4. The HIV continuum of care or treatment cascade. This figure

illustrates the steps that follow an initial diagnosis of HIV.

The HIV Care Continuum is the series of steps from the time a person is

diagnosed with HIV until they are successfully engaged in care and virally

suppressed. The HIV Care Continuum is part of the National HIV/AIDS Strategy

to improve outcomes of people living with HIV/AIDS in the US and to identify

areas in need of improvement.[195,264] According to the latest CDC analysis of the

1.2 million people living with HIV in the U.S., 86% were diagnosed with HIV. Of

the 86% diagnosed, 40% were engaged in HIV care, 37% were receiving

antiretroviral therapy, and 30% were virally suppressed.[195,264,265]

Public health practitioners should be aware that the most crucial points

along the HIV Continuum of Care (HIV testing and diagnosis, linkage to care, and

entry into care) run parallel to the most vulnerable stages of *Having the World*

Change (*world crashing down, shutting out the world, and living in a dark world).*

The model then can alert these providers of the psychosocial needs of

transgender women during the time points of HIV testing and diagnosis and entry

to care and inform strategies that may be used to help facilitate movement along

the continuum of care. Examples include employing transgender HIV testers,

encouraging individuals to bring supportive family members or friends with them

when they get tested for HIV and when they receive their results, decreasing the

lag time (currently 2-3 weeks) between the time that someone tests HIV-positive

and the time they first see a care coordinator primary HIV care provider,

engaging peers and other members of the social network in activities to engage

and retain this population in care, and addressing other structural barriers to HIV

care such as homelessness, substance abuse, and sex work.

In sum, the *Having the World Change* helps identify the stages of the

illness career during which transgender women are most emotionally vulnerable,

are most at risk for physical harm, adverse health effects, and death; and are

most at risk for not engaging in or falling out of HIV care. In this respect, the

model helps identity, in a more practical sense, the key points along the illness

career where health care professionals and important others in the social

network might be able to intervene and prevent HIV-positive transgender women

from lingering in and recycling back to vulnerable stages. Because important

others in the social network and health care providers in the treatment network

played a significant role in helping participants cope with their illness, the model

may help inform interventions that integrate support and counseling from both the social and the treatment networks.

Implications for Future Research

In their 2011 report, *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for a Better Understanding,* the IOM outlined several recommendations across a number of areas that would advance the understanding LGBT health.[266] One recommendation was to expand all aspects of evidence-based research for transgender-specific health care.[266] The Committee especially called for research that examines the social influences on the lives of LGBT people and that examines inequities in health care.[266] Because longitudinal, prospective studies are largely absent from LGBT research,[266] the next logical step might include a longitudinal prospective study to validate the stages in the model *Having the World Change* and to further explore the factors that enable and inhibit transitions across the various stages. Such a study would provide insight into how the illness trajectory for HIV-positive transgender women changes over time, would allow for further examination of how the social network can be used to engage and retain transgender women in HIV care, and to examine how changes within the health care setting and nuances of interactions with health care providers influence the illness trajectory.

In this study, differences were observed in how African American transgender women experienced the illness the career. For instance, most African American participants had unstable life patterns (homelessness, drug use, sex work, unemployment), seemed to linger in the stages of *shutting out the*

world and *living in a dangerous world*, and reported more frequent challenges with incarceration and repeat incarcerations. However the small sample size and higher representation of African American participants in this study (n=10, 55%) makes it difficult to determine if these were true differences. Therefore a subsequent study that has a larger sample size and equal distribution of participants across racial/ethnic groups, would allow for closer examination of how the HIV illness career may differ by race/ethnicity.

Again, participants in jail or prison encountered numerous barriers to HIV primary care, initiation of and adherence to HAART, HIV denial, depression, and social isolation. Studies to date have examined the role of pre-release case management on linkage to HIV care upon release and the influence of directly observed HAART therapy on viral suppression,[246,258] but there is a dearth of literature on the influence of prison-based care coordination models on adherence to HIV care and illness coping. These interventions should be explored in future studies.

The majority of participants in this study (n=12, 66%) had been living with HIV between 1-5 years, a moderate number (n=3, 16%) for 21-25 years, and a smaller number (n=1, 6%) for more than 25 years. Because health needs and relationships with important others change over the course of an illness and over the course of a lifetime, future studies should also examine how the HIV illness trajectory changes for transgender women as they age. Such a study will inform HCPs on how this populations' health care needs change over time and therefore provide insight into how treatment needs should be tailored to address the

changing needs, especially for transgender women living with HIV into later
adulthood.

The changing needs of older transgender women as they age were noted
in the current study. A few participants, who had been living with HIV for more
than 20 years, reported dealing with other health issues such as cancer and
AIDS dementia, and social issues such as loneliness and depression. According
to the CDC, people aged 55 and older accounted for more than one-quarter
(n=313,200, 26%) of the estimated 1.2 million people living with HIV in the US in
2011.[267] With advances in HIV treatment, people are now living longer and this
number will continue to increase. Therefore, more research is needed on the
health issues that HIV-positive transgender women face as they age.

Findings in this study also confirm that there is a dearth of information on
the general health needs of this population. While the participants in this study
acknowledged that HIV was a problem, for many, it was not their most pressing
health concern. Participants who had completed sexual reassignment surgery
described not knowing how to take care of their vaginas and described problems
with issues such as vaginal dryness and shrinkage. Other participants who had
breasts shared that no one ever taught them how to examine their breasts and
were unaware that hormones increased their risk for breast cancer.

Men who have sex with men (MSM) are 17 times more likely to develop
anal cancer than heterosexual men,[268] however, participants indicated that their
health care providers did not talk to them about anal cancer. In many cases
providers did not examine these parts even when participants complained of

symptoms like rectal itching, burning, and pain. Screening for anal cancer in transgender women should follow the same protocol for anal cancer screening for MSM. This calls for more research on best the practices for managing the overall health care for transgender women, regardless of their HIV status.

Participants in this study expressed having other health issues or concerns that were rarely discussed or addressed within the context of their interactions with health care providers. Therefore further research is needed to expand our understanding of the educational and competency needs of HCPs caring for transgender women and to identify additional gaps in health services for this population.

Finally, because health care settings that were non-inclusive and interactions with HCPs who were not affirming or respectful of participants' transgender status disrupted care and hindered healing, more research is urgently needed to evaluate the quality of care currently received by transgender women and to inform development of transgender-friendly environments of care.

Conclusion

The HIV illness career for transgender women is defined by concepts of trauma, loss, isolation, and withdrawal, denial, dangerous and life-threatening behaviors, and resilience. The stages in the model represent the psychosocial and behavioral efforts that this group of transgender women used to manage or cope with their HIV. The findings in this study confirm that transgender women face many complex and dynamic health, behavioral, and social challenges when attempting to cope with an HIV diagnosis. The theoretical model developed in

this study can be used to educate and inform care coordinators, primary HIV care providers, and mental health professionals about the processes and enabling factors that facilitate coping, healing, and engagement in care for transgender women living with HIV.

While the model presented in this study could apply to anyone diagnosed with HIV, meaning that most people who are diagnosed with HIV will go through similar stages, there are certain aspects that are very unique to transgender women and that should be considered when interpreting the model. Unlike non-transgender people, transgender women encounter stigma and discrimination that is solely predicated on their non-conforming gender identities. HIV adds another layer of stigma and discrimination that worsens the illness trajectory of these women and further intensifies their social isolation. The combined effect of transgender and HIV stigma factors amplifies the vulnerability that transgender women experience during the first three stages (*world crashing down, shutting out the world, and living in a dark world*) of the model, increases their risk for not linking to HIV care, and decreases their likelihood of getting the appropriate support needed to move them out of the most vulnerable stages.

Within the context of the health care encounter, gender affirmation is necessary for establishing trust with and engaging transgender women in care. Unlike non-transgender people, gender affirmation is directly tied to transgender women's emotional and mental health. Therefore, gender affirmation should be thought of as a strategy for engaging transgender women in HIV care and for acknowledging and coping with HIV throughout their illness career.
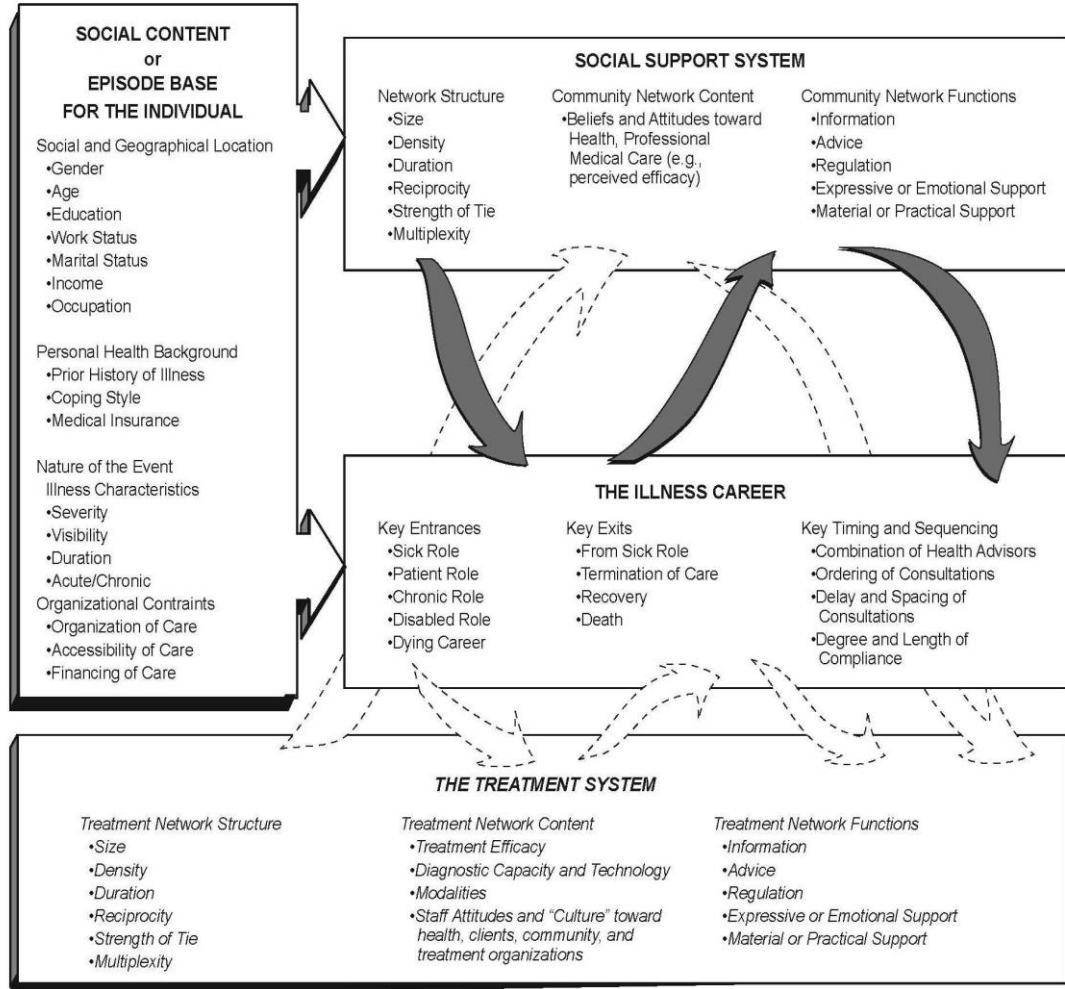
In general, health care providers are poorly prepared to care for non-transgender people. This lack of transgender health knowledge and competency among health care provider complicates the illness career of HIV-positive transgender women and threatens their well- being across all stages of the model. Therefore, the quality of the health care encounter with transgender women, particularly during the stages of *shutting out the world* and *living in a dark world*, may play a greater role in engaging and retaining transgender women in care than it would with their non-transgender counterparts.

Finally, with regards to the factors that enabled participants to move from one stage to the next, another aspect unique to transgender women was social ties with similar others. Relationships with other transgender women, chosen kin, or health care providers, who identified as gay, played a key role in helping the women cope with and acknowledge their illness.

Appendices

Appendix A

Network Episode Model

**SOCIAL CONTENT
or
EPISODE BASE
FOR THE INDIVIDUAL**

Social and Geographical Location
•Gender
•Age
•Education
•Work Status
•Marital Status
•Income
•Occupation

Personal Health Background
•Prior History of Illness
•Coping Style
•Medical Insurance

Nature of the Event
Illness Characteristics
•Severity
•Visibility
•Duration
•Acute/Chronic
Organizational Contraints
•Organization of Care
•Accessibility of Care
•Financing of Care

SOCIAL SUPPORT SYSTEM

Network Structure
•Size
•Density
•Duration
•Reciprocity
•Strength of Tie
•Multiplexity

Community Network Content
•Beliefs and Attitudes toward
  Health, Professional
  Medical Care (e.g.,
  perceived efficacy)

Community Network Functions
•Information
•Advice
•Regulation
•Expressive or Emotional Support
•Material or Practical Support

THE ILLNESS CAREER

Key Entrances
•Sick Role
•Patient Role
•Chronic Role
•Disabled Role
•Dying Career

Key Exits
•From Sick Role
•Termination of Care
•Recovery
•Death

Key Timing and Sequencing
•Combination of Health Advisors
•Ordering of Consultations
•Delay and Spacing of
  Consultations
•Degree and Length of
  Compliance

THE TREATMENT SYSTEM

Treatment Network Structure
•*Size*
•*Density*
•*Duration*
•*Reciprocity*
•*Strength of Tie*
•*Multiplexity*

Treatment Network Content
•*Treatment Efficacy*
•*Diagnostic Capacity and Technology*
•*Modalities*
•*Staff Attitudes and "Culture" toward
  health, clients, community, and
  treatment organizations*

Treatment Network Functions
•*Information*
•*Advice*
•*Regulation*
•*Expressive or Emotional Support*
•*Material or Practical Support*

Appendix B

Network Episode Model Key Terms & Definitions

The Illness Career

Key Entrances refer to the route or means through which an individual begins their illness career or trajectory. These include the sick role, patient role, chronic role, disabled role, and dying career.

Key exits refer to events that result in discharge of an individual from the illness career. These include termination of care, recovery from illness, or death.

Key timing/sequence refers to events that affect the timing and sequencing of entry and navigation through care. These include factors such as having multiple health care providers, the medical team composition, ordering of consultations, delay and spacing of consultations, and the degree and length of compliance[132]

Social Support System

Network Structure refers to the size, density, duration, reciprocity, strength of the network ties, and multiplexity.[138,269]

- **Network size** refers to the number of individuals and density to the number of links.

- **Density** refers to the ratio of the number of ties observed in a network to the number of ties theoretically possible. For example, if Participant A has only six key ties in her network, potentially she could have many others from work, her neighborhood, and her extended family.[224]

- **Duration** refers to the length of relationship time, and reciprocity is the degree of symmetry in a relationship.

- **Reciprocity** refers to a person's ability to reciprocate support, goods, and services to the people in his/her network.[224]

- **Strength of network ties** is defined as the intensity or connectedness of relationships.

- **Mulitiplexity** refers to the degree to which a pair is linked by multiple roles[138,269], or the number of people performing more than one role or function within the network.[224]*Community network content* refers to the belief and attitudes toward health and professional medical care.[138]

Community network functions refer to the information, advice, regulation, expressive or emotional support, and material or practical support that occurs within the larger support system.[138]

The Treatment System

Treatment network structure refers to the size, density, duration, reciprocity, strength of the network ties, and multiplexity of the treatment system (refer to definitions listed under the social support network structure above). [138,269]

Treatment network content refers to support obtained through formal networks such as HIV medical providers, case managers, or care coordinators, and it includes factors such as treatment efficacy, diagnostic capacity and technology, and staff attitudes and culture towards health, clients, community, and treatment organizations.[138,142]

Treatment network functions are defined as information, advice, regulation, expressive or emotional support, and material or practical support that occur within treatment systems.[138]

Appendix C

Procedure for Direct Call from Health Care Provider to Prospective Participants

Hello, I am calling to let you know about an opportunity to participate in a research study on healthcare utilization among HIV-positive transgender women.

If you are interested in being in the study you will be asked to participate in a 60-90 minute interview with a Dana Hines, a nurse researcher at Indiana University School of Nursing.

It will not cost you anything to participate in the study and if you decide that you do not want to participate it will not affect your ability to receive care and treatment at our clinic/care coordination site/agency.

If you decide to participate in the study you will be given a $50 gift card for your time.

Does this sound like a study in which you would like to participate?

If prospective participant responds yes:	If prospective participant responds no:
Okay, may have I permission to give Dana your telephone number to schedule an interview with you?	Okay, that is fine. Thank you for your time and thank you for considering.
If participant gives permission for PI to call:	
Care provider will call PI and give her the first name only of the woman and her preferred telephone number. PI will contact the participant by phone and schedule an interview.	
If participant wants to participate in the study, but does not want give permission for PI to make direct call:	
Health care provider will give instructions on how to contact researcher. "Okay, that is fine. If you are still interested in participating you can contact Dana at "xxx-xxxx" to schedule an interview. Thank you for your time".	

Appendix D

Procedure for Face-to-Face Recruitment Approach

Clinic or care coordination staff will give PI a list of dates/times that potentially eligible clients are scheduled for a clinic or care coordination appointment.

PI will schedule time to be present at the clinic or care coordination site on specified dates.

PI will wait in a private room designated by staff for study participants.

Staff responsible for the check-in process will briefly introduce the study opportunity to each transgender woman who checks in.

Specifically staff will state the following:

Staff: "Would you be interested in participating in a research study on transgender women?"

If participant responds no:
Okay, that is fine. Thank you for considering.

If prospective participant responds "yes".

Staff: "Okay, great. After your appointment you will have the opportunity to meet with a nurse researcher to talk about your experiences with healthcare utilization. Here is a copy of the study flyer and a study information sheet to explain more. Once you are done with your visit "_____" will escort you to the "____" room for your interview. There you will meet with the nurse learn more about the study and participate in an interview".

After participant is escorted to the private meeting room

PI: Hello, my name is Dana and I am a PhD student at Indiana University School of Nursing. I am conducting a study on health care use among HIV-positive transgender women. Are you interested in volunteering to be in this study?

Participant: yes.

PI: Great, thank you so much. Before we get started I would like to review some important information about the study. *Will review study information sheet, ask if participant has any questions, and then proceed with the interview.*

Appendix E

Letter to Eligible Transgender Women

DATE

Name

Dear _____,

We are writing you to let you know that you are eligible to participate in a research study. The purpose of the study is to learn more about the health care experiences of transgender women living with HIV. This study is especially interested in learning how important social relationships and health care encounters impact utilization of care. We believe that this study will help doctors, nurses, and care coordinators understand how to improve health care experiences and of transgender women.

If you are interested in being in the study, please tell the receptionist or nurse that you are interested in hearing more about the study. Dana Hines, a nurse researcher from Indiana University School of Nursing, will then come in and meet with you to discuss the details of the study. If you chose to participate, you will be given a $50 gift card for you time. You may be asked to stay an additional 60-90 minutes after your clinic appointment to complete the interview.

If you are not interested in participating, then please tell the receptionist or nurse. If you decide that you do not want to participate, it will not affect your ability to receive care and treatment at our clinic/care coordination site/agency.

Sincerely,

Clinic or Agency Director or Designee

Appendix F

Demographic Collection Sheet

1. From where did you learn about the study? _____

2. How old are you? _____

3. Which of the following best describes your gender?
   a. Female

   b. Transgender woman

   c. Gender queer

4. Which of the following best describes your sexual orientation?

   a. Gay

   b. Bisexual

   c. Heterosexual

   d. Queer

   e. Sexual

5. What was your sex at birth? _____

6. What is the highest grade or level of school you have completed?

   _____

7. Which of the following best describes your race?

   a. Black or African American

   b. White

   c. American Indian or Alaskan Native

   d. Native Hawaiian or Pacific Islander

8. Which of the following best describes your ethnicity?

    a. Hispanic

    b. Non-Hispanic

    c. Asian

9. Which of the following best describes where you live?

    a. City (urban area)

    b. Country (rural area)

10. What is your zip code?_____

11. Do you have any children?

    a. Yes

    b. No

12. Are you presently in a relationship?
    a.   Yes
    b.   No

13. If you answered yes to above, for how long have you been partnered?
    _____

14. Are you employed?

    a. Yes
    b. No

15. If you answered yes to the above, please describe the type of work that you do.
_____

_____

16. Do you have health insurance?
    a. Yes

    b. No

17. If you answered yes to the question above, please describe what kind?

_____

18. Have you ever had any major surgeries?

    a. Yes

    b. No

    If you answered yes to above, please list:

    _____

    _____

19. Please list any other health problems or concerns below:

_____

Appendix G

Semi-Structured Interview Guide and Script

1. Introduction: Thank you for taking the time to talk to me today. I really appreciate your willingness to help me out with this interview. Have you ever been interviewed before? Well, the main reason why I would like to interview you is to learn about your experiences with getting into and staying in care after learned that you were HIV positive. Findings from this study will be used to help doctors, nurses, social workers, and others better understand the unique experiences of transgender women with seeking, entering, and remaining in HIV care. Before we begin the interview would you mind completing this demographic data collection sheet for me? This information will be used to provide an overall description of the women who participated in this study. Please do not write your name on the form. After we complete the interview the information on this form will be entered into a secured data file and the paper copy destroyed.

2. Interviewee Role: I want you to feel that this is *your* interview. I am here to listen to what you have to say. I am very interested in your experiences and feelings, so please feel free to share anything that comes to mind. My job is to listen to you so that I can better understand these experiences.

3. Explain Audio Recording Procedures: As I explained when we talked on the phone, I will record our conversation so that I do not have to take notes and so I can get your complete answer. This also helps me be sure that my report will accurately reflect your experiences. In addition to me, the only other person who will ever listen to the recording is a professional transcriptionist. After the interview is transcribed I will erase it within a week. Is this okay with you?

4. Assure Interviewee of Confidentiality: Please feel free to speak openly with me. Maintaining your privacy is the most important thing to me, and anything you say during this interview will be kept private and confidential. I will not include your name or any other information that could identify you in my report. Also, if I ask you any questions that you do not want to answer, you can just say, "pass", and we will skip those questions.

5. Time Frame of Interview: The interview will last about 90 minutes. If you need a break at any time, just let me know.

6. Obtain Informed Consent: Before we begin the interview, I would like to go over the study's informed consent/information form, which describes the study, your part in the study, the steps we will take to ensure to your confidentiality, and the fact that your participation is voluntary. You can take this written copy of the form with you (Wait for the participant to read the information). Do you have any questions about the study or the information you read? If not, do you give your permission to participate in the study by being interviewed? (If the participant agrees, then start the interview). Ok thank you for your help with the study. Do

you have any more questions before we start? Ok, then I will begin recording the interview now. (Start recorder and record verbal consent prior to asking any interview questions).."We are now recording. Today is…201_. My name is Dana Hines. I am a doctoral nursing student at Indiana University Indianapolis. Today I have the privilege to be interviewing Ms. Williams (pseudonym). So Ms. Williams, I would like to ask your permission to record this interview. A professional transcriptionist will transcribe the recording from the interview and I will use the recording and the transcription for study and research purposes. The tape recording will be destroyed within a week. I will need this amount of time to verify or double check the recording against the typed copy of your interview. (If verbal consent is given and audio recorded, proceed with the interview.)

Main Interview Questions
Thank you for completing the demographic data sheet for me. First I would like for us to begin with some background questions so that I can get to know more about you before we talk about your experiences with HIV care. Afterwards, I will ask you some questions about your experiences with testing HIV positive, seeking care after finding out you had HIV, getting into care, and then staying in care. I just want to get as full a picture as I can of your experiences in your own words. Please know that I want to learn as much as I can about these important experiences of yours, but I do not want you to feel any pressure to answer any questions that make you feel uncomfortable. Just let me know if I ask a question that you would rather not answer and we will move on to the next one. Does that sound okay? Do you have any questions before we move on?

Study Aims	Opening Question	Potential Follow-Up Questions (probes)
Life as a transgender woman	About what age were you when you began to think of yourself or feel as though you were a girl (or woman)?	1. How and when did you begin the transition? 2. Was there someone that you confided in or talked to during this time? 3. How did you come to accept that you were transgender? 4. How has/does being transgendered effect how you go about day to day living? 5. Have there been (or are there) times when you did not feel safe because you were transgendered? Can you explain more about what happened?
Testing HIV Positive	Tell me about the time when you first learned that you were HIV-positive.	1. How did you cope with the news? 2. How are you coping now? 3. Who or what was helpful to you during that time? 4. What about now? From where do you get the support that you need?

| HIV Care Seeking | Please tell me about your experience of getting into care after first learning that you were HIV positive. | 6. Did you seek care right away?
7. Did anyone encourage you to seek care or is this something that you did on your own?
8. Can you describe for me what was happening in your life at the time you decided to seek care?
9. (a) What led to you to seek care the first time? Or 4 (b) If you were not getting care, but then did, what led you to that point?
10. Can you tell me about any other types of health care that you have sought since learning that you were HIV positive? |

HIV Care Entry	Talk to me about your transition into care.	Some people first see a HIV care coordinator or support person before seeing a doctor or nurse. If you met with a support provider first, please start with that experience and then move on to when and if you have ever seen a medical care provider (also allow potential probes for the reverse process to occur or no support provider).
		1. Did you enter care right away or was there a delay? Can you explain more about what happened and what it was like for you? How is it for you now?
		2. In thinking about your experience of entering or getting connected to HIV care, can you describe for me what went well? What did not go well, if anything?
		3. Did anything get in the way of you getting into care?
		4. How did you get connected to your current care coordination site?
		5. What about your HIV doctor or nurse practitioner? How did you get connected to him or her?
		6. Were there other medical providers or conditions that affected your decision to seek care?

Remaining engaged in HIV care	Talk to me about your experiences with continuing or discontinuing HIV care.	Some people enter HIV, have an initial medical visit and never return to care. Other people remain in care for long periods of time. 1. Have you stayed in care the entire time since being diagnosed with HIV? Or, have you ever stopped going to see the doctor or nurse? 2. Can you explain more about what happened to make you stay in care? Or, how long did you stay out of care? 3. How is being in care for you now? Have you been told that you needed to take medication for HIV? (a) What is taking medication like for you?
Social relationships	Who are the people in your life with whom you discuss important matters?	1. What sort of matters do you discuss with them? 2. How would describe your relationship with this person? 3. In what ways did these individuals help you in your decision to seek, enter and remain engaged in care? In what ways were they not so helpful to you during these processes?
Health care encounters	Now I would like you to tell me about the nurses, doctors, care coordinators and other support people that you have met throughout your time of living with HIV.	4. Letter to Eligible Transgender Women_11.9.13

Closing Questions
We are almost finished. Thank you again for sharing your experiences with me. One final question before we end, do you have anything else you would like to share with me about your experiences with seeking care, entering into care, and/or staying in care? Is there anything you would say to other transgender women who are seeking care for HIV? How about folks who provide services to transgender women? Would you have anything to share with them?

9. Thank you
That is it for the interview. The information you have shared with me has been very helpful. If you have any other questions or just want to talk about the interview experience, please feel free to give me a call. [Will leave flyers for snowball sampling and a HIV prevention and transgender health resource packet.]

10. Provide Compensation
Thank you again for taking the time to come and talk to me about your experiences. Here is the gift card that I mentioned as a way of saying thank you for taking the time to participate.
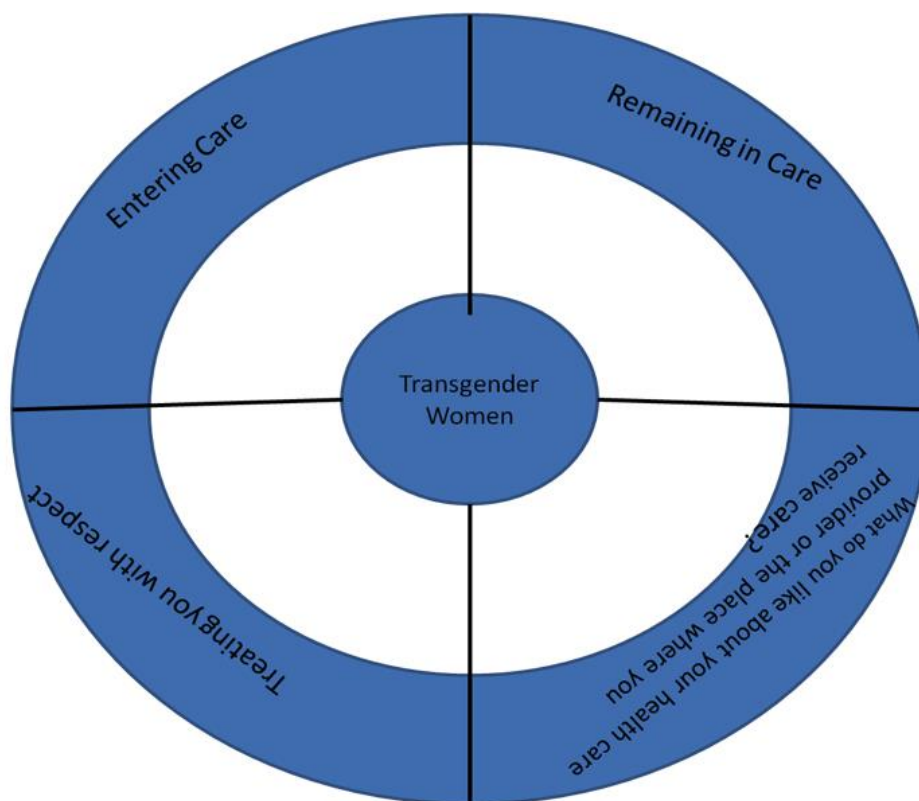
Appendix H

Social Network Map

The following data collection tool will be used to generate names of important people in the women's social network. Specifically the women will be asked to list the names of the people with whom they discuss issues related to their transgender identity, HIV, health care and other important social and health issues. This tool will also be used to generate discussions about how each person influenced their care utilization.

Transgender
Identity, Concerns ,
or Needs

HIV

Core Discussion
Group

Health
Concerns or Needs
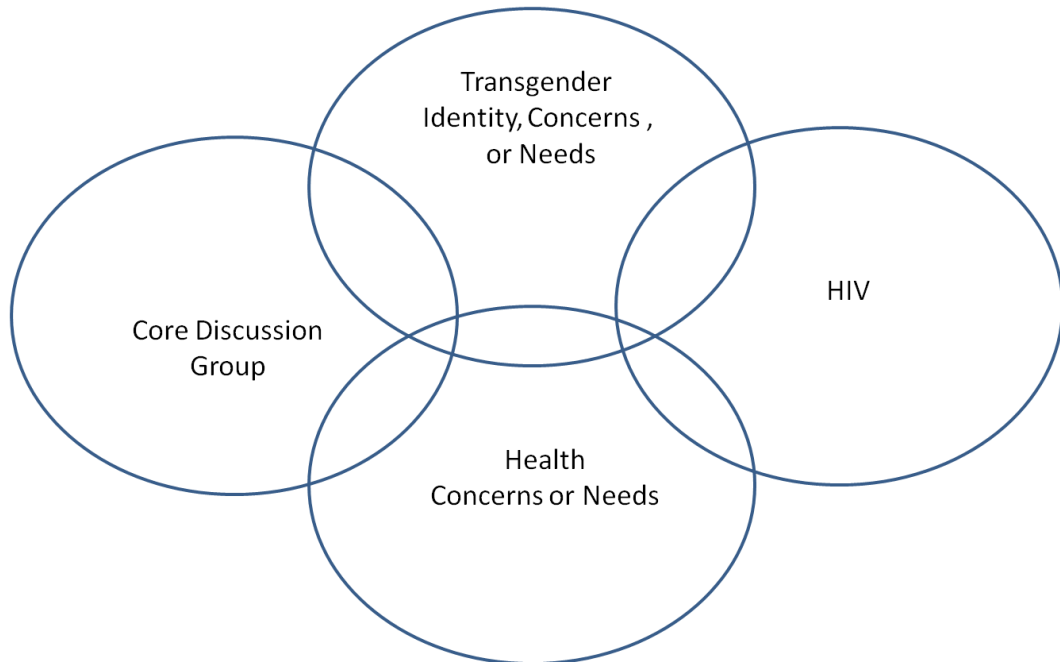
Appendix I

Trans-friendly Health Care Encounters

The Trans-friendly Health Care Encounters Wheel will be used to
generate qualities and characteristics that the women find to be helpful to them
entering care, remaining in care, and those qualities that they find to be
respectful to their transgender identity and qualities that they prefer in their
healthcare team.

Appendix J

Recruitment Flyers

Original study flyer

Are you a transgender woman who is:
Living with HIV/AIDS and at least 18 years or older?

If you answered yes to the questions above you may be able to take part in a study about the experiences of seeking, entering, and staying in HIV care. Information from this study will increase knowledge and awareness of transgender women's HIV health needs and improve the HIV healthcare experiences of transgender women.

Call Dana H. RN, MSN
Indiana University School of Nursing
at **(317) 759-3885** for more information

Please note that all eligible participants will be asked to take part in a one-on-one 60-90 minute interview. Interviews will be held in private location. Your name and personal information are not required to participate. A gift card will be given to all women who complete the interviews.

Would you like to help improve the healthcare experiences of transgender women living with HIV?

Flyer for HIV based clinic or care coordination agencies

- ❑ Are you a transgender woman living with HIV?
- ❑ Are you willing to participate in a 60-90 minute interview with a nurse researcher?
  - ❑ You will receive a $50 gift card for your time.

- ❑ Would you be willing to share your experiences about accessing health care?
- ❑ Would you like to help educate and inform health care providers about transgender women's health needs?

If yes, then I would like to hear your story!!!

I am a nurse researcher, advocate for transgender equality, and champion for quality HIV care. Contact me at **(317) 426-8102** for more information or to schedule an interview.
Your name and personal information are not required to participate.

Dana, RN, MSN
Indiana University School of Nursing

Dana 317-426-8102
Dana 317-426-8102
Dana 317-426-8102
Dana 317-426-8102
Dana 317-426-8102
Dana 317-426-8102
Dana 317-426-8102

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Would you like to help improve the healthcare experiences of transgender women?

❑ Are you a transgender woman ?

❑ Are you willing to participate in a 60-90 minute interview with a nurse researcher?

    ❑ You will receive a $50 gift card for your time.

❑ Would you be willing to share your experiences about accessing health care?

❑ Would you like to help educate and inform health care providers about transgender women's health needs?

Flyer for general recruitment venues

If yes, then I would like to hear your story!!!

I am a nurse researcher, advocate for transgender equality, and champion for quality care. Contact me at **(317) 426-8102** for more information or to schedule an interview.
Your name and personal information are not required to participate.

Dana, RN, MSN
Indiana University School of Nursing

Dana 317-426-8102
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Dana 317-426-8102

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References

1.   Centers for Disease Control and Prevention. *HIV Surveillance Report, 2009.* February 2011.
2.   Mayer KH, Wheeler DP, Bekker L-G, et al. Overcoming Biological, Behavioral, and Structural Vulnerabilities: New Directions in Research to Decrease HIV Transmission in Men Who Have Sex With Men. *JAIDS Journal of Acquired Immune Deficiency Syndromes.* 2013;63:S161-S167.
3.   Centers for Disease Control and Prevention. *HIV in the United States: At A Glance.* Atlanta February 2013 2013.
4.   Centers for Disease Control and Prevention. Statistics Center: Statistics and Surveillance. 2013; http://www.cdc.gov/hiv/statistics/. Accessed June 27, 2013.
5.   Gardner LI, Marks G, Craw J, et al. Demographic, psychological, and behavioral modifiers of the Antiretroviral Treatment Access Study (ARTAS) intervention. *AIDS Patient Care STDS.* 2009;23(9):735-742.
6.   Molitor F, Waltermeyer J, Mendoza M, et al. Locating and linking to medical care HIV-positive persons without a history of care: findings from the California Bridge Project. *AIDS Care.* 2006;18(5):456-459.
7.   Samet JH, Freedberg KA, Stein MD, et al. Trillion virion delay: time from testing positive for HIV to presentation for primary care. *Arch Intern Med.* 1998;158(7):734-740.
8.   Kaiser Family Foundation. HIV/AIDS policy fact sheet: The HIV/AIDS epidemic in the United States. 2007.
9.   Mugavero MJ, Lin HY, Allison JJ, et al. Failure to establish HIV care: characterizing the "no show" phenomenon. *Clin Infect Dis.* 2007;45(1):127-130.
10.   Gardner LI, Metsch LR, Anderson-Mahoney P, et al. Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. *AIDS.* 2005;19(4):423-431.
11.   Wanyenze RK, Hahn JA, Liechty CA, et al. Linkage to HIV care and survival following inpatient HIV counseling and testing. *AIDS Behav.* 2011;15(4):751-760.
12.   Zaller ND, Fu JJ, Nunn A, Beckwith CG. Linkage to Care for HIV-Infected Heterosexual Men in the United States. *Clinical Infectious Diseases.* 2011;52(suppl 2):S223-S230.
13.   Mugavero MJ. Improving engagement in HIV care: what can we do? *Top HIV Med.* 2008;16(5):156-161.
14.   Craw JA, Gardner LI, Marks G, et al. Brief strengths-based case management promotes entry into HIV medical care: results of the antiretroviral treatment access study-II. *J Acquir Immune Defic Syndr.* 2008;47(5):597-606.
15.   Mayer KH. Introduction: Linkage, engagement, and retention in HIV care: essential for optimal individual-and community-level outcomes in the era of highly active antiretroviral therapy. *Clinical Infectious Diseases.* 2011;52(suppl 2):S205.

16. Samet JH, Freedberg KA, Stein MD, et al. Trillion virion delay: time from testing positive for HIV to presentation for primary care. *Archives of Internal Medicine.* 1998;158(7):734.

17. Centers for Disease Control and Prevention. *HIV surveillance report: Diagnoses of HIV infection and AIDS in the United States and Dependent Areas, 2009.* Atlanta2011.

18. Centers for Disease Control and Prevention. Estimates of New HIV Infections in the United States. 2008; http://www.cdc.gov/hiv/topics/surveillance/resources/factsheets/incidence.htm. Accessed 7/16/2011, 2011.

19. Nemoto T, Operario D, Keatley J, Han L, Soma T. HIV risk behaviors among male-to-female transgender persons of color in San Francisco. *Am J Public Health.* 2004;94(7):1193-1199.

20. Centers for Disease Control and Prevention. *Vital Signs: HIV Testing and Diagnosis Among Adults --- United States, 2001--2009.* 2010.

21. Hankins C. Overview of the Current State of the Epidemic. *Current HIV/AIDS Reports.* 2013:1-11.

22. Kwakwa HA, Ghobrial MW. Female-to-Female Transmission of Human Immunodeficiency Virus. *Clinical Infectious Diseases.* 2003;36(3):e40-e41.

23. Centers for Disease Control and Prevention. *HIV/AIDS among Women Who Have Sex with Women.* Atlanta 2006.

24. Deol AKH-T, A. *HIV Risk for Lesbians,Bisexuals & Other Women, Who Have Sex With Women.* 2009.

25. Young RM, Meyer IH. The trouble with "MSM" and "WSW": Erasure of the sexual-minority person in public health discourse. *Journal Information.* 2005;95(7).

26. Balaji AB, Bowles KE, Le BC, Paz-Bailey G, Oster AM. High HIV incidence and prevalence and associated factors among young MSM, 2008. *AIDS.* 2013;27(2):269-278.

27. Hwahng SJ, Nuttbrock L. Sex workers, fem queens, and cross-dressers: Differential marginalizations and HIV vulnerabilities among three ethnocultural male-to-female transgender communities in New York City. *Sexuality Research & Social Policy.* 2007;4(4):36-59.

28. Gates GJ. How Many People are Lesbian, Gay, Bisexual, and Transgender? : The Williams Institute, UCLA School of Law; 2011: http://www3.law.ucla.edu/williamsinstitute/pdf/How-many-people-are-LGBT-Final.pdf. Accessed July 26, 2011.

29. Campaign THR. Transgender Population and Number of Transgender Employees. 2011; http://www.hrc.org/issues/9598.htm. Accessed July 19, 2011.

30. Lombardi E. Enhancing transgender health care. *Am J Public Health.* 2001;91(6):869-872.

31. Lombardi EL, van Servellen G. Correcting Deficiencies in HIV/AIDS Care for Transgendered Individuals. *Journal of the Association of Nurses in AIDS Care.* 2000;11(5):61-69.

32. Kenagy GP. Transgender health: findings from two needs assessment studies in Philadelphia. *Health Soc Work.* 2005;30(1):19-26.

33. Clements-Nolle K, Marx R, Guzman R, Katz M. HIV prevalence, risk behaviors, health care use, and mental health status of transgender persons: implications for public health intervention. *Am J Public Health.* 2001;91(6):915-921.

34. Keatley J, Bockting, W. *What are male-to-female transgender persons' (MtF) HIV prevention needs?* : CAPS & University of Minnesota; September 2008 2008.

35. Lev AI. Disordering gender identity: Gender identity disorder in the DSM-IV-TR. *Journal of Psychology & Human Sexuality.* 2006;17(3-4):35-69.

36. Ogbuokiri JE, Davis IJ. Challenges associated with HIV in transgendered patients. *HIV Clinician.* 2010;22(3):12-15.

37. Lewis A, Nin A. On Being a Gender Maverick: an Exploration of Male Cross Dressing. 2012.

38. Gilbert M. The transgendered philosopher. *International Journal of Transgenderism.* 2000;4(3).

39. Lev AI. *Transgender emergence: Therapeutic guidelines for working with gender-variant people and their families.* Routledge; 2004.

40. Lev AI. Disordering Gender Identity. *Journal of Psychology & Human Sexuality.* 2006;17(3-4):35-69.

41. Coleman E, Bockting W, Botzer M, et al. Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People, Version 7. *International Journal of Transgenderism.* 2012;13(4):165-232.

42. Sevelius JM. Gender affirmation: A framework for conceptualizing risk behavior among transgender women of color. *Sex Roles.* 2012:1-15.

43. Stryker S. Transgender history, homonormativity, and disciplinarity. *Radical History Review.* 2008;2008(100):145-157.

44. Taylor V, Rupp LJ. Chicks with Dicks, Men in Dresses. *Journal of Homosexuality.* 2004;46(3-4):113-133.

45. Doorn CD, Poortinga J, Verschoor AM. Cross-gender identity in transvestites and male transsexuals. *Archives of Sexual Behavior.* 1994;23(2):185-201.

46. Wylie K. ABC of sexual health: Gender related disorders. *BMJ: British Medical Journal.* 2004;329(7466):615.

47. Avant KC, Walker LO. *Strategies for theory construction in nursing.* Prentice hall; 1994.

48. Moynihan C. Theories in health care and research: theories of masculinity. *BMJ: British Medical Journal.* 1998;317(7165):1072.

49. Beyrer C, Baral SD, van Griensven F, et al. Global epidemiology of HIV infection in men who have sex with men. *The Lancet.*380(9839):367-377.

50. Edwards JW, Fisher DG, Reynolds GL. Male-to-female transgender and transsexual clients of HIV service programs in Los Angeles County, California. *Am J Public Health.* 2007;97(6):1030-1033.

51.   Crosby RA, Pitts NL. Caught Between Different Worlds: How Transgendered Women May Be "Forced" Into Risky Sex. *Journal of Sex Research.* 2007;44(1):43-48.

52.   Boles J, Elifson KW. The social organization of transvestite prostitution and AIDS. *Social science & medicine.* 1994;39(1):85-93.

53.   Operario D, Burton J, Underhill K, Sevelius J. Men who have sex with transgender women: Challenges to category-based HIV prevention. *AIDS and behavior.* 2008;12(1):18-26.

54.   Coan DL, Schrager W, Packer T. The Role of Male Sexual Partners in HIV Infection Among Male-to-Female Transgendered Individuals. *International Journal of Transgenderism.* 2005;8(2-3):21-30.

55.   Operario D, Soma T, Underhill K. Sex Work and HIV Status Among Transgender Women: Systematic Review and Meta-Analysis. *JAIDS Journal of Acquired Immune Deficiency Syndromes.* 2008;48(1):97-103 110.1097/QAI.1090b1013e31816e33971.

56.   Reback CJ, Lombardi EL, Simon PA, Frye DM. HIV seroprevalence and risk behaviors among transgendered women who exchange sex in comparison with those who do not. *Journal of Psychology & Human Sexuality.* 2005;17(1-2):5-22.

57.   Sausa LA, Keatley J, Operario D. Perceived risks and benefits of sex work among transgender women of color in San Francisco. *Archives of Sexual Behavior.* 2007;36(6):768-777.

58.   Meyer IH. Why lesbian, gay, bisexual, and transgender public health? *Am J Public Health.* 2001;91(6):856-859.

59.   Farley M, Barkan H. Prostitution, violence, and posttraumatic stress disorder. *Women & Health.* 1998;27(3):37-49.

60.   Lombardi EL, van Servellen G. Building culturally sensitive substance use prevention and treatment programs for transgendered populations. *Journal of Substance Abuse Treatment.* 2000;19(3):291-296.

61.   Kenagy GP. HIV among transgendered people. *AIDS Care.* 2002;14(1):127-134.

62.   Pinto RM, Melendez RM, Spector AY. Male-to-female transgender individuals building social support and capital from within a gender-focused network. *Journal of gay & lesbian social services.* 2008;20(3):203.

63.   Sanchez NF, Sanchez JP, Danoff A. Health care utilization, barriers to care, and hormone usage among male-to-female transgender persons in New York City. *Am J Public Health.* 2009;99(4):713-719.

64.   Melendez RM, Pinto RM. HIV prevention and primary care for transgender women in a community-based clinic. *JANAC: Journal of the Association of Nurses in AIDS Care.* 2009;20(5):387-397.

65.   Rotondi NK, Bauer GR, Scanlon K, Kaay M, Travers R, Travers A. Nonprescribed Hormone Use and Self-Performed Surgeries: "Do-It-Yourself" Transitions in Transgender Communities in Ontario, Canada. *American journal of public health.* 2013;103(10):1830-1836.

66.   Garofalo R, Deleon J, Osmer E, Doll M, Harper GW. Overlooked, misunderstood and at-risk: Exploring the lives and HIV risk of ethnic

minority male-to-female transgender youth. *Journal of Adolescent Health.* 2006;38(3):230-236.

67. Moore E, Wisniewski A, Dobs A. Endocrine treatment of transsexual people: a review of treatment regimens, outcomes, and adverse effects. *Journal of Clinical Endocrinology & Metabolism.* 2003;88(8):3467-3473.

68. Hage JJ, Kanhai RC, Oen AL, van Diest PJ, Karim RB. The devastating outcome of massive subcutaneous injection of highly viscous fluids in male-to-female transsexuals. *Plastic and reconstructive surgery.* 2001;107(3):734-741.

69. Rapaport MJ, Vinnik C, Zarem H. Injectable silicone: cause of facial nodules, cellulitis, ulceration, and migration. *Aesthetic plastic surgery.* 1996;20(3):267-276.

70. Rollins CE, Reiber G, Guinee Jr DG, Lie J. Disseminated lipogranulomas and sudden death from self-administered mineral oil injection. *The American journal of forensic medicine and pathology.* 1997;18(1):100-103.

71. Mueller A, Gooren L. Hormone-related tumors in transsexuals receiving treatment with cross-sex hormones. *European Journal of Endocrinology.* 2008;159(3):197-202.

72. Sevelius JM, Carrico A, Johnson MO. Antiretroviral therapy adherence among transgender women living with HIV. *J Assoc Nurses AIDS Care.* 2010;21(3):256-264.

73. Grossman AH, D'Augelli AR. Transgender Youth. *Journal of Homosexuality.* 2006;51(1):111-128.

74. Bockting WO, Robinson BE, Rosser BRS. Transgender HIV prevention: A qualitative needs assessment. *AIDS Care.* 1998;10(4):505-525.

75. Baumeister RF. *Social psychology and human sexuality: essential readings.* Psychology Pr; 2001.

76. Simon W, Gagnon JH. Sexual scripts: Origins, influences and changes. *Qualitative sociology.* 2003;26(4):491-497.

77. Brickell C. Sexuality and the Dimensions of Power. *Sexuality & Culture.* 2009;13(2):57-74.

78. Simon W, Gagnon JH. Sexual scripts: permanence and change. *Archives of Sexual Behavior.* 1986;15(2):97-120.

79. Diamond LM. What does sexual orientation orient? A biobehavioral model distinguishing romantic love and sexual desire. *Psychological review.* 2003;110(1):173.

80. Unger CA. Care of the transgender patient: the role of the gynecologist. *American Journal of Obstetrics and Gynecology.* (0).

81. Association AP. Guidelines for psychological practice with lesbian, gay, and bisexual clients. *American Psychologist.* 2012;67(1):10-42.

82. Lombardi EL. Integration Within a Transgender Social Network and Its Effect upon Members' Socialand Political Activity. *Journal of Homosexuality.* 1999;37(1):109-126.

83. Pinto RM, Melendez RM, Spector AY. Male-to-Female Transgender Individuals Building Social Support and Capital From Within a Gender-Focused Network. *J Gay Lesbian Soc Serv.* 2008;20(3):203-220.

84.   Chen M-L, Deng S-L, Chang H-K. A comparison of the health locus of control and perceived social support between cancer and AIDS patients. *Scandinavian Journal of Caring Sciences.* 2001;15(1):92-98.

85.   Burns MN, Kamen C, Lehman KA, Beach SRH. Minority Stress and Attributions for Discriminatory Events Predict Social Anxiety in Gay Men. *Cognitive Therapy and Research.* 2012;36(1):25.

86.   Kelleher C. Minority stress and health: Implications for lesbian, gay, bisexual, transgender, and questioning (LGBTQ) young people. *Counselling psychology quarterly.* 2009;22(4):373-379.

87.   Williams ME, Freeman PA. Transgender Health. *Journal of Gay & Lesbian Social Services.* 2007;18(3-4):93-108.

88.   Grant JM, Mottet LA, Tanis J, Harrison J, Herman JL, Keisling M. *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey.* National Gay and Lesbian Task Force and the National Center for Transgender Equality; 2010.

89.   Burns MN, Kamen C, Lehman KA, Beach SRH. Minority Stress and Attributions for Discriminatory Events Predict Social Anxiety in Gay Men. *Cognitive Therapy and Research.*1-11.

90.   Kelleher C. Minority stress and health: Implications for lesbian, gay, bisexual, transgender, and questioning (LGBTQ) young people. 2009.

91.   Mahajan AP, Sayles JN, Patel VA, et al. Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. *AIDS.* 2008;22 Suppl 2:S67-79.

92.   Poteat T, German D, Kerrigan D. Managing uncertainty: A grounded theory of stigma in transgender health care encounters. *Social science & medicine.* 2013.

93.   Schulden JD, Song B, Barros A, et al. Rapid HIV testing in transgender communities by community-based organizations in three cities. *Public Health Rep.* 2008;123 Suppl 3:101-114.

94.   Johnson C. HHS unveils plan to start data collection on LGBT health. *Washington Blade.* June 29, 2011, 2011.

95.   Mayer KH, Bradford JB, Makadon HJ, Stall R, Goldhammer H, Landers S. Sexual and gender minority health: what we know and what needs to be done. *Am J Public Health.* 2008;98(6):989-995.

96.   Office of National A, Policy. *National HIV/AIDS Strategy.* Washington, D.C.: The White House Office of National AIDS Policy;2010.

97.   People H. *Healthy People 2020 Transgender Health Fact Sheet.* November 2010.

98.   Wiessing LG, van Roosmalen MS, Koedijk P, Bieleman B, Houweling H. Silicones, hormones and HIV in transgender street prostitutes. *AIDS.* 1999;13(16):2315-2316.

99.   Herbst JH, Jacobs ED, Finlayson TJ, McKleroy VS, Neumann MS, Crepaz N. Estimating HIV prevalence and risk behaviors of transgender persons in the United States: a systematic review. *AIDS Behav.* 2008;12(1):1-17.

100. Hwahng SJ, Nuttbrock L. Sex Workers, Fem Queens, and Cross-Dressers: Differential Marginalizations and HIV Vulnerabilities Among

Three Ethnocultural Male-to-Female Transgender Communities in New York City. *Sex Res Social Policy.* 2007;4(4):36-59.

101. Prevention CfDCa. HIV among transgender people. [Fact sheet]. 2015; http://www.cdc.gov/hiv/risk/transgender/. Accessed May 25, 2015.

102. Nuttbrock L, Hwahng S, Bockting W, et al. Lifetime risk factors for HIV/STI infections among male-to-female transgender persons. *Journal of acquired immune deficiency syndromes (1999).* 2009;52(3):417.

103. Baral SD, Poteat T, Strömdahl S, Wirtz AL, Guadamuz TE, Beyrer C. Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. *The Lancet infectious diseases.* 2012.

104. Craddock S, Oppong J, Ghosh J. HIV and AIDS in Africa: Beyond Epidemiology. Oxford: Blackwell Publishing; 2004.

105. Epstein S. *Inclusion: The politics of difference in medical research.* University of Chicago Press; 2008.

106. Marshall WE. Aids, race and the limits of science. *Social science & medicine.* 2005;60(11):2515-2525.

107. Roberts S. *Infectious fear: politics, disease, and the health effects of segregation.* UNC Press; 2009.

108. Triechler PA. *How to have theory in an epidemic: Cultural chronicles of AIDS.* Duke University Press; 1999.

109. Boehmer U. Twenty years of public health research: inclusion of lesbian, gay, bisexual, and transgender populations. *Am J Public Health.* 2002;92(7):1125-1130.

110. Medicine Io. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding.* Washington, D.C. March 31, 2011 2011.

111. Keisling M, Pearlman AJ. *Transgender Equality and the Federal Government* Washington, D.C.: National Center for Transgender Equality;2009.

112. Organization WH. Prevention and treatment of HIV and other sexually transmitted infections among men who have sex with men and transgender people:. *Recommendations for a public health approach.* Geneva, Switzerland: WHO Document Production Services; 2011: http://whqlibdoc.who.int/publications/2011/9789241501750_eng.pdf. Accessed July 18, 2011.

113. Krehely J. How to Close the LGBT Health Disparities Gap. 2009; http://www.americanprogress.org/issues/2009/12/lgbt_health_disparities.html.

114. Ogbuokiri JE, Davis I. Challenges associated with HIV in transgendered patients. *HIV Clin.* 2010;22(3):12-15.

115. Prevention CfDCa. *Guidelines for national Human Immunodeficiency Virus case surveillance, including monitoring for human immunodeficiency virus infection and acquired immunodeficiency syndrome.* 1999.

116. Sausa LA, Sevelius, J., Keatley, J., Iñiguez, J. R., & Reyes, M. *Recommendations for Inclusive Data Collection of Trans People in HIV*

Prevention, Care & Services. San Francisco University of California, San Francisco 3/16/2009 2009.

117. Pathela P, Hajat A, Schillinger J, Blank S, Sell R, Mostashari F. Discordance between sexual behavior and self-reported sexual identity: a population-based survey of New York City men. *Annals of Internal Medicine.* 2006;145(6):416-425.

118. Policy OoNA. *National HIV/AIDS Strategy.* Washington, D.C.: The White House Office of National AIDS Policy;2010.

119. Prevention CfDCa. *About the National Health Interview Survey.* Atlanta: Centers for Disease Control and Prevention and National Center for Health Statistics; April 18, 2011 2011.

120. Equality NCfT. *Understanding transgender: Frequently asked questions about transgender people.* Washington, D.C2009.

121. Policy OoNA. *National HIV/AIDS Strategy.* Washington, D.C.2010.

122. Sausa LA, Sevelius, J., Keatley, J., Iñiguez, J. R., & Reyes, M. . *Policy recommendations for inclusive data collection of trans people in HIV prevention, care & services.* San Francisco: Center of Excellence for Transgender HIV Prevention;2009.

123. Bauer GR, Hammond R, Travers R, Kaay M, Hohenadel KM, Boyce M. "I don't think this is theoretical; this is our lives": How erasure impacts health care for transgender people. *Journal of the Association of Nurses in AIDS Care.* 2009;20(5):348-361.

124. Laumann EO. *The social organization of sexuality: Sexual practices in the United States.* University of Chicago Press; 1994.

125. Health NIo. Plans for advancing LGBT health research. 2013; http://www.nih.gov/about/director/01032013_lgbt_plan.htm. Accessed May 25, 2015.

126. Association AP. NIH invites broad range of research on LGBTI health. 2012; http://www.apa.org/science/about/psa/2012/03/lgbti-health.aspx. Accessed May 25, 2015.

127. Services USDoHaH. *Advancing LGBT health and well-being. .* 2014.

128. Services UDoHaH. Enhancing engagement and retention in quality HIVcare for transgender women of color. 2012; http://hab.hrsa.gov/abouthab/special/transgenderwomen.html - a. Accessed May 25, 2015.

129. Nahmias L. State agencies launch LGBT data-collection effort. Capital New York; 2014.

130. LGBTQ Cultural Competency Continuing Education Amendment Act of. 2015. 2015.

131. Eisfeld J, Gunther, S and Shlasko, D. . *The State of Trans* and Intersex Organizing: A case for increased support for growing but under-funded movements for human rights.* New York2013.

132. Pescosolido BA. Beyond rational choice: The social dynamics of how people seek help. *American Journal of Sociology.* 1992:1096-1138.

133. Stiffman AR, Pescosolido B, Cabassa LJ. Building a model to understand youth service access: the gateway provider model. *Mental Health Services Research.* 2004;6(4):189-198.

134. Pescosolido BA, Kronenfeld JJ. Health, illness, and healing in an uncertain era: challenges from and for medical sociology. *Journal of Health and Social Behavior.* 1995:5-33.

135. Pescosolido BA, Gardner CB, Lubell KM. How people get into mental health services: Stories of choice, coercion and" muddling through" from" first-timers". *Social Science & Medicine.* 1998.

136. Pescosolido BA, Boyer CA. How do people come to use mental health services? Current knowledge and changing perspectives. 1999.

137. Pescosolido BA. *Handbook of the Sociology of Health, Illness, and Healing.* Springer Verlag; 2010.

138. Pescosolido BA. Of pride and prejudice: the role of sociology and social networks in integrating the health sciences. *J Health Soc Behav.* 2006;47(3):189-208.

139. Charmaz K. *Constructing grounded theory: A practical guide through qualitative analysis.* Sage Publications Ltd; 2006.

140. Glaser BG, Strauss AL. *The discovery of grounded theory: Strategies for qualitative research.* Aldine Publ.; 1977.

141. Friedman SR, Aral S. Social networks, risk-potential networks, health, and disease. *Journal of Urban Health.* 2001;78(3):411-418.

142. George S, Garth B, Wohl AR, Galvan FH, Garland W, Myers HF. Sources and types of social support that influence engagement in HIV care among Latinos and African Americans. *Journal of health care for the poor and underserved.* 2009;20(4):1012.

143. Campaign THR. *Transgender Population and Number of Transgender Employees.* The Human Rights Campaign;2011.

144. Klovdahl AS, Potterat JJ, Woodhouse DE, Muth JB, Muth SQ, Darrow WW. Social networks and infectious disease: The Colorado Springs study. *Social science & medicine.* 1994;38(1):79-88.

145. Onnela J-P, Arbesman S, González MC, Barabási A-L, Christakis NA. Geographic constraints on social network groups. *PLoS one.* 2011;6(4):e16939.

146. Sugano E, Nemoto T, Operario D. The impact of exposure to transphobia on HIV risk behavior in a sample of transgendered women of color in San Francisco. *AIDS Behav.* 2006;10(2):217-225.

147. T T. Gender and HIV/AIDS. *International Journal of Gynecology & Obstetrics.* 2003;82(3):411-418.

148. Wingood GM, Scd, DiClemente RJ. Application of the theory of gender and power to examine HIV-related exposures, risk factors, and effective interventions for women. *Health Educ Behav.* 2000;27(5):539-565.

149. DiClemente RJ, Crosby RA, Kegler MC. *Emerging theories in health promotion practice and research.* San Francisco, CA: Jossey-Bass; 2009.

150. Ryle R. *Questioning Gender: A Sociological Exploration.* Pine Forge Pr; 2011.

151. Schilt K, Wiswall, M. Before and After: Gender Transitions, Human Capital, and Workplace Experiences. *The B.E. Journal of Economic Analysis & Policy.* 2008;8(1).

152. Sen G, Östlin P, George A. Unequal, unfair, ineffective and inefficient. Gender inequity in health: why it exists and how we can change it. *Final Report to the WHO Commission on Social Determinants of Health.* 2007.

153. Sausa LA, Sevelius, J., Keatley, J., Rouse Iñiguez, J., & Reyes, EM. Policy Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care & Services. 2009; http://www.transhealth.ucsf.edu.

154. Christakis NA. Connected: The surprising power of social networks and how they shape our lives. [Video lecture]. video lecture at Harvard University. Available at: http://christakis.med.harvard.edu/pages/media-talks/video.html. Accessed August 27, 2013, 2013.

155. Mayer K, O'Cleirigh C, Skeer M, et al. Which HIV-infected men who have sex with men in care are engaging in risky sex and acquiring sexually transmitted infections: findings from a Boston community health centre. *Sexually transmitted infections.* 2010;86(1):66-70.

156. Hixson BA, Omer SB, del Rio C, Frew PM. Spatial clustering of HIV prevalence in Atlanta, Georgia and population characteristics associated with case concentrations. *Journal of Urban Health.* 2011;88(1):129-141.

157. Scribner RA, Johnson SA, Cohen DA, Robinson W, Farley TA, Gruenewald P. Geospatial methods for identification of core groups for HIV/AIDS. *Substance use & misuse.* 2008;43(2):203-221.

158. Grant JM, Mottet LA, Tanis J, Herman JL, Harrison J, Keisling M. National Transgender Discrimination Survey Report on health and health care. *National Center for Transgender Equality and National Gay and Lesbian Task Force. Washington, DC.* 2010:1-23.

159. Kenagy GP. HIV among transgendered people. *AIDS Care.* 2002;14(1):127-134.

160. Thornhill L, Klein P. Creating Environments of Care With Transgender Communities. *Journal of the Association of Nurses in AIDS Care.* 2010;21(3):230-239.

161. Sayles JN, Wong MD, Kinsler JJ, Martins D, Cunningham WE. The association of stigma with self-reported access to medical care and antiretroviral therapy adherence in persons living with HIV/AIDS. *J Gen Intern Med.* 2009;24(10):1101-1108.

162. Sayles JN, Wong MD, Martins D, Cunningham WE. The association of stigma with self-reported access to medical care and antiretroviral therapy adherence in persons living with HIV/AIDS. *Journal of General Internal Medicine.* 2009;24(10):1101-1108.

163. Fleishman JA, Fogel B. Coping and depressive symptoms among young people with AIDS. *Health Psychology.* 1994;13(2):156.

164. Craw JA, Gardner LI, Marks G, et al. Brief strengths-based case management promotes entry into HIV medical care: results of the antiretroviral treatment access study-II. *JAIDS Journal of Acquired Immune Deficiency Syndromes.* 2008;47(5):597.

165. Fleishman JA, Hsia DC, Hellinger F. Correlates of medical service utilization among people with HIV infection. *Health Services Research.* 1994;29(5):527.

166. Axelrad JE, Mimiaga MJ, Grasso C, Mayer KH. Trends in the spectrum of engagement in HIV care and subsequent clinical outcomes among men who have sex with men (MSM) at a Boston community health center. *AIDS patient care and STDs.* 2013;27(5):287-296.

167. Samet JH, Freedberg KA, Savetsky JB, Sullivan LM, Stein MD. Understanding delay to medical care for HIV infection: the long-term non-presenter. *AIDS.* 2001;15(1):77-85.

168. Chesney MA, Smith AW. Critical delays in HIV testing and care. *American Behavioral Scientist.* 1999;42(7):1162-1174.

169. Gandhi NR, Skanderson M, Gordon KS, Concato J, Justice AC. Delayed presentation for human immunodeficiency virus (HIV) care among veterans: A problem of access or screening? *Medical care.* 2007;45(11):1105.

170. McCoy SI, Miller WC, MacDonald PD, et al. Barriers and facilitators to HIV testing and linkage to primary care: narratives of people with advanced HIV in the Southeast. *AIDS Care.* 2009;21(10):1313-1320.

171. Prevention CfDC. *CDC Fact Sheet: HIV in the United States: The Stages of Care.* Atlanta: Centers for Disease Control & Prevention;2012.

172. Mugavero MJ, Norton WE, Saag MS. Health care system and policy factors influencing engagement in HIV medical care: piecing together the fragments of a fractured health care delivery system. *Clinical Infectious Diseases.* 2011;52(suppl 2):S238.

173. Ulett KB, Willig JH, Lin HY, et al. The therapeutic implications of timely linkage and early retention in HIV care. *AIDS Patient Care STDS.* 2009;23(1):41-49.

174. Tobias CR, Cunningham W, Cabral HD, et al. Living with HIV but without medical care: Barriers to engagement. *AIDS patient care and STDs.* 2007;21(6):426-434.

175. Rajabiun S, Mallinson RK, McCoy K, et al. "Getting me back on track": The role of outreach interventions in engaging and retaining people living with HIV/AIDS in medical care. *AIDS patient care and STDs.* 2007;21(S1):20-29.

176. Eliason MJ, Dibble S, DeJoseph J. Nursing's silence on lesbian, gay, bisexual, and transgender issues: The need for emancipatory efforts. *Advances in Nursing Science.* 2010;33(3):206-218.

177. Safer J, Pearce E. A simple curriculum content change increased medical student comfort with transgender medicine. *Endocrine Practice.* 2013;19(4):633-637.

178. Dorsen C. An integrative review of nurse attitudes towards lesbian, gay, bisexual, and transgender patients. *CJNR (Canadian Journal of Nursing Research).* 2012;44(3):18-43.

179. Lim F, Levitt N. Lesbian, gay, bisexual, and transgender health. *AJN The American Journal of Nursing.* 2011;111(11):11.

180. Elifson KW, Boles J, Posey E, Sweat M, Darrow W, Elsea W. Male transvestite prostitutes and HIV risk. *American Journal of Public Health.* 1993;83(2):260.

181. Prevention CfDCa. Lesbian, Gay, Bisexual and Transgender Health. 2011; http://www.cdc.gov/lgbthealth/youth.htm. Accessed July 16, 2011.

182. Blanchard R. Nonhomosexual Gender Dysphoria. *The Journal of Sex Research.* 1988;24(ArticleType: research-article / Full publication date: 1988 / Copyright © 1988 Taylor & Francis, Ltd.):188-193.

183. Freidson E. *Profession of medicine: a study of the sociology of applied knowledge.* University of Chicago Press; 1988.

184. Serovich JM. A test of two HIV disclosure theories. *AIDS education and prevention: official publication of the International Society for AIDS Education.* 2001;13(4):355.

185. Maman S, Mbwambo J, Hogan N, Kilonzo G, Sweat M. Women's barriers to HIV-1 testing and disclosure: challenges for HIV-1 voluntary counselling and testing. *AIDS Care.* 2001;13(5):595-603.

186. Samet JH, Retondo MJ, Freedberg KA, Stein MD, Heeren T, Libman H. Factors associated with initiation of primary medical care for HIV-infected persons. *The American journal of medicine.* 1994;97(4):347-353.

187. Samet JH, Freedberg KA, Savetsky JB, Sullivan LM, Stein MD. Understanding delay to medical care for HIV infection: the long-term non-presenter. *AIDS.* 2001;15(1):77.

188. Beer L, Fagan JL, Valverde E, Bertolli J. Health-related beliefs and decisions about accessing HIV medical care among HIV-infected persons who are not receiving care. *AIDS patient care and STDs.* 2009;23(9):785-792.

189. Fagan JL, Bertolli J, McNaghten A. Understanding people who have never received HIV medical care: A population-based approach. *Public Health Reports.* 2010;125(4):520.

190. Zaller ND, Fu JJ, Nunn A, Beckwith CG. Linkage to care for HIV-infected heterosexual men in the United States. *Clinical Infectious Diseases.* 2011;52(suppl 2):S223.

191. Andersen R, Newman JF. Societal and individual determinants of medical care utilization in the United States. *Milbank Quarterly.* 2005;83(4):Online-only-Online-only.

192. Raveis V, Siegel K, Gorey E. Factors associated with HIV-infected women's delay in seeking medical care. *AIDS Care.* 1998;10(5):549-562.

193. RENESES B, MUÑOZ E, LÓPEZ-IBOR JJ. Factors predicting drop-out in community mental health centres. *World Psychiatry.* 2009;8(3):173.

194. Mitchell AJ, Selmes T. Why don't patients attend their appointments? Maintaining engagement with psychiatric services. *Advances in Psychiatric Treatment.* 2007;13(6):423-434.

195. Gardner EM, McLees MP, Steiner JF, del Rio C, Burman WJ. The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection. *Clinical Infectious Diseases.* 2011;52(6):793-800.

196. Klein D, Hurley LB, Merrill D, Quesenberry Jr CP. Review of medical encounters in the 5 years before a diagnosis of HIV-1 infection: implications for early detection. *JAIDS Journal of Acquired Immune Deficiency Syndromes.* 2003;32(2):143-152.

197. Krawczyk CS, Funkhouser E, Kilby JM, Kaslow RA, Bey AK, Vermund SH. Factors associated with delayed initiation of HIV medical care among infected persons attending a southern HIV/AIDS clinic. *Southern medical journal.* 2006;99(5):472.

198. Cunningham WE, Sohler NL, Tobias C, et al. Health services utilization for people with HIV infection: comparison of a population targeted for outreach with the US population in care. *Medical care.* 2006;44(11):1038-1047.

199. Ickovics JR, Forsyth B, Ethier KA, Harris P, Rodin J. Delayed entry into health care for women with HIV disease. *AIDS patient care and STDs.* 1996;10(1):21-24.

200. McPherson M, Smith-Lovin L, Cook JM. Birds of a Feather: Homophily in Social Networks. *Annual Review of Sociology.* 2001;27(ArticleType: research-article / Full publication date: 2001 / Copyright © 2001 Annual Reviews):415-444.

201. Edwards LM. Measuring perceived social support in Mexican American youth: Psychometric properties of the Multidimensional Scale of Perceived Social Support. *Hispanic Journal of Behavioral Sciences.* 2004;26(2):187.

202. Kawachi I, Berkman LF. Social Ties and Mental Health. *Journal of Urban Health: Bulletin of the New York Academy of Medicine.* 2001;78(3):458-467.

203. Berkman LF, Glass T, Brissette I, Seeman TE. From social integration to health: Durkheim in the new millennium. *Social Science & Medicine.* 2000;51(6):843-857.

204. Chen ML, Deng SL, Chang HK. A comparison of the health locus of control and perceived social support between cancer and AIDS patients. *Scandinavian Journal of Caring Sciences.* 2001;15(1):92-98.

205. Anderson SEH. Personality, appraisal, and adaptational outcomes in HIV seropositive men and women. *Research in nursing & health.* 1995;18(4):303-312.

206. Mehta S, Moore RD, Graham NM. Potential factors affecting adherence with HIV therapy. *AIDS.* 1997;11(14):1665-1670.

207. Arnold EA, Bailey MM. Constructing home and family: How the ballroom community supports African American GLBTQ youth in the face of HIV/AIDS. *Journal of gay & lesbian social services.* 2009;21(2):171-188.

208. Hwahng SJ, Nuttbrock L. Sex workers, fem queens, and cross-dressers: Differential marginalizations and HIV vulnerabilities among three ethnocultural male-to-female transgender communities in New York City. *Sexuality Research and Social Policy.* 2007;4(4):36-59.

209. Kawachi I, Berkman LF. Social ties and mental health. *J Urban Health.* 2001;78(3):458-467.

210. Pescosolido BA, Wright ER, Sullivan WP. Communities of care: A theoretical perspective on case management models in mental health. *Advances in Medical Sociology.* 1995;6:37-80.
211. Craw J, Gardner L, Rossman A, et al. Structural factors and best practices in implementing a linkage to HIV care program using the ARTAS model. *BMC Health Services Research.* 2010;10(1):246.
212. Cunningham CO, Sohler NL, Wong MD, et al. Utilization of health care services in hard-to-reach marginalized HIV-infected individuals. *AIDS patient care and STDs.* 2007;21(3):177-186.
213. Mawar N, Saha S, Pandit A, Mahajan U. The third phase of HIV pandemic: social consequences of HIV/AIDS stigma and discrimination and future needs. *The Indian journal of medical research.* 2005;122(6):471-484.
214. Melendez RM, Pinto RM. HIV prevention and primary care for transgender women in a community-based clinic. *Journal of the Association of Nurses in AIDS Care.* 2009;20(5):387-397.
215. Thomas JC, Eng E, Clark M, Robinson J, Blumenthal C. Lay health advisors: sexually transmitted disease prevention through community involvement. *American journal of public health.* 1998;88(8):1252.
216. Blumer H. *Symbolic interactionism: Perspective and method.* University of California Pr; 1986.
217. Jeon YH. The application of grounded theory and symbolic interactionism. *Scandinavian Journal of Caring Sciences.* 2004;18(3):249-256.
218. Benoliel JQ. Grounded theory and nursing knowledge. *Qualitative health research.* 1996;6(3):406-428.
219. Little D. *Varieties of social explanation.* Westview Press Boulder, CO; 1991.
220. Rubin HJR, I.S. *Qualitative Interviewsing: The Art of Hearing Data.* Thousand Oaks: SAGE Publications; 1995.
221. Sandelowski M. Qualitative analysis: what it is and how to begin. *Res Nurs Health.* 1995;18(4):371-375.
222. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health.* 2000;23(4):334-340.
223. Sandelowski M. What's in a name? Qualitative description revisited. *Res Nurs Health.* 2010;33(1):77-84.
224. Pinto RM. USING SOCIAL NETWORK INTERVENTIONS TO IMPROVE MENTALLY ILL CLIENTS'WELL-BEING. *Clinical social work journal.* 2006;34(1):83-100.
225. Bryant A, Charmaz K. *The Sage handbook of grounded theory.* Sage Publications Ltd; 2010.
226. Sandelowski M. The use of quotes in qualitative research. *Res Nurs Health.* 1994;17(6):479-482.
227. Rossman GBR, S.F. Learning in the field: an introduction to qualitative research. Sage Publications; 2003: http://books.google.com/books?hl=en&lr=&id=luFJQwpCoBgC&oi=fnd&pg =PR13&dq=Encouraging+the+use+of+reflexivity+in+the+writing+up+of+q

ualitative+research.&ots=-
OlS0RFCwL&sig=3g_PF9bJL9BidP5KaLo45oROqCU -
v=onepage&q=reflexivity&f=false.

228. McGhee G, Marland GR, Atkinson J. Grounded theory research: literature reviewing and reflexivity. *Journal of Advanced Nursing.* 2007;60(3):334-342.

229. Mays N, Pope C. Qualitative research in health care. Assessing quality in qualitative research. *BMJ.* 2000;320(7226):50-52.

230. Verbs M-HDoAIaP. crash down. n.d.;
http://idioms.thefreedictionary.com/crash+down. Accessed May 25, 2015.

231. American Heritage Dictionary of the English Language FE. shutting out. 2011; http://www.thefreedictionary.com/shutting+out. Accessed May 25, 2015.

232. Unabridged. Dc. dark. n.d.; http://dictionary.reference.com/browse/dark. Accessed May 24, 2015.

233. American Heritage Dictionary of the English Language FE. reconstruction. 2011; http://www.thefreedictionary.com/reconstruction. Accessed May 25, 2015.

234. Herman JL. *Trauma and recovery.* Basic books; 1997.

235. Christopoulos KA, Massey AD, Lopez AM, et al. "Taking a Half Day at a Time:" Patient Perspectives and the HIV Engagement in Care Continuum. *AIDS patient care and STDs.* 2013;27(4):223-230.

236. Sevelius JM, Patouhas E, Keatley JG, Johnson MO. Barriers and facilitators to engagement and retention in care among transgender women living with human immunodeficiency virus. *Annals of Behavioral Medicine.* 2014;47(1):5-16.

237. Catania JA, Turner HA, Choi K-H, Coates TJ. Coping with death anxiety: help-seeking and social support among gay men with various HIV diagnoses. *Aids.* 1992;6(9):999-1006.

238. Weitz R. Uncertainty and the lives of persons with AIDS. *Journal of Health and Social Behavior.* 1989:270-281.

239. Powell-Cope GM. The experiences of gay couples affected by HIV infection. *Qualitative Health Research.* 1995;5(1):36-62.

240. De Santis JP, Florom-Smith A, Vermeesch A, Barroso S, DeLeon DA. Motivation, Management, and Mastery A Theory of Resilience in the Context of HIV Infection. *Journal of the American Psychiatric Nurses Association.* 2013;19(1):36-46.

241. Kübler-Ross E, Kessler D. *On grief and grieving: Finding the meaning of grief through the five stages of loss.* Simon and Schuster; 2014.

242. Folkman S. Personal control and stress and coping processes: a theoretical analysis. *Journal of personality and social psychology.* 1984;46(4):839.

243. Pescosolido BA, Gardner CB, Lubell KM. How people get into mental health services: Stories of choice, coercion and "muddling through" from "first-timers". *Social science & medicine.* 1998;46(2):275-286.

244. Albrecht TL, Adelman MB. *Communicating social support.* Sage Publications, Inc; 1987.

245. Bradford JB, Coleman S, Cunningham W. HIV System Navigation: an emerging model to improve HIV care access. *AIDS patient care and STDs.* 2007;21(S1):S-49-S-58.

246. Wohl DA, Scheyett A, Golin CE, et al. Intensive case management before and after prison release is no more effective than comprehensive pre-release discharge planning in linking HIV-infected prisoners to care: a randomized trial. *AIDS and Behavior.* 2011;15(2):356-364.

247. Kalichman SC, DiMarco M, Austin J, Luke W, DiFonzo K. Stress, social support, and HIV-status disclosure to family and friends among HIV-positive men and women. *Journal of behavioral medicine.* 2003;26(4):315-332.

248. Holt R, Court P, Vedhara K, Nott K, Holmes J, Snow M. The role of disclosure in coping with HIV infection. *AIDS care.* 1998;10(1):49-60.

249. Derlega VJ, Winstead BA, Greene K, Serovich J, Elwood WN. Reasons for HIV disclosure/nondisclosure in close relationships: testing a model of HIV–disclosure decision making. *Journal of Social and Clinical Psychology.* 2004;23(6):747-767.

250. Pecoraro A, Royer-Malvestuto C, Rosenwasser B, et al. Factors contributing to dropping out from and returning to HIV treatment in an inner city primary care HIV clinic in the United States. *AIDS care.* 2013;25(11):1399-1406.

251. Stall R, Friedman M, Catania JA. Interacting epidemics and gay men's health: a theory of syndemic production among urban gay men. *Unequal opportunity: Health disparities affecting gay and bisexual men in the United States.* 2008:251-274.

252. Stall R, Mills TC, Williamson J, et al. Association of co-occurring psychosocial health problems and increased vulnerability to HIV/AIDS among urban men who have sex with men. *American journal of public health.* 2003;93(6):939-942.

253. Stall R, Purcell DW. Intertwining epidemics: a review of research on substance use among men who have sex with men and its connection to the AIDS epidemic. *AIDS and Behavior.* 2000;4(2):181-192.

254. Singer M. Dose of Drugs, a Touch of Violence, a Case of AIDS: Conceptualizing the SAVA Syndemic. *Free Inquiry in Creative Sociology.* 1996;24(2):99-110.

255. Singer MC, Erickson PI, Badiane L, et al. Syndemics, sex and the city: understanding sexually transmitted diseases in social and cultural context. *Social science & medicine.* 2006;63(8):2010-2021.

256. Pescosolido B. THE SOCIOLOGY OF SOCIAL NETWORKS. 2006:208-217.

257. Palepu A, Tyndall MW, Chan K, Wood E, Montaner J, Hogg RS. Initiating highly active antiretroviral therapy and continuity of HIV care: the impact of incarceration and prison release on adherence and HIV treatment outcomes. *Antiviral therapy.* 2004;9(5):713-720.

258. Abagiu AO, Gruia R, Ștefan LF. Brief intervention to strengthen adherence to ART in prison. *BMC Infectious Diseases.* 2014;14(Suppl 4):P13.
259. Small W, Wood E, Betteridge G, Montaner J, Kerr T. The impact of incarceration upon adherence to HIV treatment among HIV-positive injection drug users: a qualitative study. *AIDS care.* 2009;21(6):708-714.
260. Emanuele P. Antiretroviral treatment in correctional facilities. *HIV clinical trials.* 2005;6(1):25-37.
261. Rosen DL, Golin CE, Schoenbach VJ, et al. Availability of and access to medical services among HIV-infected inmates incarcerated in North Carolina county jails. *Journal of health care for the poor and underserved.* 2004;15(3):413-425.
262. Catz SL, Thibodeau L, BlueSpruce J, et al. Prevention needs of HIV-positive men and women awaiting release from prison. *AIDS and Behavior.* 2012;16(1):108-120.
263. Dixon PS, Flanigan TP, DeBuono BA, et al. Infection with the human immunodeficiency virus in prisoners: meeting the health care challenge. *The American journal of medicine.* 1993;95(6):629-635.
264. Centers for Disease Control and Prevention. Understanding the HIV care continuum. 2014.
265. Services USDoHH. HIV care continuum. 2015.
266. Medicine Io. The health of lesbian, gay, bisexual, and transgender people: Building a foundation for better understanding. National Academies Press Washington, DC; 2011.
267. Centers for Disease Control and Prevention. HIV among people aged 50 and older. 2015; http://www.cdc.gov/hiv/risk/age/olderamericans/index.html. Accessed June 7, 2015.
268. Centers for Disease Control and Prevention. Gay and bisexual men's health. 2014; http://www.cdc.gov/msmhealth/STD.htm. Accessed June 7, 2015.
269. Tichy NM, Tushman ML, Fombrun C. Social network analysis for organizations. *Academy of Management Review.* 1979:507-519.

CURRICULUM VITAE

Dana D. Hines

EDUCATION:

Institution	Degree	Date Awarded
DOCTORAL		
Indiana University Purdue University	PhD in Nursing	9/2015
GRADUATE		
Indiana University Purdue University	MSN	12/2006
UNDERGRADUATE		
University of Evansville	BSN	5/1998

LICENSURE, CERTIFICATION, SPECIALTY BOARD STATUS

Credential	Inclusive Dates
Registered Nurse	5/1998-Present

PROFESSIONAL ORGANIZATIONS:

Organization	Role	Inclusive Dates
Academy Health	Member	2014-2015
American Sociological Association	Member	2014-2015
Midwest Nursing Research Society	Member	2012-Present
Black Nurses Association	Local Member	2013-2013
American Public Health Association	Member of Public Health Nursing Section	2008-2012
Association of Nurses in AIDS Care	Member	2010-2014

PROFESSIONAL HONORS AND AWARDS:

SERVICE		
Award Name	**Awarded By**	**Date Awarded**
Quality of Care Award for Leadership	The National Quality Center	9/2010
HIV Medical Association (HIVMA)	HIVMA and the	11/2010

Scholarship Award	Forum for Collaborative HIV Research		
Employee Recognition Award	Marion County Public Health Department	11/2010	
Emily Holmquist Award, presented by the in April 2012.	Indiana University School of Nursing Alumni Association	4/2012	
Diversity Scholars Network	Academy Health	4/2014	

RESEARCH/CREATIVE ACTIVITY:
AWARDED GRANTS/FELLOWSHIPS

Title	Granting Agency	Award Amount	Inclusive Dates
Travel Fellowship	Indiana University School of Nursing	$500	2012-2013
Health Behaviors Research Training Program	NIH-NINR T32 NR07066	$23,480	7/2010-7/2012
F31: Social Patterns and Pathways of Healthcare Utilization among HIV-Positive Transgender Women	National Institute of Nursing Research (NINR), **F31NR013864-01**	$55,048	7/1/2012-7/1/2015
Research Incentive Funds	Indiana University School of Nursing	$10,000	5/2012-5/2013
Research Incentive Funds	Indiana University School of Nursing	$10,000	5/2011-5/2012
Research Incentive Funds	Indiana University School of Nursing	$10,000	5/2010-5/2011

SUBMITTED GRANTS/FELLOWSHIPS

Title	Granting Agency	Award Amount	Inclusive Dates
Social Patterns & Pathways of Healthcare Utilization among HIV-Positive Transgender Women	Sigma Theta Tau International	$5000	6/2013-6/2014

Healthcare Utilization in HIV-Positive Transgender Women	Midwest Nursing Research Society	$2500	3/2013-3/2014

RESEARCH ACTIVITIES
Research Assistant

What I'm told, what I want, and what I do: Examining the meaning of sex and sexual health for black MSM. **Mentor:** Dr. Marlon M. Bailey. Dates: 5/2014-present

Indiana State-wide LGBT Youth and Adult Risk Behavior Surveys. **Mentor:** Dr. Eric Wright. **Dates:** 1/2012-2013.

Salivary Rapid HIV Testing: Health Seeking and Coping in African Americans (AA) (7K01NR10086-01). **Mentor:** Dr. Barbara Habermann. **Outcomes:** Assisted in gender sub-analysis of focus group data and presented preliminary findings at the National HIV Collaborative Forum in Washington, D.C. in 11/2010. **Dates:** 8/2010-12/2010.

The Experiences of Preceptors in Dedicated Education Units in the Public Hospital Environment. **Mentor:** Dr. Joe Burrage. **Outcomes:** Conducted 11 in-depth interviews with nurse preceptors, digitally recorded interviews, and conducted thematic content analysis to identify patterns and meanings. **Dates:** 8/2009-12/2009.

Independent Research

Social Patterns and Pathways of HIV Care among HIV-Positive Transgender Women. **Mentors:** Drs. Barbara Habermann and Eric Wright. **Anticipated outcomes:** A theoretical framework that describes how HIV-positive transgender women seek care and how their social network influences their care decisions. Results will be used to inform development of a nursing and sociological intervention that can be implemented by the community to reduce the delay in seeking care and increase retention in care. **Dates:** January 2014-present.

Using participant evaluation to refine development of a semi-structured interview guide. **Mentor:** Dr. Barbara Habermann. **Outcomes:** The purpose of this study was to pilot-test recruitment and data collection methods in a small sample of transgender women. Findings were used to refine recruitment methods for dissertation research. **Dates:** 5/2011-11/2012.

Barriers and facilitators to HIV testing and treatment in African Americans (AA): Integrative review of literature. **Mentor:** Dr. Joe Burrage. **Outcomes:** Summarized existing literature on determinants of HIV testing, late diagnosis, and delayed treatment and to identify gaps in current prevention methods. **Dates:** 5/2010-5/2011.

TEACHING ACTIVITIES
<u>**Teaching Assistant**</u>

A Multi-System Approach to the Health of the Community, Indiana University, Indianapolis, IN. Assisted with the development of the course syllabus, core assignments, and co-led select lectures. **Dates:** 8/2013-12/2013.

PROFESSIONAL SERVICE:

NATIONAL	Activity	Inclusive Dates
Journal of the Association of Nurses in AIDS Care	Peer-reviewer	May 2012-2013

LOCAL

Organization	Activity	Inclusive Dates
Marion County Public Health Department	Responsible for coordinating the Local Pharmacy Assistance Program (LPAP) advisory board, an interdisciplinary Board that is responsible for monitoring and ensuring timely access to emergency pharmaceuticals, for people living with HIV/AIDS in the Indianapolis Transitional Grant Area.	2014-present
Marion County Public Health Department	Responsible for coordinating the Quality Management Program, which monitors adherence to HIV/AIDS Bureau (HAB) standards of care and patient-level health outcomes.	2010-present
Marion County Public Health Department (MCPHD) and the Indiana State Department of Health	Started a perinatal HIV work group to investigate maternal-child HIV transmission that occurred in a ten-county metropolitan area. This resulted in two major statewide public health initiatives in 2009: the *Fetal/Infant Mortality Review/HIV* and the *One Test, Two Lives Prevent HIV Indiana*.	2009-2010

Marion County Public Health Department	Established relationships between the county jail, the HIV surveillance program, and Minority AIDS Initiative at the MCPHD. This facilitated entry into care for HIV positive inmates.	2008-2009

PROFESSIONAL DEVELOPMENT

Course/Workshop Title	Provider	Inclusive Dates
Mixed Methods in the Social, Behavioral, Health Sciences and STEM Fields	Center for Teaching and Learning (CTL) and Stem Education Research Institute (SERI)	2/26/2014
Shaping Policy for Health	American Public Health Association Directors of Health Promotion and Education	10/29-10/30/2011
Scientific Writing from the Reader's Perspective	Indiana University School of Medicine Dr. George D. Gopen	6/27-28/2011
Biostatistics for Health Care Researchers	Indiana University School of Medicine Division of Biostatistics	5/10-5/11/2011

COMMUNITY SERVICE: LOCAL

Organization	Activity	Inclusive Dates
Nazarene Missionary Baptist Church-Teen Ministry Workshop	Invited speaker: HIV among African American Youth	10/18/2014
Christian Theological Seminary, Butler University	Invited panelist: Spirit and Place: Risky conversation: Faith, HIV/AIDS, and Community.	11/6/2013
Kelley Office of Diversity Initiatives-Kelley School of Business, Indiana University in Bloomington	Invited speaker: Finding Your Passion	9/26/2013

AIDS Resource Group, Evansville, Indiana	Invited keynote speaker Annual Candlelight Ceremony	5/18/2012
Nazarene Missionary Baptist Church-Women's Ministry	Invited speaker: HIV/AIDS in Black Women	9/2011

PUBLICATIONS AND PEER-REVIEWED PRESENTATIONS (former name Cheatem)
Publications

2014   Draucker, C.B., Al-Kattab, H. & **Hines, D.D**. Racial and Ethnic Diversity in Grounded Theory Research. *The Qualitative Report.* Accepted for publication January 2014.

2012   Habermann, B., **Hines, D.D**., Davis, L.L. & Caregiving for Parents with Parkinson's or Alzheimer's: A Qualitative Description. *Clinical Nurse Specialist: The Journal for Advanced Nursing Practice*.

2011   **Hines, D.D**. Using QI principles and concept analysis to refine the role of HIV case management. *Care Management*, Oct/Nov 2011. Accessible via: http://joinaccm.org/Documents/OCT_NOV_11_CM.pdf.

Peer-Reviewed Podium/Paper Presentations

2015   Al-Khattab, H. & **Hines, D.D.** *Racial and ethnic diversity in grounded theory.* Presented at the Qualitative Report 6th Annual Conference on January 10, 2015, Ft. Lauderdale, FL.

2014   **Hines, D.D.,** Habermann, B., & Wright, E. *Experiences of health care utilization among HIV-positive transgender women.* Presented at the 3rd Annual Chicago LGBTQ Health and Wellness Conference. October 10, 2014.

2013   **Hines, D.D.,** Habermann, B., & Wright, E. *How to reach the hidden: strategies for recruiting HIV-positive transgender women.* Presented at the Midwest Nursing Research Society (MNRS) Conference. March 8, 2013, Chicago, IL.

2011   **Hines, D.D.** *Characteristics of transgendered persons who accessed HIV services.* Paper presented at the American Public Health Association Conference. October 31, 2011,Washington, D.C.

2011   Burrage, J.W. and **Hines, D.D**. *Development of gender specific interventions to enhance salivary rapid HIV testing in African Americans.* Paper to be presented at the American Public Health Association conference. November 1, 2011, Washington, D.C.

2011 Miller, M. and **Hines, D.D.** *The Invisible Life: Using peer-led programs to address the   HIV prevention and treatment needs of transgender women.* National LGBTI Health Summit, July 17, 2011, Bloomington, IN.

2010 **Cheatem, D.D.** *Implementing client-level dating reporting at HIV medical and supportive service agencies.* American Public Health Association conference. November 9, 2010, Denver, CO.

2010 **Cheatem, D.D.** *Using concept analysis to define the role of medical case management.* American Public Health Association conference, November 10, 2010 Denver, CO.

2009 **Cheatem, D.D.,** Bryson, L.M. & Buckner, D. *Social Workers: The critical link in HIV/AIDS prevention, treatment, and survival.* National Association of Black Social Workers, Inc., 41st annual conference, April, Louisville, KY.

Poster Presentations

2011 Lincoln, J., **Hines, D**., & Gill, C. (2011). Differences in HIV service utilization patterns   among clients in an HIV services program in the Indianapolis Transitional Grant Area. North American Housing and HIV/AIDS Research Summit. New Orleans, LA, September 21-23, 2011.

2010   Burrage, J., **Cheatem, D**.D., Nyamathi, A., Habermann, B., and Zimet, G. *Barriers and facilitators to salivary rapid HIV testing.* Poster presentation at the National Summit on HIV Diagnosis, Prevention, and Access to Care. November 18, 2010, Washington, D.C.

2009 **Cheatem, D.D**. *Using the PDCA cycle to improve cervical cancer screening at an HIV clinic. Poster presentation at the American Public Health Association conference*, November 8, 2009, Philadelphia, PA.

Concept Paper and Program Development

2009 **Cheatem, D.D**. National Quality Center Fellowship Program: Concept paper presentation to the National Quality Center's National Steering Committee, September 2009, Washington, D.C. Concept paper and program overview accessible via: http://nationalqualitycenter.org/index.cfm/5847/21482.