

**THE EFFECT OF DISCRIMINATION AND STIGMA ON
HEALTH CARE ACCESS: QUALITATIVE RESEARCH
WITH TRANSGENDER TENNESSEANS**

by

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The existing research suggests that discrimination and stigma against transgender individuals plays a large role in many of the barriers to health care access, including geographic location. A few studies suggest that rural LGBT populations experience more discrimination and different barriers to health care, but transgender health care experiences in rural locations have not been the primary focus of any research studies. This study explored the impact that discrimination and stigma has on the ability of rural and urban transgender individuals to access health care. Qualitative research was conducted using focus group discussions with self-identified transgender individuals in the Nashville and Knoxville regions of Tennessee. Four major themes emerged in the analysis of these discussions: (1) transgender individuals feel that health care providers' attitudes and behavior toward them bely a lack of personal respect and believe that their health care is compromised as a result; (2) transition health care is impeded because physicians and health insurance policies do not recognize gender transition as a medical necessity; (3) anti-trans discrimination in both rural and urban communities in Tennessee lead to expectations of similar treatment from health care providers; (4) and participants prioritized the need to increase the number of health care professionals who are well educated on transgender health concerns, as well as the roles of advocacy and social support in facilitating health care access. This study concluded that the medical education system must be improved to adequately

prepare health care providers to provide appropriate health care to transgender patients. Health research is lacking in key areas of transgender health, including the implementation of a medical curriculum that successfully incorporates transgender health care, and there should be more funding opportunities for trans health research. Finally, the attitudes of health care providers can and should be addressed from within the health care profession through community advocacy for transgender patients' rights, and through trans-inclusive anti-discrimination laws that will carry legal consequences for providers who discriminate against transgender patients. The passage of laws such as the Employment Nondiscrimination Act currently sidelined in the Senate should be a priority.

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1.0 INTRODUCTION

What is known about transgender health care access in the United States is sparse and inconsistent. Transgender health research is still in its infancy, and a base is needed on which to build more specific research, and in order to develop relevant and successful health interventions. The significance of improving health care access for marginalized populations such as the transgender population is demonstrated by Healthy People 2010, which has identified the need to intervene in population health disparities and improve health care access¹. Health care access must be considered whenever we devise interventions to alleviate population health disparities² and as such, its study provides a natural base for the field of transgender health research.

Stigma and discrimination against lesbian, gay, bisexual, and transgender (LGBT) individuals are deeply embedded in barriers to health care access, and transgender individuals are even more vulnerable to experiences of stigma and discrimination in health care than other LGB populations¹⁻³. A few studies of LGBT populations suggest that individuals who live in rural areas experience more discrimination and different barriers to health care than those who live in urban locations^{4,5}, but thus far, transgender health care experiences in rural locations have not been the primary focus of any research studies. It is essential to understand how transgender health care experiences are different in geographically distinct locations in order to contextualize

the findings of other transgender health research, as well as devise appropriate interventions for these populations.

This thesis will begin with a brief critical review of the literature and public health theories which are relevant to this study, followed by a description of the research methodology used to explore the relationships between health care access, anti-transgender discrimination and stigma, and geography. Next, four themes which emerged in the course of data analysis will be described, and the conceptual components of health care experiences that connect the findings of this study with the existing literature as well as relevant theories will be explored. Finally, the public health implications of the findings presented in this thesis will be discussed and recommendations will be made for future research and intervention.

2.0 BACKGROUND

The definition of health care access has evolved considerably in the last several decades, from the very basic criteria that individuals possess health insurance, the ability to pay for services, and live where there are health care facilities⁹, to more complex definitions that expand on these factors to acknowledge the impact of social and cultural elements⁹⁻¹². There is still no generally accepted public health definition of health care access, making comparisons between research studies difficult and imprecise.

Among the factors considered to be relevant to health care access are legal rights¹³, possession of health insurance^{8,14}, financial means^{4,14}, travel time and wait time for doctor appointments¹⁰, geography^{15,16}, and the ability to access transportation^{10,12,15}. Social and culturally-influenced factors include appropriate public health education^{17,18} and positive associations with health care providers and the health care system¹⁹⁻²², including trust in providers' knowledge and feeling welcome or comfortable in health care facilities^{5,23,24}. The experiences of minority and marginalized populations demonstrate the correlation between health care access and many of these factors. In the absence of information that is trans-specific, we will draw on what is known about related populations, in order to place factors affecting health care access in an appropriate context^{1,2}.

2.1 THE POPULATION: TRANSGENDER AMERICANS

2.1.1 Transgender: A Public Health Definition

Although the gender identity spectrum can be defined very broadly²⁵, for the purpose of this paper, the term “transgender” will refer to “male-to-female” (MTF) and “female-to-male” (FTM) individuals; that is, persons whose self-identified gender is incongruent with their biological sex. The participants in these studies may or may not be “transsexual,” or have undertaken or intend to undertake medical or surgical options to alter their physical primary sex traits, but they present themselves publically as their self-identified gender, most or all of the time. In the discussion of the existing research literature as well as the current study, an individual whose biological sex is female but who identifies as male will be referred to as transgender female-to-male (FTM). Likewise, male-to-female (MTF) will refer to one whose biological sex is male but who identifies as female. In order to maintain simplicity of language I will use “transgender” throughout this paper as an umbrella term. However, I have no intention of imposing this label on those who reject it, nor do I use it without full awareness that in some cases its use is anachronistic or imprecise. The prefix “trans” is also used to refer generally to subjects relating to transgender individuals or health care.

2.1.2 A Search in the Literature: Transgender Health

To identify relevant information, a search was conducted for peer-reviewed articles using PubMed. Google Scholar was used as well, with minimal success, but search results were less helpful, due to an inability to categorize the search results. As of September 2010, there are

more than 20 million records in PubMed²⁶. The PubMed Medical Subject Heading (MeSH) terms “transsexualism,” (2,302 results) and “health services accessibility” (66,720 results) were the basis of this literature search; however, when paired, these terms produced only 21 results (15 September 2010). A number of key words such as “transgender” and “health care access,” were used to expand the search, which then located other articles that were not categorized using either of the two MeSH terms. A major source of information on all LGBT health research comes from the *Healthy People 2010 Companion Document for LGBT People*². This comprehensive review was compiled by the Gay and Lesbian Medical Association in response to *Healthy People 2010*, which did not present a satisfactory review of the health or health needs of LGBT Americans. The difficulty of finding existing research on this topic is apparent, and this lack of knowledge has a demonstrable effect on practical efforts to address health disparities for transgender populations^{7,27,28}. There are few concrete data to confirm that significant or unique health issues exist for the transgender population.

2.2 TRANSGENDER HEALTH

The majority of what is known about transgender health is clustered around three topics: HIV/AIDS, mental health, and intramuscular use of hormones and subcutaneous use of silicone. Research that considers the specific implications of barriers and facilitators to health care access is scarce, and this deficit is recognized as a limitation by researchers considering other aspects of transgender health²⁹⁻³¹. Researchers have frequently studied mental health concerns in transgender populations, with controversial conclusions that have impacted the field for decades. What is known about the prevalence and incidence of HIV/AIDS and its impact on male-to-

female individuals has evolved from the vigor of the broader, population-based HIV/AIDS research agenda, and the additional risk of contracting HIV/AIDS from shared needles has made hormone access and usage a topic of major concern as well. These are not the only topics of interest or importance to the transgender population but those for which there is enough research available to make some plausible conclusions.

2.2.1 Mental Health

In the early 20th century psychiatrists believed that trans-identified patients suffered from a personality disorder or some other form of mental illness that explained their rejection of their assigned gender³². There is a large body of literature which asserts, disputes, and discusses the implications of trans-identity for mental illness diagnoses³³⁻³⁷. While there are some psychiatrists who persist in the belief that trans-identity is itself a form of mental illness³⁵, today many psychiatrists and trans-advocates reject this notion as misdirected and hurtful to the trans population^{33,37,38}. Instead, common mental health problems such as depression, suicidality, and social mal-adaptation are attributed to unresolved body dysphoria^{39,40} and experiences of social stigma and discrimination based on transphobia^{27,39,41}. It is significant that this changing trend in mental health research rejects transgender identity as a mental illness itself and instead focuses on other mental health indicators as they may be related to a transgender individual's experiences and mental health needs.

A number of factors that contribute to mental illness in transgender individuals were identified in a study that examined gender-based violence and discrimination as predictors of suicide attempts among 515 transgender individuals in San Francisco⁴². This study reported that 60% of participants were depressed, and 32% had attempted suicide, which is consistent with the

prevalence found in other studies^{29,43}. In attempting to identify factors potentially related to suicide attempts, the authors discovered that 28% had been in alcohol or drug treatment, 59% had experienced sexual violence, 62% experienced gender discrimination, 83% experienced verbal gender victimization, and 36% reported physical gender victimization. This was the first study to specifically address suicidality in the transgender population⁴², and there are distinct similarities to LGB individuals who have attempted suicide^{3,7,44,45}. The analogy is superficial, given the paucity of research on transgender mental health in comparison to research on LGB mental health, but common experiences of discrimination, violence, sexual, and physical abuse point to causes of mental health problems that do not directly result from gender identity or sexual orientation^{27,44-47}.

Finally, it is important to note that studies of HIV risk behavior in both MSM and transgender individuals report correlations between HIV risk behavior and depression, suicidality, low self-esteem, and experiences of discrimination and stigma^{27,42,48}. The theory of syndemics has been suggested as a model to explain HIV risk behavior among gay men⁴⁸. This theory provides a framework that describes a set of co-occurring psycho-social health problems that have been shown to result in an additive effect on HIV risk behavior. We can only speculate on the applicability of the syndemics model to transgender HIV risk behavior, but regardless, findings that correlate mental health problems with other health problems such as HIV^{42,43,49,50} highlight the urgency in addressing transgender mental health.

2.2.2 HIV/ AIDS

There is no question that HIV prevalence in the transgender population is disproportionately high, with African American and Latina MTF individuals being the most

affected^{43,51-56}. A recent meta-analysis reports that approximately 27% of MTF participants and 2% of FTM participants tested positive for HIV⁵⁰. By comparison, the HIV prevalence among men who have sex with men (MSM) is approximately 19%⁵⁷ and less than 1% in the general U.S. population⁵⁸.

Echoing what is generally known about HIV prevalence among racial and ethnic minorities, studies found much higher prevalence of HIV infection in MTF African-American⁵⁵ and Latino populations^{55,59} than among Caucasian MTF populations which is 16.7 percent⁵⁰. A meta-analysis found an overall HIV prevalence of 56.3% among study participants who were African-American MTF⁵⁰. Researchers have found the prevalence of HIV among African-Americans to be from 34% among 51 MTF youth⁴⁹ to as high as 81% in a sample of 37 Atlanta MTF sex-workers⁵¹. Studies in San Francisco found HIV prevalence between 44% and 63% in African American MTF individuals^{42,55}. Latina MTF populations also experience disparate rates of HIV infection, with prevalence reported from between 23% and 26%⁵⁹ to 29%^{43,55}.

As is documented in other populations that suffer from high HIV/AIDS prevalence⁶⁰, factors which may be related to the high prevalence of HIV among MTF individuals include experiences of economic and social marginalization^{25,43,61,62}, violence and physical abuse^{62,63}, and mental illness⁴³, in addition to transphobia⁶⁴ and lack of health care for other specifically transgender health needs^{25,50}. Transgender MTF who have multiple sex partners, are intravenous drug users, or who have paying sex partners have an increased risk for contracting HIV^{43,50-52,59}. Individuals who shared needles when injecting gender hormones or silicone were also at increased risk for acquiring HIV^{49,61}. It is through this route that FTM individuals are at the greatest risk of contracting HIV⁴³, although some are also at risk through unprotected receptive anal or vaginal sex with an HIV positive partner⁴³. These studies emphasized the need for HIV

educators to focus on trans-specific prevention activities; however, the lack of research on trans-specific HIV prevention programs^{61,65,66} is a significant barrier to this end.

2.2.3 Hormone Therapy

The World Professional Association of Transgender Health Standards of Care (WPATH SOC) are recommendations that are widely used by some health care providers in many countries to guide their care of transgender patients²⁵. The SOC emphasize that access to gender hormones is an essential element of supportive transition(ed) health care, in order to help individuals “achieve lasting comfort with the gendered self” (pg 1)⁶⁸. That many transgender individuals themselves believe gender hormones to be a necessary element of transitioning is evidenced by the voracity with which these hormones are pursued, through legitimate medical channels and illicit street and internet sources alike^{67,69}. A high number of attendees at a FTM conference in California (110 of 122 total participants) used or planned to use hormones³¹, and FTMs participating in a quality-of-life study who received gender hormone therapy (testosterone) reported better quality of life than FTM who did not³⁰. Two-thirds of 229 MTF and 41% of 121 FTM were taking hormones at the time of a state-wide survey in Virginia, and 48% of MTF and FTM not currently taking hormones planned to do so in the future⁶⁹.

While transgender people in some other countries can rely on affordable, safe, and accessible hormone treatment, this is not the case in the United States³⁰. Transgender individuals have reported accessing hormones outside of a health care provider’s office at rates between 29% and 63%^{2,7,67,69,71,72}. These data identify the use of unregulated hormones, silicone, and other substances as of significant concern for FTM and MTF individuals, because of the increased risk of HIV transmission through the reuse of needles^{7,17,43,54,61,73,74}. In addition, the risks associated

with the long-term effects of using gender hormones and other body-forming substances such as silicone are unknown, putting individuals at risk for future health problems if they do not consult with a physician^{2,7,49,74-76}.

2.3 THE IMPACT OF STIGMA AND DISCRIMINATION ON HEALTH CARE ACCESS

2.3.1 Discrimination in Employment and Health Insurance Policies

The Equal Employment Opportunity Commission enforces federal laws designed to protect individuals from discrimination in employment based on a number of personal characteristics, including sex, age, race, ethnicity, national origin, religion, and disability⁷⁷. In 2009 the Employment Non-Discrimination Act (ENDA) was introduced in Congress, which would have expanded these protections to include both sexual orientation and gender identity. To date, ENDA remains stalled in Congress⁷⁸.

It is extensively documented that transgender individuals have suffered employment discrimination^{7,79}; in a meta-analysis, studies reported that between 15% to 57% of participants had direct experiences of employment discrimination⁸⁰. Discrimination in employment has two significant effects on health care access: lack of access to health insurance, and lack of income for health care expenditures¹. Studies have suggested that 21% to 53% of transgender individuals are uninsured⁷⁹, while the national average is 17.5%⁸¹. Thirty-one percent of 113 MTF and 73% of 69 FTM individuals who were surveyed in Philadelphia reported that they were unable to gain access to at least one health service due to cost; the authors of this study suggested that the lack of basic resources such as income and health insurance impact trans health care

access²⁹. Transgender individuals are more likely to resort to sex work when legitimate modes of income are denied to them and to go to illicit sources for hormones when they cannot afford to have them prescribed by a health care provider^{2,7,67}.

Those transgender individuals who do possess health insurance are better able to address many health needs, but most plans will not cover gender transition surgeries or hormone prescriptions related to patients' transgender status^{25,29,67,69}. Sixty-eight percent of 122 FTM participants who had health insurance reported that their insurance policies excluded or did not fully include medical services for transgender-specific health needs³¹. In addition to the standard health insurance exclusions of trans health needs⁸², some health insurance plans will not cover any medical care at all for an individual who identifies as transgender^{83,84}.

Several transgender individuals had successful suits against private health insurance companies and Medicaid and won coverage for hormone therapy and transition surgeries^{83,84}, but this is uncommon, and these court rulings have not resulted in changes to federal anti-discrimination laws regarding health insurance that would protect all transgender individuals from this form of discrimination⁸³. Some states and cities have trans-inclusive anti-discrimination laws that address health insurance coverage and employment discrimination, but many do not, and to date, no federal laws have specific protection for transgender individuals⁸³.

2.3.2 Discrimination and Stigma Impact Health Care-Seeking Behaviors

Research strongly suggests that culturally-sanctioned discrimination and stigma are at the root of unequal or inaccessible health care for marginalized populations in the United States, including individuals who are HIV-positive^{85,86}, African-Americans⁶, and LGB individuals².

Historically, in many instances health care providers faced no social or legal sanctions if they refused or provided sub-standard services to patients from marginalized populations^{6,87-89}. In response, marginalized populations learn to distrust health care providers and are less likely to seek out health care and to believe that health care providers have their best interests in mind^{6,89,90}. Trans patients may also be skeptical of the health care system because there is little education or research available to inform the practice of health care providers when treating trans patients^{61,67,91}. The documented history of stigma and discrimination as barriers to health care for other marginalized populations^{92,93} suggests that a similar link may be found in the transgender population as well, although much of the literature does not address this population directly.

In *Healthy People 2010* some of the direct and indirect impacts of stigma and discrimination against gay men are identified, although little is said about lesbian women and nothing at all about bisexual or transgender populations. The report recognizes that societal disapproval places a heavy burden on the mental health of gay men, and some of the consequences are mentioned, including substance abuse, depression, and suicide, as well as the association between mental health, high risk sexual behavior and HIV and STI infection¹. Similarly, transgender individuals frequently experience both external and internalized transphobia, and the impact of stigma reaches beyond mental health to affect many other issues related to trans-health and health care access^{25,91,94}. Negative health outcomes arise when experiences of stigma and discrimination implicitly discourage transgender individuals from accessing health care services for fear of further discrimination, and these outcomes have been documented in other LGB populations as well^{2,6,93,95-97}.

Sexual and gender minorities have frequently reported experiences of discrimination in the health care setting, and in some cases report being flatly denied services with direct reference to their sexual orientation or gender identity. One study of more than 800 women reports that lesbian women, who accounted for about 12% of the study sample, were approximately twice as likely as heterosexual women to report general perceptions of prejudice in a health care setting and almost four times more likely to report personal experiences of prejudice⁹³. A research study reported that about one quarter of 182 FTM and MTF Philadelphians surveyed were directly denied medical services because they were transgender²⁹. It is significant to note that not only actual experiences of discrimination but perceived prejudice or discrimination also impact an individual's attitude toward the accessibility of health care services.

A national survey of over 700 gay, bisexual and lesbian physicians and medical students revealed that two-thirds of respondents knew patients who were refused care or received lower-quality care due to their sexual orientation, and nearly half of the respondents knew of heterosexual colleagues who had refused to provide care or provided lower-quality care to patients whose sexual orientation was known to them⁴⁶. In 1999 a survey of medical students found 25% of respondents believed homosexuality to be immoral⁹⁸, results which echoed a 1991 study of 1121 primary care physicians. In that study 35% agreed that they would be uncomfortable around a group of homosexuals, and approximately one-third felt that homosexuality threatened traditional social structures⁹⁹. A meta-analysis showed that between 31% and 89% of providers reacted negatively when a gay or lesbian patient came out to them³. Although these studies may not reflect changes in attitudes during the past decade, they represent some of the most recent research available.

2.3.3 Health Care Providers Lack Knowledge and Resources

Although the field of trans health care is relatively new, most American medical schools do not include trans health issues in their curricula at all or may touch only upon broader LGBT issues in special forums or optional sessions¹⁰⁰. The reported number of educational hours medical students receive encompassing all LGBT health subjects is estimated to be between 2.5 and four hours total for the duration of medical school^{2,47,100}. Medical texts might mention gay men only in the context of HIV/AIDS and no other health issues and frequently do not provide information about other sexual or gender minorities³.

Likewise, only a few studies have evaluated the knowledge of health care providers about transgenderism and trans health needs. A Swedish study of 124 medical and nursing students' knowledge of "LGBT" health issues reported insufficient knowledge across the board for both groups, irrespective of religion or sex, with 66% of participants failing to pass the survey used in this study¹⁰¹. Knowledge of transgender health issues was not reported on separately. A 1986 survey sent to physicians in the United States from a variety of specialties showed that among 202 responses, participants answered factual questions about transsexualism only 64% of the time, with some differences across specialties¹⁰². Similar studies in the United States have not been reported on in recent years.

Discrimination in research funding has stunted independent research on LGB and especially transgender health disparities²⁸. Federally funded national health surveys have almost never included questions relating to sexual orientation or gender identity, in effect denying researchers access to a large cache of population data that is nearly impossible to obtain otherwise, due to the small numbers of LGBT individuals in the population⁷. Lacking research

resources and trans health education, health care providers must frequently rely on their patients for information about transgender health issues^{2,7,103,104}.

Many widely accepted surgical procedures have been developed for MTF and FTM gender confirmation surgery¹⁰⁵, but there is little research that reports on the relative success of these procedures, and standards for surgical procedures and follow-up health care are lacking¹⁰⁶. Knowledge of the long-term effects of FTM and MTF hormone regimens on other health measures are insufficient for health care providers to adequately address the needs of either FTM or MTF populations^{2,107}. The field of transition health care continues to be stifled by lack of funding and lack of perceived legitimacy in the scientific world, fueled by the same stigma that affects transgender individuals themselves²⁸.

2.3.4 Discrimination in Rural Geographic Locations

Only 10% of U.S. physicians serve rural Americans, although 25% of the country's population lives in rural areas¹⁰⁸. Attitudes and behaviors of health care providers toward marginalized populations are particularly important in small or rural communities, as individuals may have few health care options from which to choose^{4,5}. Populations that have multiple minority status, e.g. who are African-American and rural residents¹⁰⁹, or who need mental health services and are rural residents¹¹⁰, have disparate rates of health care utilization. For example, rural residents are less likely than their urban counterparts to seek mental health care, in part due to lack of information and partially out of fear of stigmatization if their mental health needs are exposed to their communities by health care providers¹¹⁰. Likewise, LGBT individuals fear "outing" by providers; similarly, experiences of discrimination and stigma in their community may lead to fears of additional discrimination and stigma from their health care provider as well⁴.

Research in the mental health services-seeking behavior of rural LGBT individuals in New Mexico demonstrates that the challenges to this population intersect at significant points with attitudes of communities, providers, and LGBT individuals as well^{4,5}. LGBT individuals who had sought or used mental health services in rural areas found providers to be uncomfortable, unknowledgeable, or to have a negative judgment associated with their sexual orientation or gender identity⁴. Some were told by providers that they should attempt to suppress their homosexuality or gender non-conformity, or were blamed by providers when they experienced discrimination. Patients responded by deciding not to return to that provider or others, or simply by remaining silent on the topic in the future⁴.

Even well-intentioned providers in the same parts of New Mexico did not have the knowledge or training to help them address LGBT identity as it related to their patients' mental health⁵. Providers emphasized that they treated all of their patients the same; the authors argued that this attitude ignores the mental health impact of stigma and discrimination as well as internalized homophobia and transphobia. Providers discouraged discussion of LGBT-identity in group therapy. Some in-patient services refused to accept LGBT-identified youths, or isolated them out of the belief that they would be harassed by non-LGBT patients, or else to protect the non-LGBT youths from "conversion"⁵.

Rural patients could not simply seek LGBT-friendly services in urban areas because of distance or finances, and LGBT community networks were ill-defined and poor sources of information about local LGBT-friendly providers⁴. When professional services were lacking, participants instead reached out to non-LGBT networks such as family, traditional or religious communities, with mixed results. While many of the American Indian and Hispanic participants found local support from their families, Anglo and urban-to-rural immigrants felt that they had to

remain closeted in order to continue to be accepted in their communities or by religious organizations. A transgender participant experienced extreme stigmatization when she did reveal her gender identity at the Pentecostal church where she sought support after professional mental health services failed her⁴.

The research discussed above represents one of a very few studies that has addressed health care access or health disparities between rural and urban LGBT populations. There are no studies that specifically address health care access for transgender individuals in rural areas, and many of the existing studies represent the experiences of only one or two transgender individuals along with many more LGB individuals^{4,5,111,112}. As with urban and suburban populations, health care access in rural settings is affected by many population characteristics, including race or ethnicity⁴, employment, and possession of health insurance¹. No statistics describe employment and health insurance among transgender individuals in rural locations, but nationally, rural populations in general are under-employed and under-insured, or lack health insurance altogether¹⁰⁸. Health disparities between urban and rural populations are found in other marginalized populations¹⁰⁹, and it is likely that the barriers to health care for transgender individuals are also different based on geographic location.

2.4 RELEVANT PUBLIC HEALTH THEORIES

The literature demonstrates that the barriers to health care access of marginalized American populations are often due to the effects of discrimination, and the current study seeks

to provide further evidence that the transgender population is similarly affected. However it is not sufficient to demonstrate that discrimination creates barriers to health care access for the transgender population; we must also understand why these barriers exist and how they are built, as our ultimate goal is to dismantle them. As the literature demonstrates, there are several levels of influence on which discrimination impacts health care access, the Behavioral Ecological Model¹¹³ is useful in exploring how and why these factors are influential. Furthermore, we have found that health care providers and individuals seeking health care are affected in their attitudes by many outside forces including societal and community attitudes. The theory of Minority Stress^{45,90} holds that sexual and gender minority populations experience continuous stress from encountering stigmatization and discrimination in multiple aspects of their lives, with the result that individuals have low self-esteem and self-efficacy, which affects their health behaviors and health outcomes. The theory of Statistical Discrimination^{87,88} posits that conscious and subconscious attitudes held by health care providers toward their patients affect their ability to accurately assess and understand their patients' health status, and may provide insight into how knowledge and understanding of transgenderism influences provider attitudes toward transgender patients.

2.4.1 Behavioral Ecological Model

The Behavioral Ecological Model suggests layers of influence which interact with and impact the individual, and which in turn are impacted by the individual¹¹³. Each level of influence is defined by several factors. *Intrapersonal factors* are the knowledge, abilities, and attitudes of an individual. This level influences, and is influenced by other levels both directly

and through the interactions of other levels, which involve *interpersonal factors*, *institutional factors*, *community factors*, and *public policy factors*.

With respect to this paper's topic, an individual's drive and ability to self-advocate are affected by *intrapersonal* factors; for example, individuals who feel badly about their transgenderism or do not believe they can affect their access to health care are unlikely to try. The most direct effect on these *intrapersonal* factors are *interpersonal* factors such as disapproval from family or others close to the individual. Parents may have been influenced at the *community* level to reject a child's transgenderism if they belong to a congregation that insists on traditionally strict gender roles. A local hospital might enforce *institutional* policies which categorically deny trans health care, either out of shared beliefs or in order to avoid antagonizing an influential *community* power. Self-efficacy, an *intrapersonal* factor, may be directly affected when an individual seeking trans health care at this hospital is rejected, based on the *institutional* policy. Finally, *public policy* comes into play when considering the rights of the individual. For example, because the courts have upheld laws excluding transgender individuals from protection against discrimination, there is no legal incentive for health insurance companies to add transgender health care to their services. On the other hand community that accepts diverse gender expression and identity may have *individual* and *community* resources that influence health care providers to accept transgender patients, thus mitigating contradictory *community* and *institutional* influences.

2.4.2 Minority Stress Theory

Meyer has posited the concept of "minority stress" to explain the connection between societal discrimination based on one's minority status and negative mental health outcomes^{44,45}.

A study of over 700 gay men in New York City found that minority stress affected participants in three key ways: internalized homophobia and low self-worth; fear of discrimination or stigma based on prior experience or peer-reported; and actual experiences of discrimination and stigma⁴⁴. These factors caused additional strain on individuals that impacted their ability to have positive social interactions with other people and in group settings and was indicative of the higher levels of mental distress, which Meyer concluded were associated with “minority stress.” Simply put, the response of society to an individual’s minority status has a profound impact on his or her self-perception and affects not only the value assigned to the individual by society but also that individual’s self-worth or value⁴⁴.

Meyer built upon this work to explain the connection between disparities in access to and use of health care services among minority populations. Research among other disenfranchised populations suggests that individuals with low self-worth are at increased risk of engaging in behaviors associated with negative health outcomes⁴⁵. Therefore it is not surprising that LGBT individuals in particular are likely to neglect their health or engage in high risk behaviors such as avoiding necessary health care services⁴⁵. Transgender individuals may not seek out regular or urgent health care, not only out of fear of discrimination by their health care providers but because they have internalized society’s transphobia.

2.4.3 Statistical Discrimination

The theory of “statistical discrimination” has been proposed as a way to explain how the broad historical context of discrimination within our society can lead to specific disparities in the treatment of marginalized populations by health care providers^{87,88}. Balsa suggests that health care providers are less likely to understand their minority patients’ reported symptoms, leading to

less rigorous treatment and therefore poorer outcomes for those patients. The by-product of a society in which there is pervasive discrimination of a specific population may be that a health care provider hears or sees a minority patient through a filter which is skewed by the societal perception with which the provider was reared. The health care provider may in fact have no conscious intention to treat marginalized patients differently than he or she treats other patients, but the life-long influences of witnessing common societal discrimination may embed biases in a health care provider that she or he does not recognize.

For example, Balsa suggests that a Latina woman who speaks English as a second language may be perceived as less credible to her white male physician when reporting symptoms which he would take seriously if reported by a white male patient who speaks English as a first language⁸⁷. Miscommunication occurs when the physician and patient do not understand the other's cultural norms, such as language, accent, or other culturally-influenced aspects of communication, such as body language or tone of voice. Balsa suggests that Caucasian health care providers with African American or Latino patients are likely to treat them differently than their Caucasian patients, based largely on socially engrained stereotypes of these populations. It may be assumed that symptoms presented by a minority patient are not as severe as the patient indicates, or that minority patient compliance with treatment regimens will be poor, and therefore not worth the provider's effort.

The result of these often subconscious assumptions is two-fold: providers treat minority patients differently than non-minority patients, and minority patients perceive that providers do not respect them and treat them differently. In response, minority populations have developed a resistance to seeking health care, mistrust of specific diagnoses and treatments as well as general suspicion and resentment of the health care system^{87, 88}. Therefore both physician and patient do

the patient a disservice, the former not recognizing personal biases and the latter not knowing how to address those biases, or giving up in frustration.

Societal discrimination is relevant to health care access insofar as it may influence health care providers to deny transgender patients the same quality of services as their other patients. Exposure to discrimination in settings outside of health care may predispose transgender patients to be afraid of encountering health care providers with attitudes of discrimination that are similar to those the individual has encountered at school, at home, or in relation to legal and civil protections. This theory may help to explain why such situations are particularly difficult to address from the perspective of public health interventions, given the impact of the greater cultural or societal factors on the behavior of both patient and health care provider.

2.5 GAPS IN THE LITERATURE

The numerous gaps in the literature addressed in this section are an indication that the stigma and discrimination that transgender individuals experience affect transgender health research as well. The lack of funding and support from research institutions as well as a lack of interest from researchers demonstrate the difficulties in this field of study^{2,7,28}. The following is a laundry list of subjects that should be further pursued in order to gain a fuller understanding of the health of transgender individuals and implement practices that narrow the disparities in health between transgender Americans and the general population. The gaps in the literature fall into several categories, some of which include: demographics, specific trans health issues, intervention, and discrimination.

Some studies have shown that transgender individuals who are also from minority racial or ethnic populations suffer more severely from some health concerns, such as HIV, than their Caucasian counter-parts, but more research is needed to understand why these health disparities affect these populations. Other demographic characteristics of the transgender population that bear further consideration include geographic distribution between urban and rural locations as well as different cultural regions of the U.S, and levels of and access to education and employment as well as socio-economic status, including possession of health insurance.

Researchers should focus on a variety of issues relating to transitional health, as well as other aspects of health. Little is known about the health and wellbeing of transgender youth, including the implications and advantages of beginning gender hormone therapy before puberty⁷, and the unique issues that may face transgender elders also remain largely unaddressed⁴⁷. The long-term implication of gender hormone use for both MTF and FTM populations is understudied, as well as the potential for negative interactions with other medicines including HIV drugs. HIV has been studied in relation to some MTF populations, but its impact on the FTM population has not yet been explored, although the reported incidence for that population is significantly higher than that of the general population⁵⁰. Mental health, substance abuse, anti-trans violence, childhood sexual abuse, and intimate partner violence are all important but their impact on transgender individuals is little understood.

Some important research studies have explored ways of presenting successful HIV prevention and educational interventions to MTF individuals⁶⁶, but research addressing interventions for different health issues and populations of transgender individuals is lacking. Sexual health education should be tailored to individuals of various gender identities as well as to the sex of their partners, including FTM individuals who have sex with men, FTM individuals

who have sex with women, MTF individuals who have sex with men and those who have sex with women, as well as FTM and MTF individuals who have sex with other FTM and MTF individuals. Suicide prevention, anti-violence and anti-bullying interventions are lacking as well, although in recent years, LGBT bullying among students has made headlines, and public health research has begun to respond to social concern¹¹⁴. Location, culture, and age are all factors that have been under-studied in relation to developing relevant interventions for transgender health issues.

Finally, there is sparse research on the incorporation of transgender health into medical school curricula and professional education for other health care professions. The number of medical schools and other educational and professional programs that currently have transgender health content included in their curricula is unknown, nor have researchers evaluated the existing transgender health content in health care provider education, including non-medical care such as mental health therapy.

3.0 METHODOLOGY

This descriptive study was used to explore the impact on health care access that discrimination and stigma has on transgender individuals, and to examine the differences in health care access experiences reported by transgender individuals living in rural and urban Tennessee. To this end, a study was proposed which included asking transgender Tennesseans about health care access in 6-10 focus group discussions and an unspecified number of individual in-person and telephone interviews. The focus group discussions and interviews would take place in up to five regions of Tennessee where the author and a note-taker would travel by car, in or around the major towns or cities in those regions: Nashville (central), Memphis (south-west), Chattanooga (south-east), Knoxville (eastern-central), and Johnson City/tri-cities region (north-east). The author had previously-established relationships with two of the organizations from which participants were recruited and both were asked to provide further references for organizations from which to recruit participants. Key community members in each region were consulted about where to hold each focus group discussion, in order to ensure the maximum comfort and safety of the participants. Due to the extreme vulnerability of the population involved, the study was designed with multiple safeguards for the safety and anonymity of participants, which are detailed below. Data collection was conducted from March 2-17, 2010. This qualitative research design was approved by the University of Pittsburgh Institutional Review Board (IRB) (See Appendix B.)

3.1 SAMPLING

The eligibility criteria for this study were originally designed as follows: individuals who self-identify as transgender and who live publicly at least part-time in that self-identified gender (male-to-female, female-to-male), are at least aged 18 years or older, and are currently living in the state of Tennessee. Participants must also be able to attend one of the focus group discussions.

During focus group discussions in Chattanooga, Memphis, and Nashville, several participants indicated that they actually lived in another state, although they were connected with the Tennessee-based social support groups. Because these individuals' primary support networks and in some cases health care providers came out of their connection with these social support groups, and because the author did not want to alienate other participants by seeming to exclude some, these individuals were allowed to participate in the focus group discussions.

Some of the non-transgender partners of transgender participants attended the focus group discussions in Knoxville and Nashville. Again, out of concern that excluding these individuals would make their partners less willing to participate, the author chose instead to include these individuals. Due to the specifications of the IRB approval, the author asked the non-transgender partners to allow transgender participants to be the main speakers but invited partners to speak with her further after the focus group discussion or contact the author via phone or email if they had particular experiences or opinions they wanted to express. As none opted to contact the author after the focus group discussions, no further action was taken with the IRB.

3.2 RECRUITMENT

Recruitment was conducted in two stages. In the first stage, the author contacted two LGBT and transgender advocacy groups in Tennessee with whom she had existing connections: Tennessee Equality Project (TEP) and Tennessee Transgender Political Coalition (TTPC). Through contacts at these organizations the author was ultimately able to connect with four other transgender social support groups around the state, all of which agreed to disseminate recruitment information to their membership lists. Some individuals heard about the study directly from TEP or TTPC. However, key informants within these communities strongly recommended that the author contact local social support groups as well, in order to maximize participation in areas that were not well-connected with the state-wide organizations, by virtue of distance or other reasons.

TEP is a state-wide LGBT advocacy group based in Nashville. Participants were recruited through this organization in three ways: two emails with the recruitment notice were sent to the TEP list-serve; recruitment information was posted on the TEP website; and the author appeared in person at an annual event in Nashville to recruit participants. At this event, “Advancing Equality on the Hill Day” (AE Day), the president of TEP introduced the author at the two information sessions preceding the main event and invited her to speak briefly about the study and recruit participants. (AE Day is an annual lobbying day when LGBT people from across the state convene in Nashville and meet with state legislators about relevant legislation.)

TTPC is a state-wide transgender political lobbying and advocacy group based in Nashville. TTPC also sent the recruitment notice to its list-serve. Additionally, its president, Marisa Richmond, is a friend and mentor to the author, and she was the source of contact

information and personal introductions to the facilitators of several other transgender social support groups around the state.

Transgender social support groups in four regions of Tennessee publicized the study recruitment notice to their memberships via email. Two groups (Chattanooga Transcenders and Knoxville Boyz and Girlz) contacted the author after receiving the recruitment email from TEP or TTPC or both organizations. The author had previously emailed with the co-facilitators of the T-Vals and T-Men (Nashville) and she also met representatives of the Nashville group and the Memphis group (Perpetual Transitions) at AE Day.

3.3 FOCUS GROUP DISCUSSIONS

The focus group was chosen as the primary research tool for this study. The author had previously been trained in this method by Dr. Martha Ann Terry at the University of Pittsburgh Graduate School of Public Health. Focus group discussions were the optimal choice to obtain a significant amount of data, given that time and funding were limited. The focus group format also allows for group dynamics to be observed and used to encourage participation, as well as providing a measure of protection for individuals who might otherwise be wary of sharing intimate details of their lives one-on-one with a stranger.

Two focus group discussions of the six total conducted were chosen for analysis for practical reasons. Three of the focus group discussions had only three or four participants, and were therefore not ideal for analysis. Of the remaining three, two were conducted in Nashville and one in Knoxville. In order to describe the diverse experiences of individuals across the state

of Tennessee, focus groups from different cities were chosen. As time was also limited, the first Nashville focus group discussion to be transcribed was used in this analysis.

3.4 TRANSCRIPTION

All discussions were audio-recorded, and audio files were transcribed into Microsoft Office Word© documents by two transcribers. As per IRB requirements, participants were invited to use a pseudonym during the focus group discussions, and personal identifiers were removed during transcription to protect participants' identity. Transcribers were required to create passwords for audio and document files as well as for the computers used for transcription, and when the transcription was complete, they destroyed or returned the audio cd provided by the author. As an added precaution for participants who chose to use their real names, the author substituted pseudonyms for all names of individuals in the transcriptions. The names of towns where participants lived were removed from the transcripts; however, the names of the major towns and cities used as reference points in conversation were preserved, in order to give a fuller description of the regions of Tennessee where this research was based. All audio and document files were saved under password by the author, and audio recordings will be destroyed when research on these data is completed, as per IRB requirements.

3.5 ANALYSIS

Data from this research study were largely analyzed using constructivist grounded theory¹¹⁶ as well as thematic analysis to examine the transcripts and recordings from two focus group discussions conducted in Nashville and Knoxville. Continuous coding of the focus group discussions allowed the author to identify recurrent themes in the data while simultaneously suggesting theoretical ties among attitudes and experiences, recurrent themes, and other theoretical constructs. Thematic analysis was also utilized as a tool to organize and explain connections and distinctions among the emerging codes¹¹⁵. These two analytic methods guided the author in formulating a theoretic framework with which to understand the significance of the focus group discussion results.

Constructivist grounded theory is a contemporary modification of the original grounded theory, which instructs the researcher in inductive methods of qualitative data collection and analysis¹¹⁶. Classical grounded theory is characterized by simultaneous data collection and analysis, comparison of raw data, codes, and early categorization, and multiple layers of analytic writing throughout the process, leading eventually to theory development. Constructivist grounded theory builds on these principles to further recognize that the researcher must take a non-linear approach to the research process, and also be self-aware of the impact of the research process. As such, the researcher is cautioned to recognize that the research is never conducted without an impact on the research participants, that the researcher must be cognizant of the personal biases one brings to the data collection and analysis, and that the truths which are stated or that emerge from the research process are themselves subjective¹¹⁶. This reflexive, self-aware process allowed the author to engage the influence of the setting under which this research was necessarily conducted in the analysis of the data.

Thematic analysis facilitated identifying and analyzing themes within the data and presenting these findings while “minimally organizing” and thereby preserving the richness of the data¹¹⁵. The process of thematic analysis is also cautious to recognize the role of the researcher in identifying and deciding which “emerging themes” to emphasize, which is in essential agreement with the self-awareness that is found in constructivist grounded theory, if the two methods are to be co-influences within a research study.

The transcripts of each of the two focus group discussion were read at least twice by the author, followed by an initial coding during the third reading, after which the codes from each transcript were methodologically compared with the codes identified in the other transcript of the focus group discussions. Codes were organized into the categories that subsequently formed the thematic basis of this analysis. The grounded theory practices of memo-writing and theoretical sampling¹¹⁶ were used simultaneously to check the validity of nascent theories with and against the coded transcripts and resulted in the discussion and conclusions which follow.

4.0 RESULTS

The original goals of this research study were to examine the barriers and facilitators to health care access for transgender Tennesseans and to compare the experiences of participants who lived in rural and urban areas of the state, as identified by residential zip code. However, of the nine participants for whom demographic information was collected, only one lived in a zip code that was classified as rural, making a true urban/rural comparison impossible. Therefore, the analysis of the relationship between health care and geographic locations in the focus group discussions shifted to examining participants' attitudes about health care access in rural and urban areas, and it became evident that these attitudes were very much interconnected with the other themes that emerged from the analysis of the barriers and facilitators to health care access for this population.

4.1 RESEARCH CHARACTERISTICS

4.1.1 Focus Group Discussions

Three of the four social support groups (Knoxville, Nashville, and Memphis) hosted a focus group discussion during their regular monthly meeting time, and a member of the Chattanooga group arranged for the author to conduct a focus group discussion at the Metropolitan

Community Church (MCC) of Chattanooga, in addition to inviting her to observe the Chattanooga Transcenders' regular meeting, which was later the same day.

Because safety and comfort were crucial for participants, the author asked the local social support groups for assistance in finding a safe location, and the existing monthly meeting times and places of these groups were offered by their group facilitators. The focus group discussions were conducted at unpublicized locations already known to the participants and were arranged during regular monthly meeting hours when participants were likely to be available. As the author was unknown to the social support-group facilitators in two of the four cities where focus group discussions were held (Chattanooga and Knoxville), she was vetted by a group member ahead of time and interviewed to determine if she could be trusted with the meeting location, at which point she was led to or given directions to the meeting. Participants who were not already group members were vetted separately in a similar manner before being given the group meeting location.

The focus group discussion in Knoxville had 6 participants and lasted approximately two hours. There were nine participants in the Nashville focus group discussion, which lasted approximately one hour and forty-four minutes, with a five minute break after one hour. Refreshments were provided and small incentives of chocolate gift packages were given to participants at the end of each focus group discussion. Focus group discussions were recorded using a digital recorder and transcribed at a later date. Although a note-taker was originally enlisted for the duration of the study, she had a death in the family on the morning she arrived in Tennessee and had to excuse herself from the study.

At the end of the focus group discussions participants were asked to fill out a brief (five question), anonymous, demographic survey, but participation was voluntary. Participants were

invited to leave an email address or phone number if they wanted to remain in touch with the author, or hear about her progress on her thesis, and many of the participants chose to do so.

4.1.2 Focus Group Participants

What follows are the results of two of the six focus group discussions conducted during the data collection-phase of this research. For the purposes of this thesis two focus group discussions, one in Knoxville and one Nashville, were analyzed.¹ All but one individual in each group completed the brief survey handed out at the end of each focus group discussion.² Participants were also asked to describe their gender identity during focus group introductions. The Knoxville session had six participants in total. Five participants self-identified as transgender and one self-identified as the partner of a transgender individual. In Nashville, there were five transgender participants and four partners of the transgender participants.³ Overall, seven individuals identified themselves as Male or Male/Trans, two identified as Female or MTF, and one identified as “both/ mostly female.” All four partners of transgender participants identified as female.

All participants in both groups identified as white or Caucasian, with one participant in Knoxville identifying as white and Native American. Participants in Nashville were younger than the Knoxville participants, with five of the six participants between 19-32, and one participant who was 72. Participants in Knoxville were more homogenous in age, which ranged

¹ Three focus group discussions were conducted in Nashville, and the third of these is analyzed in this paper. This focus group discussion was conducted on 13 March 2010, and was the second of two sessions that day. Only one focus group was conducted in Knoxville.

² In order to safeguard participants’ anonymity some demographics will be reported on for the whole sample, rather than identified by the city where each focus group discussion was held.

³ Only transgender participants and not their partners were asked to fill out questionnaires.

from 44-49. Although one of the aims of this study was to compare the differences in health care access between residents of urban and rural areas, an analysis of zip codes revealed that only one individual in Knoxville and none in Nashville lived in a rural area; however, several more participants described their towns as rural, or “country.”

All participants had finished high school or had a GED, and all but one had at least two years of college. At least one participant in Knoxville had a graduate level education.⁴ One participant in this study was a retired teacher and minister, and two were students. Jobs held by the other participants included law enforcement, pizza delivery, hospitality, home inspection, truck driving, veterinary technician, and sales management.

4.2 EMERGING THEMES

The most pressing concerns expressed by this population differed little on gender, age or stage of transition. There were marked similarities in the language used by participants: “freak,” “alien,” “it,” “catching,” “they don’t understand,” “medical necessity,” were used to describe how participants thought they were seen by health care providers and why they were unable to get the health care they sought. Often stories were echoed by others within and across these two focus group discussions. Four over-arching themes are described in the following sections: Two broadly defined themes emerged, under which belong many of the attitudes and experiences with health care access that were expressed by participants: (1) *Characterization of Gender Identity in Patient-Provider Interactions*; (2) *Legitimizing Transition Medicine to Health Care Providers*

⁴ Participants’ answers were free-form, and two others were not clear about their level of education.

and Health Insurance Companies; (3) “Rednecks” and “Country Folk:” Perceptions of Attitudes in Town, and Participants’ Attitudes Toward Town; and (4) Facilitators to Trans Health Care and Prioritizing Future Needs.

Characterization of Gender Identity in Patient-Provider Interactions is an exploration of the different ways in which participants felt that their gender identity was not respected by health care providers. Participants were unhappy that providers sometimes refused to use their self-identified names and gender pronouns, and felt that providers exhibited their discomfort with transgender individuals by their physical interaction with them. In addition to avoiding further stigmatizing experiences in health care settings, participants were reluctant to return or seek health care because they did not feel that they were given appropriate and adequate care by providers who were more concerned with their gender identity than the health problem with which they were presented.

Participants discussed the frustration they felt at defending their need for health care in the following section: *Legitimizing Transition Medicine to Health Care Providers and Health Insurance Companies*. They explained that their attempts to get health care were sometimes thwarted by providers who did not believe that there was a need for the transition-related health care they sought, and sometimes by health insurance policies that did not consider trans health care medically necessary, and therefore would not cover prescription hormones, or surgery.

“Rednecks” and “Country Folk:” Perceptions of Attitudes in Town, and Participants’ Attitudes Toward Town is a discussion of the notable characteristics of the areas where participants live and their interactions with people in these towns, as these relate to their gender-presentation or gender-identity. Some participants described family or other support systems that were helpful in navigating the health care system, and some discuss the difficulty posed by

Tennessee state laws that ban the reversal of legal gender status. Participants identified the colloquially identified “redneck” or “good old boys” as the major threat to acceptance in their communities, and several describe leaving smaller communities for larger, more liberal towns and cities.

The final theme discussed in this section is *Facilitators to Trans Health Care and Prioritizing Future Needs*. Participants report that among these are community ties such as the transgender social support groups with which the author partnered for this research, and working individually with health care providers and others to create acceptance and foster understanding and education about transgenderism.

4.2.1 Characterization of Gender Identity in Patient-Provider Interactions

Several of the complex issues affecting participants’ health care access discussed in this section are introduced in the following story. A young male-identified participant, Toby, described an emergency room visit for acute costochondritis, a breathing condition that is common among trans-men who bind their chests. Toby had a frustrating exchange with the intake nurse when he gave his name, and when he was moved to triage, found that he was still identified as female to the emergency room personnel:

And of course I’m sitting here talking as low as I possibly can to the receptionist... And I have a full male name. And then she’s like, can I have your Social security Number. I’m like “crap.” And I’ve of course been there before as a child and have my birth name still on record so I give her that. And then she’s like, “Oh, but this says So and So.” And I’m like, “Yeah, I had my name legally changed.” And they were like...OK... I get back there and they strap me with this bracelet that says a big bright F. And I’m like, great (Toby)⁵.

⁵ Most quotations from the transcripts are attributed to an individual; however, sometimes it was difficult to identify the speaker from the audio files, and these quotations do not have an attribution.

Participants echoed Toby's frustration that health care providers did not recognize the negative impact of using the wrong name or gender pronoun. They emphasized that being "outed" in the midst of a health crisis both exacerbated their embarrassment or anger at feeling the need to defend their gender identity, and increased their discomfort in seeking health care. Furthermore, there was consensus that health care providers appeared to be uncomfortable touching them, because of their gender non-conforming appearance.

...the Triage nurse treated me like I was some sort of alien. She didn't want to touch me... Basically they just didn't want to do anything about it. ...They were like "Do you possibly do strenuous things to your chest?" You know, I didn't want to tell them I bind.

[Interviewer: So you didn't feel comfortable sharing...]

No, not in that. The doctor, when he touched my chest, it was kinda like he was afraid he'd get a disease. I was just like, "I'm not gonna rub off. You're not gonna get gay from touching me. Come on, just figure out what's wrong with me. Come on, just figure out what's wrong with me (Toby).

(3) Finally, participants reported that their medical care was denied or slowed by confused health care providers and support staff when a perceived gender incongruity was revealed, and that negative experiences with health care providers discouraged them from seeking future services.

It was a hassle. Ever since then, I do not want to go back to that hospital. I would rather go to [name of hospital] Medical, 30-40 minutes away, just to see a doctor" (Toby).

Participants emphasized that whether intentional or unintentional, the behavior and language of health care providers still had the ability to affect the feelings and behaviors of the patients at whom it was directed, including discouraging them to seek health care in the future. These three themes are described in further detail in the sections that follow.

4.2.1.1 The significance of names, pronouns, and gender markers

She, he, it. Whatever (Justin).

Participants stressed that beyond the usual discomforts associated with needing health care, the anticipation of having to explain their gender identity or tolerate health care providers who refused to recognize their chosen (and often legally changed) names has a significant impact on their decision to seek care. Justin described an occasion when he sought emergency medical attention for shortness of breath at a hospital that he and his girlfriend chose because it had a reputation of being “gay friendly”:

I had been there three years prior so my old name popped up... I’m sitting there gasping. My girlfriend proceeds to tell them, “He’s transgender.” The nurse was like... “We need to put it in as Jessica...” And I finally take the mask off and say, “No, my name is Justin. Legally, it’s Justin.” The nurse said: “Whatever, It.” I got so pissed. And she was like, “She, he, it, whatever. Just lay back down and put your shit down.” And I got so mad. (Justin).

References to being called “It” were found throughout the transcripts and emphasize the insult felt by participants and its impact on their health care-seeking behavior. When asked what he does if he gets sick, one participant’s answer was simple:

I stay sick... I haven’t been to the doctor in three years... I don’t want the stigma of ‘It’ or I’m gonna give them something if they touch me (Sebastian).

Ariana recounted taking a MTF friend to the emergency room who was repeatedly referred to as “He” after she explained that she was there because of complications from recent gender confirmation surgery:

Referring to Her as He, the whole time. On purpose...But you know, they stopped the bleeding a little bit and... They didn't do anything for her surgery, or anything like that. And the mental damage that it caused her... I mean they would have called her a Her had we not pointed out that she had had this surgery and this is why she's bleeding. They would have never known. But as soon as they found it out, everything was changed then... I don't know why. I couldn't figure it out- if it was to reinforce to them that they were dealing with a surgical reconstruction they used the male pronoun, or just because they wanted to hurt this person. Because, it was very degrading to her... (Ariana).

While she suggested that there could have been other reasons that the health care providers used male pronouns while treating her friend, Ariana pointed out that their intentions did not change

the fact that the experience was degrading to their patient and affected Ariana's willingness to seek health care as well.

Ariana described herself as lucky not to have experienced direct health care discrimination; however, she lived with bronchitis for months in the fall of 2009 before being sent to the emergency room for treatment:

And that was nerve-wracking. It shouldn't be, but just because of what happened with her, you know... Y'all don't care about us anyway. (Ariana)

Ariana felt that her friend was not only treated with disrespect, but also that she had not been given adequate treatment. These two sentiments were expressed by several participants, who were reluctant to seek health care for those reasons.

Conversely, the doctor's proper use of his name and male pronouns was part of the reason that Chris continued to use this health care provider's office. He emphasized that in addition to actually receiving the medical services he needed, a number of factors were important to his relationship with his health care providers:

At least my current doctor... They'll touch me...Even though my ID and my Medicare card says male. When I go to the office I am treated respectfully. They use the right pronouns. They touch me. I get all my scripts except my testosterone. (Chris)

For Chris, these considerations were so important that even though his health care providers would not prescribe him testosterone, he was willing to forego hormones for the present, in order to be treated with the respect and recognition he wants. The importance of normal physical interaction between transgender patients and health care providers is explored in the next section.

4.2.1.2 Health care providers appear reluctant to touch trans patients

I've had doctors treat me, but not treat me. You'll go, and they'll do med refills or something. But as far as doing a physical examination, it's almost like... they just don't know what to do... I've had doctors not touch me. (Chris)

Normal physical interaction between providers and trans patients was an important topic for many participants who expressed frustration at the hesitancy or avoidance of health care providers to give routine physical examinations. Participants said they avoid seeking health care because they do not want to be treated like “I’m gonna give them something if they touch me.” (Sebastian) or that it seemed that health care providers in their region “still think we’re another species.” (Joseph) Anxiety and impatience over being treated as if their transgenderism was a contagious illness characterized many participants’ experiences:

[The doctor] was just like, he pressed [on my chest] and he was like, “Well you have this.” And just walked out. And I’m like, “You don’t wanna check if anything else is possibly wrong... The doctor, he was, he just didn’t wanna, when he touched my chest, it was kinda like, like he was afraid he’d get a disease. (Toby)

A few participants also described being isolated in health care facilities, and feeling as if they were being quarantined from others because they were transgender. Chris, who accompanied Joseph to the hospital for surgery on one occasion, described feeling that Joseph was discriminated against because he was given an isolation room for no clearly stated reason.

Chris: And about the only discrimination that we've seen here, and we couldn't understand it at the time. He may not even remember this. After his bladder surgery, they put him in an isolation room... It was one of those new-fangled ones because it had like zero pressure. Because you went through like two doors.

Joseph: You saw that as when I had the tranny cooties? I thought damn, it's quiet, I can get some sleep (Chris and Joseph).

Sometimes participants indicated that while they were sensitive to anti-trans discrimination, other meanings might apply to events such as Joseph’s hospital room assignment. Chris believed that Joseph had been treated as if he had a contagious disease, whereas Joseph attached no significance to that experience. In the section above Ariana also remarked that the emergency room doctors might have used the male pronoun when discussing her MTF friend in order to emphasize the nature of her injury. However, participants also emphasized that their instincts

told them when their health care providers were uncomfortable being in their presence or touching them: “It might have a lot to do with that feeling, just like feeling like a freak” (Justin). They were also greatly concerned that among health care providers there is a lack of understanding of transgender identity, which participants believed feeds their discomfort of touching transgender patients.

Because they don’t understand, is the problem that I’m running in to. They kind of, they’re afraid to touch. I think that’s it. It’s kind of like they’re going to catch something if they touch me, to do an examination. That is what I feel from the conversation and the course of the examination. I get – “Okay, well take a deep breath,” and that won’t work. I don’t have anything that you’re going to catch, okay? It’s who I am and people like me have health issues as well, so I’m just trying to get a little follow-up here (Scott).

Scott discovered that when he revealed his gender identity and that he has a female partner, doctors had significant discomfort in touching him, and he had difficulty obtaining the necessary lab tests and follow-up exam to earlier health concerns. He and other participants expressed concern that not only were they affected by providers’ negative attitudes toward trans patients, but that they received sub-par health care or none at all as a result of their gender identity.

4.2.1.3 Trans patients’ health care is inadequate or delayed

The thing is that you're a doctor, and you take care of what's sick... Forget about the other stuff. (Joseph)

Participants in the focus group discussions were frustrated with the manner in which they were treated by health care providers, and they were persistent in demanding the necessary health care. They felt devalued when their gender identity seemed to be a bigger deal than the medical complaint they were presenting:

All of a sudden my gender identity [takes precedence over] say, a seizure... Can we move on please, you know what I mean...they don’t see you for what medical conditions you’re going through, they don’t wanna deal with you (Justin).

Some participants felt that they waited a long time when seeking urgent health care, because providers did not know what to do with them or were uncomfortable examining or treating them. Similar accounts of being required to wait until the “GLBT nurse” was available to treat them were described by two participants who had visited the same hospital on separate occasions:

I can't breathe, no machines at this point. Nothing to help me. They put me in a hallway on a gurney. Nobody goes to see me, nobody's talking to me. I sit there for an hour and a half...People that I had seen [in the waiting room] were getting rooms...I would hear people whispering like in the thing...They had to go find the GLBT nurse...It's like they almost only let GLBT people deal with people like us. (Justin)

It seemed to some participants they were given cursory examinations by physicians, and inadequate or inappropriate treatment. Chris shared that when he sought mental health care he was housed with women and was not permitted to present himself in his male identity, or discuss his gender identity in therapy:

They required me to...share a room with a female. Even after I had told them about being trans. They told me I couldn't talk about being trans in group. If I did I would be expelled and they would send me to the state mental hospital (Chris).

Being denied health care or turned away from a health care provider's office was also discussed and participants talked about the implications- physical, mental, and financial- of being denied health care. Frequently health care providers explained to the transgender patients that they were uncomfortable treating them or that they did not want to or know how to help them. In other cases participants were simply told to seek care elsewhere, as with Scott, whose providers rejected him after he explained that his partner is female:

And then, “You probably need to see another doctor...” I go to another physician and start talking openly and honestly with him, and he too suggested that I find another physician... They really don't want to talk about it out here. (Scott)

Abbi, whose partner is transgender, told about going to multiple intake appointments with different providers, costing them money but still resulting in being denied health care:

They rack up about \$250 in tests, we go back to a second visit and that is when both of them said, “You know, I really appreciate that this is your lifestyle and this is your choice, but I am not comfortable treating you”...What does comfortable mean?...But I'm sick to my stomach the whole time because I don't want this person that I love to be mistreated...At least be honest and say...”I can't help you... maybe I can find someone.” But we haven't had very much luck with that either. (Abbi, partner)

That sometimes health care providers would not even treat them for non-gender-related health care baffled the participants, who more than once expressed confusion between their experiences of being denied health care and their perception of a health care provider's role in society as the individual who is obligated to care for all health needs in a community.

You don't want to give me hormones? Fine, but I've got edema, and I've got a heart history in my family. Take care of that and forget about the other stuff. And that doesn't seem to sink in with some people. (Joseph)

The frustration and anger that participants felt was explicit in their language, sighing, slumped shoulders, and other physical clues which suggest that the emotional toll of these experiences also included symptoms of depression. One participant described how her inability to continue the transition process led her to be suicidal:

In the 70s, I was in the Vanderbilt transition operation...Several of my friends had surgery over there...in the late 70s they discontinued it. Me and a whole slough of us left out in the cold. We was on hormones...Body hair totally gone. Breast development was there. It left us in an area where we couldn't do anything...This built up in me a long time. I suppressed it with work. Finally August 24th of '08 I almost committed suicide (Faith).

4.2.2 Legitimizing Transition Health Care to Providers and Insurance Companies

Many transgender individuals who want a medical and/or surgical transition find that acquiring hormones and health care providers who will support them in the transition process is a particular challenge. Health issues that result from binding and other transition-related behaviors may be less familiar to health care providers, and patients often find themselves being blamed for

health conditions instead of getting help for them. Participants resented that many providers did not recognize the medical necessity of transitional health care and that health insurance plans would cover prescription hormones and surgical procedures for non-transgender policy holders such as mastectomies, but which are almost always excluded for transgender individuals. In the following account, Abbi recalled going to a health care provider with her partner in the hopes of getting a prescription for hormones, which was refused:

And I said, “We'll have to go to the internet and buy them.” And she said, “Do you know how dangerous that is?” And I took a really deep breath, and I said, “Do you know how dangerous it is for someone to need your help, and you not be willing to help them, or find somebody [who will]?” (Abbi, partner).

Participants talked about the health risks which they took because other options were not available as a result of being refused insurance coverage and the difficulty of finding responsive and qualified health care providers. They were angry that they frequently encountered health care providers who would not treat them at all if the patients insisted on being given appropriate trans health care as well.

4.2.2.1 Patients are blamed for transition-related health problems

Well, it's just those hormones that you're taking and there's nothing I can do (Abbi, partner).

There was a general consensus among participants that health care providers believed that transitioning was the cause of many of their health problems. Some suggested that their patients did not deserve treatment for a condition the patient had “caused.” Others found that their health care providers would only recommend that they stop taking hormones:

Samuel is transitioning, or we were, or... And Samuel is not well right now. The fourth doctor that we went to, she simply said, “Well, it's just those hormones that you're taking and there's nothing I can do” (Abbi, partner).

Several participants recounted how they had been unsuccessful in explaining to providers that as they would do with any medical intervention, transgender individuals decide to transition after considering the accompanying health risks and ultimately determining the greater value of being comfortable with their bodies and with their appearance to the outer world.

Right, I try to explain it to one doctor one time. Somebody who has depression... They take medicine but they have side effects. It causes anxiety attacks. It causes diarrhea...What's the difference... [The doctor] said, "There is a difference, because you're harming yourself." Well, every time you take a pill you're harming yourself. Just because I'm binding my chest for my mental sanity like doesn't mean I don't have the same rights as everyone else (Justin).

Female-to-male participants who bind their chests were reprimanded by doctors when they developed problems with their chest or lungs, but the doctors were also unwilling to recommend breast reductions or mastectomies in the place of binding.

I've been binding for almost eight years now and that's longer than you're supposed to bind. So my ribs have caved in and my organs have shifted and I've got a hole in my stomach and it's a big hot mess. But it's not a medical necessity to get my chest off at this point. [sarcasm] But I was told that if my lung popped, [the doctor] might consider taking my chest off. So I was like "Well, that's lovely" (Justin).

FTM participants were emphatic that even at the cost of potential health problems, binding was crucial to their appearance and self-confidence and protected them from anti-trans violence, issues to which they felt their health care providers were insensitive.

4.2.2.2 Health insurance avoids covering trans health care expenses

The sarcasm and hyperbole in participants' language suggest they felt that providers and health insurance companies are hypocritical in claiming that medical procedures that are regularly approved for non-transgender patients are not "medically necessary" for transgender patients. They were unconvinced that there was legitimate cause for their health insurance policies to deny them coverage for treatment based purely on transgender identity:

Say you've got this huge bust, you come out of the military, you find out that you can't be taken seriously as a professional...The VA will give you a bust reduction to whatever size you want. But they find that you're also trans, they'll deny you as cosmetic surgery. So if even if you have the coverage you're still getting screwed by the people who should be paying for it. (Joseph)

One participant was told that although a mastectomy should have been medically necessary, the doctor knew that his health insurance would not approve the surgery. He voiced frustration at having multiple medical opinions, confirming the need for medical treatment that his health insurance policy would not cover.

[The doctor is] saying my chest needs to go. My psychiatrist is saying I need to be on these hormones. Why isn't the insurance companies looking at me and going, "OK, you've got the green thumbs up." Why make it worse before you make it better?

Participants in Nashville had a lively conversation about health insurance policies denying coverage for trans health care, particularly gender confirmation surgeries. One commented that while most policies categorically denied trans health costs, Cigna health insurance group plans specifically included coverage for trans health care, including surgeries. Participants understood that the cost of their surgeries had to be accounted for and there was agreement that other insurance companies should consult with Cigna to find out how to make trans-inclusive policies financially viable. A 72 year old participant remarked that Medicare has not yet heeded recommendations that it too should provide for transgender clients' health care needs. She also suggested that such a concession by a federal agency might have implications for other transgender rights:

But the AMA you know has approved... (I know, this don't apply to you, but for me it does) It says that Medicare should pick it up. Well, if that's the case, there are some other policies that the government has that should fall in line with it too. (Faith)

4.2.3 “Rednecks” and “Country Folk:” Perceptions of Attitudes in Town, and Participants’ Attitudes Toward Town

I’m from a little town between Nashville and Clarksville. Two totally different worlds... It’s, 98.9% of the census...and I’m not joking, white Protestant. Churches everywhere you can go to. We have two red lights now. People still ride horses. It’s a farm town...I grew up in that. I’m used to the rednecks, hardcore. Rebel flags everywhere. And you know, you can’t even be black and be there (Justin).

Although only one person reported a postal zip code that was classified as a rural location, a number of participants reported living in small towns and rural areas as well as the major cities in the region: Nashville, Murfreesboro (a “sister city” to Nashville, where several participants lived) and Knoxville. The participants gave similar examples of health care experiences regardless of location, but there seemed to be a strong general perception of anti-trans attitudes in rural areas. Some participants reflected on the need to “pass” where they lived, whether to avoid losing a job or simply keep the peace:

But my employers know my condition and the only problem is, is if I presented as female – and I’m obviously not – that it would really hurt business... (Kayla)

And I have had some fears [about transitioning], because I live in rural Tennessee, as to the reaction. But...some of the good ol’ boys, they have no clue...You know, I can stretch back and grab my crotch the same as anybody else can, you know? [laughing] I mean, if you’re going to be realistic about it, you know, I have to do that. (Scott)

Several participants shared a personal experience of trans-discrimination or threats of violence in their towns. Most knew stories about others’ experiences as well and expressed their own fears that they were at risk of violence and discrimination.

I have experienced discrimination in the sense that I was a male teacher in [name] County schools, and tried to transition during a summer, and they weren’t too happy about that, even though they knew I was doing it. So I lost that job (Ariana).

I’m born and raised in Tennessee and actually live in a little bitty town...and they’re not very open to anything really. I used to have a Pride Flag ribbon on the back of my car. I’ve had people stand next to my car with baseball bats...And I’m sometimes scared to go out. So it’s...I spend most of my time in Murfreesboro (Jennifer, partner).

Participants described the areas where they lived as insular communities with homogenous populations. Those who expressed concerns about their safety, unavailability of local health services and feelings of isolation from other transgender individuals were also likely to describe their neighbors as “rednecks,” “good ol’ boys,” and being entrenched in traditional, rigid definitions of masculinity and femininity.

There’s a difference between being a country folk and a redneck...There’s a certain attitude about them. They’re like a watered-down version of a KKK member. [laughter]...But they take the country life and they kind of build...a bubble [around it,] and if you’re not in that bubble, they don’t like you (Justin).

I think the rednecks, they don’t really talk intelligently about things...A lot more violence [than] a country person. Country people have manners. They grow up a certain way. Rednecks are loud and obnoxious. It’s their way or no way...And they’re just asses (Michael).

Participants were emphatic and emotional when they characterized the people who lived around them, and although their descriptions implied feelings of rejection and isolation, these discussions were punctuated with frequent group laughter and disparaging jokes.

The prominence of churches in their communities in both Nashville and Knoxville was frequently discussed among participants. Body language and tone of voice suggested that participants had an aversion to these churches, and it was hinted that church members engage in anti-trans rhetoric.

I’m living in a thriving metropolis, that great, progressive Mecca called [name of town,] Tennessee. Home of 4800 people...and there are 66 Baptist churches, alone okay? (Kayla).

I live in a community that’s predominately poor blacks. A lot of disabled people. If they knew, would they judge me? Who knows? Because a lot of them are very Christian. They probably have more churches than anything else in our neighborhood (Joseph).

Not all participants felt threatened in their neighborhoods. Several described their neighborhoods as neutral or very accepting of them. In contrast to the experiences she described

with health care providers, Abbi was proud to point out how accepting and inclusive the neighbors were of her transgender partner, Samuel.

4.2.3.1 Accessing health care in Tennessee: “There’s not a lot of opportunity here, as far as I know.”

Most transgender people’s families look at them and already don’t understand. For us to go out in society and then see doctors who are there to help us and you think they’re gonna make you feel better. And then you go in there and they look at you like you’re disgusting like everyone else does. They turn around and look at the suicide rates among transgendered [people] and gays and lesbians. (partner)

Participants’ attitudes about their towns and communities bespoke the impact that other lived experiences had on their expectations of health care providers in these communities. The more obvious their gender-variance was to others in their communities, the greater was their risk of anti-trans violence, and they were exasperated that providers did not understand this aspect of their lives:

And the doctor ...got disgusted with me: “You have to make a decision if you want to live like this or live a normal life.” [another FTM friend], was like, “You don’t understand. We can’t live without it.” If I don’t bind, I’m not being a bearded lady in Tennessee. Rednecks will come attacking me...I’m gonna be outed and I’m never gonna leave the house. So at this point in my life, I’m like, “Medical necessity.” They just don’t get it... (Justin)

Living far from LGBT-friendly health care providers was a complication with which most participants had dealt. Some responded by persisting until they found a reliable health care source, even if it was at significant distance from home. Jennifer worried about her partner, Daniel, because he did not have a local source of health care, but he preferred to make semi-annual visits home to Illinois for health care and hormone prescriptions rather than try to find a supportive doctor who was closer to home:

I’ve had my care done at [Howard Brown clinic] in downtown Chicago...I’ll probably continue my health care there for the time being because there’s not a lot of opportunity here as far as I know. I know I’m being treated very well there (Daniel).

Participants acknowledged that the closed-mindedness they anticipated in small town health care providers was a stereotype and not always accurate. Some described finding their staunchest supporters in rural areas, when providers in urban areas were unreceptive to their needs:

[Town name] is...a little town, with big city growing pains. But we have had more luck with doctors out there than we do in Knoxville itself. There's not even a gay bar in [town name]...However, we've had good luck (Joseph).

Having only a few available providers was also a burden on the providers, who might not be able to accommodate the many requests for health care. Both Nashville and Knoxville participants indicated that only one or two health care providers in their regions were known to address the majority of trans health care needs.

But the thing is, is that once that door is open to a doctor- everybody in the community is so desperate for health care that we just beat these poor doctors to death (Chris).

Sometimes patients would try to circumvent policies such as the WPATH Standards of Care recommendation that transition health care be approved by a therapist and a medical doctor. Participants reported that some individuals in their communities had forged necessary letters from therapists or doctors that recommended hormone therapy or surgery. When their ploy was discovered, health care providers who were previously willing to treat transgender patients would no longer do so.

In some cases providers were willing to treat trans-patients who had taken hormones long enough to “pass” but did not want to accept new patients whose trans-identity was apparent or would be suspected:

His staff doesn't want him treating us. And he's afraid that if we have people going up there that are [visibly transgender] he will lose staff as well as patients. Or he's afraid that his staff will mistreat us. But to say, ok, I'll treat you today, but I don't want you in my waiting room anymore, it's just as bad as denying care in the first place (Joseph).

Most participants perceived rural areas to have less accepting and less knowledgeable health care providers. Some reported actual experiences seeking care in rural areas that led to this expectation, but nearly all participants agreed that general attitudes of rural health care providers toward transgender individuals were negative, and they were reluctant to seek care in a rural area if there was another option.

I'm from a really small town in southern Kentucky. It's basically the buckle of the Bible Belt. There's a total- I've met two other trans guys in that town, or within 30 miles of it. The doctors, they don't know, they don't understand anything like that. Basically nobody does around there (Toby).

4.2.3.2 Tennessee laws on gender markers affect trans health care access

Even if your name is Bubba, they're going to be like, 'What's the deal with 'F'?' (Michael).

On several occasions participants in the focus group discussions who had identified as transgender for longer than others demonstrated their role as advisors or mentors for those who are newer to the process. Several times the subject of gender markers on birth certificates came up. It was clearly of significant concern to participants, who felt that having a gender identity congruent with their medical records would facilitate smooth interactions with health care providers. In the following exchange in Nashville, Justin explained to Michael that Tennessee's law bans an individual from changing the gender marker on a birth certificate, driver's license, or any other legal forms of identification:

Michael: Okay in Tennessee...my name's not changed - I'm working on that...Okay, if you were born in Tennessee, we can't get our gender changed on our license or anything like that. So we're always gonna be that big F...Even if your name is Bubba and you go [to a doctor] and have the big F...Even if you have top surgery and bottom surgery...They're gonna be like "what's the deal with 'F'?" Isn't there always gonna be a problem?...

Justin: Well, hopefully something'll pass in a couple of years...There's like three or four states in the entire United States that won't let you change your marker- even if- I can go to California and still be unable to change it because I was born in Tennessee. I think that kind of sucks monkey balls, to be honest with you [laughter].

Not only native Tennesseans were concerned about the effect that gender incongruity on medical or legal documentation could have on their health care experiences. Daniel's out-of-state driver's license did in fact reflect his correct gender identity, but he was worried that he would be hassled by health care providers anyway.

Because everything says male but obviously my whole body isn't male. I just wear a compression shirt because I don't have a big chest. Do I wear that? Because it's a bit awkward when you're using a stethoscope. Or do I play it off: "Oh, my boobs are man-boobs." [laughter] (Daniel).

Daniel's story and the exchange between Justin and Michael were also notable because the participants frequently reflected the serious implications of these concerns with humor. In the role of an informal mentor, Justin educated his peers about Tennessee laws and also offered reassurance with the suggestion that the prohibitive laws could change in the foreseeable future.

4.2.4 Facilitators to Trans Health Care and Prioritizing Future Needs

We've kind of gone on the journey of learning together, in a way (Chris).

Participants were asked how they had addressed perceived barriers to health care, and to describe their successes and what else they thought would improve their access to health care. They used the terms "advocate for yourself" and "education" repeatedly. The social support systems that they had discovered or helped to develop were highly valued by participants. They also found themselves educating providers, directing their trans friends to supportive health care services and defending themselves and their friends to unsympathetic or unknowledgeable providers. For many, the Internet was a source of information and making connections with other transgender individuals.

There was a strong consensus that health care providers needed more medical education for trans health needs and that transgender individuals needed reliable sources of information as well. Participants were emphatic that trans-health care should be covered by health insurance policies. They encouraged transgender individuals to become health care providers, and several expressed their intention to do so as a result of their personal health care experiences.

4.2.4.1 Developing networks with trans individuals and health care providers

Assume your doctor knows nothing about transgender medicine, but do not feel like you are the one that is obligated to teach them (Chris).

The strong support networks that participants had developed or become a part of were among the most commonly referenced tools that help participants to mitigate the barriers to health care they encountered. Many of the stories came from participants whose friends went to the doctor with them. Participants in both focus group discussions named social support and their involvement in the Nashville and Knoxville organizations as their primary way of finding health care providers, as well as other local resources and general information about transgender health.

Peer education was evidenced in exchanges between participants in both focus group discussions, and participants in Nashville and Knoxville said that they also found information on the websites maintained by the T-Men and T-Vals, and Knox Boyz and Girlz. Hudson's FTM guide, Laura's Playground, and TS Roadmap were other websites mentioned as sources of information, and several participants said they found health care providers online through these or other websites.

Participants also talked about successful and unsuccessful strategies for approaching a new provider:

And that's like giving people permission to discriminate against you. I've never once walked up to a doctor and said "I'm a transsexual, I need." It's always been "I have this

problem, fix." But they never discriminated against me because I never gave them permission. (Joseph)

Some believed that transgender patients should discuss their gender identity or transitional health care with a provider only if it was relevant to a particular health issue, such as discussing gender hormones with an endocrinologist when being treated for diabetes. Several mentioned that they had one doctor who addressed their trans health care needs but avoided disclosing their transgender status to other health care providers if possible.

Several participants talked about the difficulty of affording doctor visits and hormone prescriptions. Michael was drawing unemployment, and in order to afford his appointment, labs, and hormone prescriptions, he made appointments with his doctor months in advance in order to be sure he had enough money saved. Another participant whose insurance covered his hormone prescription lost his job and thus needed to work hard to find another source of hormones:

I stretched my hormones as far as I could go and then I stopped. Then I had a friend who was a pharmacist who made me stuff to kind of get me through. And then finally, I had a friend who lives in a different state who... has an abundance of testosterone and just gives me his... It's not that I necessarily went black market or anything like that.

One participant talked about being prepared for an emergency by always carrying with him an open letter to any health care provider. This letter explained transgenderism and laid out his civil rights as well as advice to providers about where to look for more information about treating transgender patients:

I have a safety letter that Howard Brown wrote for me. I think that if I ever get into that situation where I'm unable to speak. I'll just hand any health care professional the safety letter. (Daniel)

Joseph and Chris talked about the importance of partnering with health care providers who were willing to learn about transgender health from their patients and adapt their clinics and services to better meet their needs. Joseph recalled that when they met their gynecologist in

1999, she asked him and Chris to bring a female friend with them to appointments, so as to be less conspicuous in the waiting room. Describing a recent visit, he was clearly proud to report the changes that had taken place over the past decade:

And one of [the doctor's staff] decided that she didn't want the hairy women as she referred to us, coming to the clinic. And our doctor said, "You have a choice. Change your attitude or start packing." She no longer works for that practice...The rest of them are like, "You know what, you need medical treatment? We got medical treatment. For whatever it is that's sick. If that part of you is sick, we're here to help you." And that's pretty damn awesome. (Joseph)

Chris became an active participant in his own treatment by bringing research to another doctor in Knoxville who prescribed his hormones:

We've kind of gone on the journey of learning together, in a way. And that was one of the reasons that he was very much by the Standards Of Care [WPATH]...I would find research and I'd say "Listen, people are doing this"... He'd say, "Let me do some research and...then he'd say "I'm willing to try this. Or, I'm not willing to try it." (Chris)

Participants emphasized repeatedly that transgender individuals must advocate for themselves, by insisting on the health care they believed they needed, reaching out to providers even when it was uncomfortable or awkward, and educating themselves as much as they could, while also insisting that health care providers must learn how to provide for trans health care needs.

4.2.4.2 Improvement of trans health education for providers prioritized

We need to educate them. Someone needs to go in and educate them. Someone needs to educate them and explain it to them (partner).

The partner of a FTM participant felt that the lack of trans health knowledge among health care providers was a two-part problem. First, providers did not understand the body dysphoria that her partner lived with, which explained why they would tell a transgender individual to stop an activity like binding, which was causing other health problems, without considering the other repercussions of their advice, such as stress, or that an ambiguous gender

appearance could put them in danger of anti-trans violence. Secondly, the providers were not prepared to offer more constructive solutions:

They need to stop and educate themselves and tell these people preventative issues. “You need to wear a binder that’s not so tight. There’s other ways to move your chest to make it flat.”...Because they’re not gonna stop doing it. That’s like telling 16 year old girls to quit having sex. [laughter]...You’ve gotta hand them a condom. It’s the preventive stuff. Fix the problem. Don’t just tell them not to do it (partner).

Participants wanted their health care providers to be more knowledgeable about transgender preventive health issues as well as transitional health care.

Well, the closest that we could even come to a specialist doctor I guess would be an endocrinologist. For our treatment of the hormonal issues. They're the ones that know the least about how to work with us, but they're the ones that should know the most (Ariana).

Participants identified the need for gender clinics in Tennessee; Vanderbilt University, the University of Tennessee and Eastern Tennessee State University were suggested as possible sites. Participants suggested that local transgender patients at these clinics would benefit from improved access to health care, in addition to the benefit such clinics would provide to residents who would be able to study trans medicine, including those who were studying endocrinology.

Participants believed that another significant barrier to health insurance coverage for trans health issues is misinformation about gender identity that the health insurance companies use for guidance in approving or rejecting insurance claims. They gave the example that lacking better understanding of the spectrum of gender identity, health insurance companies seemed to view transgender individuals as “crazy” and consider trans health care only through the lens of psychiatric treatment:

They don’t realize that the medical people are shouting, sometimes, going “We need to cover this.” Because this [Gender Identity Disorder] isn’t just a mental thing. It’s a physical thing. These surgeries need to happen to improve the quality of these people’s lives. It’s not something that they can just take a pill and it’s gonna go away and they don’t want the surgery.

Participants said that they expected to be treated “like human beings” and given respect when they sought health care and equal treatment by health insurance companies. They were frustrated that insurance companies often had categorical exclusions for both general health care and transition-related health care for transgender individuals.

That's something else I wanted to say. Because we are struggling as a nation with what to do with under or non-insured persons. People. Humans. And too many health insurances exclude basic treatment for a transgender issue (Chris).

They believed that advocacy was an essential tool that could help to force systemic changes to improve transgender health care. Gay-straight alliances, students in the health sciences, gay, lesbian, and bisexual populations as well as transgender individuals themselves were identified as potential allies. The importance of seeing transgender individuals in the health professions was highlighted as an effective method to show health care providers who transgender individuals are and why they should be given equal care and respect.

I'm thinking I'm gonna go to school to be a nurse. Hopefully, I'm gonna be as out as I can to educate people at the hospital I'll eventually work at to at least think about it more than just putting people down (Daniel).

5.0 DISCUSSION

From these findings and with respect to relevant data in the literature, three conceptual components of health care experiences that affect access for transgender individuals stand out: (1) attitudes, (2) behavior, and (3) knowledge. The “Behavioral Ecological Model”¹³ is a helpful theoretical guide to understanding how each component affects and is affected by the various levels of influence, including transgender individuals, health care providers, and the greater community in which one lives. In addition to this conceptual perspective on health care access, the findings of this research study suggest that Tennessee residence and Tennessee nativity are explicitly related to the issue of health care accessibility for study participants. By understanding how each of these components influences transgender health care access in Tennessee, we arrive at important implications for future research and interventions, which are discussed later in this paper.

5.1 THE IMPACT OF COMMUNITY ATTITUDES AND BEHAVIORS

The influences of the attitudes and behaviors of people in their communities were important to participants’ beliefs about their own self-worth and self-efficacy, as well as beliefs about the value ascribed to them by others. Participants described discrimination in employment, legal rights pertaining to gender identity, and perhaps most importantly, the stigma

they experienced when family, friends, and strangers expressed disapproval of transgender identity. Many transgender individuals had experienced prolonged and pervasive discrimination and stigma in their communities, and this led them to have similar expectations for their experiences with health care providers.

Meyer's theory that stress can be specifically associated with minority status in the community is useful in explaining the response of transgender individuals to negative community attitudes and behaviors⁴⁵. Aversion to repeat experiences: "I don't want the stigma of 'it,'" and reluctance to seek health care: "What's the point?" illustrate Meyer's description of individuals whose ability to self-advocate is hampered by low self-esteem and self-efficacy⁴⁵. Conversely, some participants described feeling accepted in their communities and respected by their families and thus had a general expectation of respect and acceptance from others. Participants who had become involved in transgender communities and who had partners and friends who supported them were likely to persist in seeking health care and voiced the belief that they deserved good health care and respect for their gender identity from health care providers.

5.2 THE IMPACT OF THE ATTITUDES AND BEHAVIORS OF HEALTH CARE PROVIDERS

The existence of minority stress in the experiences of the participants is further demonstrated by the specific attitudes and behaviors of their health care providers. Participants who felt they had been previously stigmatized by health care providers expected that they would encounter similar attitudes from other providers. Some of these experiences were feeling

disrespected by providers who misused their names and gender pronouns; sensing that providers were disgusted by them, and being told by providers that the transgender individuals had caused their own health problems. Likewise, some participants were discouraged from seeking health care when they heard of other transgender patients who received similar treatment. Although participants may have in fact received health care, some were discouraged by the attitudes that they encountered from health care providers and chose not to seek services again. These individuals were likely to talk about the experiences they wanted to avoid as the reason they were reluctant to seek services. Participants who saw that their gender identity was respected by health care providers and that providers appeared to treat them as well as other patients were likely to express the belief that they deserved comparable health care and respect and to talk about the lengths to which they went to ensure this outcome.

The direct effect of the behavior of health care providers who refused to treat transgender patients was that the patients' health complaints remained untreated. In some cases, participants were denied access to prescriptions for gender hormones or gender confirmation surgeries. Participants seeking regular check-ups to monitor heart conditions or mammograms were denied treatment and told to find another doctor, costing them time and money. Participants in this study explained that the experience of being refused health care or of being given inadequate health care also impacted their attitudes about health care accessibility. Similarly, the inaccessibility of health insurance coverage for transgender health needs discouraged patients from believing that they could afford the necessary health care.

Some participants chose not to seek health care services when it had previously been denied to them, because they did not feel confident that they would be more successful on another occasion, or that it was worth the risk of rejection. The resiliency of some participants

was demonstrated as they continued to reach out until they found a responsive health care provider. Participants also responded by forming networks of transgender individuals in their communities and sharing information about health care providers whom they knew to be open to accepting transgender patients. Although many participants talked about reasons not to seek out health care and described unpleasant experiences that they did not want to relive, there was also a strong sense that participants believed that they deserved health care, and they gave many examples of how to find and demand the services they needed. Participants talked about being defended by a friend who spoke to the doctor on their behalf, offered to go with newer transgendered individuals who were nervous or afraid, and who encouraged one another to overcome the experience of being denied health care by continuing to seek the services they needed elsewhere.

5.3 THE IMPACT ON HEALTH CARE PROVIDERS AND TRANSGENDER INDIVIDUALS OF HAVING OR LACKING KNOWLEDGE

As is described in the theory of Statistical Discrimination⁸⁷⁻⁸⁸, health care providers' attitudes about transgender identity are informed by their surroundings in the health care field as well as their broader communities. They are also influenced by personal interactions with transgender individuals, and perhaps most significantly, they are informed by the knowledge they have of transgenderism as a medical designation. Participants frequently said that health care providers did not understand transgender identity and did not know enough, or anything, about health problems and medical issues that are unique to transgender patients, and they felt that much of the aversion to treating transgender patients came from this ignorance. They

believed that standard education for health care providers should include transgender health care, and that better educated health care providers would not only provide better health care for their patients but would be more willing to advocate for them to health insurance companies and in other situations. Thus, knowledge was also an influential factor in the behavior of health care providers toward transgender patients.

Health care providers' knowledge of trans health issues influences their ability to provide appropriate health care. Knowledgeable providers are clearly in a better position to improve the quality of the care they give their patients. Participants described relationships with health care providers which improved over time as the providers gained insight and knowledge about transgender identity and trans health care by learning with and from their transgender patients. These relationships proved to be mutually beneficial by improving providers' respect for transgender identity and by increasing transgender patients' trust in their health care providers. Participants also believed that if decision-makers at health insurance companies were taught definitions of transgenderism more complex than simply the psychiatric designation of Gender Identity Disorder, they would be more likely to approve coverage for medically recommended treatments such as hormones and gender confirmation surgery.

The exchange of knowledge between transgender patients and their health care providers was viewed by participants as both positive and negative. Participants were proud when they were able to communicate effectively with a provider to teach them about transgender identity and trans health care needs. They also recognized that the usual route of information about health was from the provider to the patient, and they did not like feeling obliged to educate their health care providers. Participants were concerned about the transgender health issues for which there was little research and emphasized that they could teach their providers only to a certain

point. They valued education from health care providers that could prevent health problems and suggested that a lack of preventive trans health care was another barrier to health.

5.4 THE IMPACT OF SEEKING HEALTH CARE IN TENNESSEE

Although specific comparisons of health care access in Tennessee and other geographic locations were not invited by the author, comments from participants who had lived or received health care in other states are worth noting and shed light on the importance of location in this context. A significant difference in transgender health care access between urban and rural locations was not demonstrated by the findings of this study; however, there was a distinct difference in participants' perceptions of opportunities for transgender health care in Tennessee and those opportunities in other states. One participant preferred to drive eight hours to Chicago for his health care. Another lived in San Francisco earlier in his life and remembered the Health Department there conducting "Tranny Tuesdays" in order to offer health care specific to transgender needs. A participant originally from Phoenix, Arizona, was questioned by his partner why he did not transition there instead of rural Tennessee, and a partner described feeling "shoved back in the closet" when she moved to Tennessee from San Diego. The frustration with being born in one of the few remaining states that does not allow gender markers to be changed on birth certificates was perhaps the most indicative of the participants' general feelings that the state, rather than the geographic location, had the greatest effect on their ability to access health care.

Ultimately, the behavior of participants and health care providers decided if and how individuals received health care. The behavioral ecological model describes many of the layers

of influence that have been elaborated on in this section. Patients obviously did not receive health care when they did not seek it or when it was denied by health care providers or health insurance policies. Sometimes participants did not seek health care because they did not have health insurance or were unemployed and could not afford to pay for services, but the overwhelming reason that participants avoided seeking health care was they did not want to be subjected to stigma and discrimination by health care providers. The lack of knowledge among health care providers was seen as a significant barrier, both to being treated with dignity and respect, and to receiving adequate and appropriate health care. Participants also demonstrated that when health care providers and transgender individuals were able to improve their own and others' attitudes, behavior, and knowledge about transgenderism and the health care system, it had the effect of increasing access to health care for transgender individuals. Finally, participants indicated that there were state-wide barriers to health care access that needed to be addressed in order to fully include transgender individuals in equal opportunities for health care.

6.0 IMPLICATIONS AND CONCLUSION

Although definitions may vary within the field of public health, health care access is considered to be a key factor in individual and population health^{1,2,6-12}. What is known about transgender individuals' health care experiences suggests that anti-trans discrimination significantly affects their ability to access health care^{2,3}. A few studies of rural LGBT populations suggest that they may experience more discrimination and unique barriers to health care^{4,5}. This thesis undertook an exploration of barriers and facilitators to transgender health care access in Tennessee, as well as considering the impact of geographic location on these health care experiences.

Issues of mental health, HIV/AIDS, and hormone usage are better understood by health care professionals than other trans health issues due to more thorough research in these areas. While transgender feelings or identity were considered themselves a sign of mental illness in early psychological thinking, today most psychologists believe that mental illness affects trans individuals more often than others because of the adversity they face from social, cultural, and legal anti-trans discrimination, rather than by virtue of their transgender identity. HIV/AIDS has affected MTF transgender individuals disproportionately, particularly those who are African-American or Latina, or who engage in sex work, in much the same way that those populations are affected among those who do not identify as transgender. Finally, the unique experiences of gender hormone usage among both FTM and MTF individuals indicates that while many trans

individuals desire hormones, there are few who can access them legally and who have insurance that will cover hormone prescriptions. The inability of many trans individuals to access medically supported hormone use has led to widespread usage of hormones distributed through unlicensed street sources and the internet. Furthermore, un-monitored hormone use at a time when the long-term consequences are still largely unknown poses other potential health risks. While these are only a few issues affecting transgender health, they are among the best understood due to a lack of research in many other areas.

Transgender individuals experience discrimination from health care professionals who refuse to provide them with health care or provide substandard care. Furthermore, the lack of legal protection from anti-trans discrimination in employment and health insurance coverage is prohibitive to affording health care. Stigma and past experiences of discrimination also discourage trans individuals from seeking health care in order to avoid feeling stigmatized or having further experiences of discrimination. While there has been only a nominal amount of research demonstrating the impact of anti-trans discrimination and stigma on health care access, discrimination and stigma have been shown to impact the health care seeking behaviors of lesbian, gay, and bisexual individuals, as well as ethnic and racial minorities. The lack of trans health research and basic medical education for trans health issues results in the inability of providers to provide informed, comprehensive health care to trans patients. In rural areas, these various elements of discrimination and stigma are of greater impact as trans individuals are more isolated than in urban areas, and have fewer choices of health care providers and services.

Focus group discussions were conducted in several cities in Tennessee, where transgender individuals from the surrounding areas were invited to discuss their experiences with health care access. Ultimately, two focus group discussions, held in Nashville and Knoxville

were analyzed in this thesis, and four major themes were identified. (1) Transgender individuals feel that health care providers' attitudes and behavior toward them belie a lack of personal respect and believe that their health care is compromised as a result; (2) transition health care is impeded because physicians and health insurance policies do not recognize gender transition as a medical necessity; (3) anti-trans discrimination in both rural and urban communities in Tennessee lead to expectations of similar treatment from health care providers; (4) and advocacy and social support facilitates their health care access, as well as health care professionals who are well educated on transgender health concerns.

The themes that were described in this paper are interconnected with several conceptual components: the attitudes, knowledge, and behaviors of health care providers, communities, and transgender individuals, all of which have an impact on the health care experiences of transgender individuals in Tennessee. Finally, although rural and urban comparisons could not be made with the study sample, this research did demonstrate that there are specific attitudes associated with the accessibility of health care in urban and rural locations. The findings also identified specific barriers to health care access for transgender individuals seeking health care in Tennessee. The implications of these findings should inform public health practice and future research on this topic.

6.1 IMPLICATIONS

The findings presented in this research study are primarily exploratory and describe the health care experiences of some transgender individuals who live in central and eastern Tennessee. While these findings are not generalizable to all transgender people, or even all

transgender Tennesseans, they do present new information about barriers and facilitators to health care access for a marginalized and under-studied population. The previous section discussed the attitudes, behaviors, and knowledge of transgender individuals, health care providers, and the communities in which these people lived. What follows are recommendations for how the field of public health should respond to these findings.

Clearly, health care providers must improve their knowledge of transgender health care and transgender medicine. Participants emphasized that much of the fault lies with the medical education system, which does not adequately prepare health care providers to actually provide appropriate health care to transgender patients. Furthermore, the lack of literature demonstrates that research itself is lacking in key areas of transgender health. Additionally, there is little written about implementing a medical curriculum that successfully incorporates transgender health care, or adding medical specialties specific to transgender health care needs. Research opportunities must be improved by designating funding for trans health research and offering scholarships and research fellowships to graduate students in public health and medical research with an interest in transgender issues. Furthermore, population-based research surveys and the U.S. Census should be improved by including questions that provide much needed data about transgender individuals.

Health care providers who have anti-transgender attitudes pose a significant threat to health care access, because their attitudes lead them to provide inadequate health care or refuse care altogether. In addition, transgender patients who experience negative attitudes from health care providers are themselves likely to develop or confirm negative attitudes about health care accessibility. The vicious circle of influential attitudes is further complicated by a pervasive anti-transgender sentiment in American culture, which already discourages transgender

individuals from believing they have equal rights and opportunities (because in fact, they do not). These attitudes likely also influence their own self-efficacy in seeking health care as well as their expectations of encountering further anti-transgender attitudes and behaviors from health care providers.

Public health solutions to altering a societal attitude might be generously described as Napoleonic-the macrocosm of influences that affect societal attitudes are impossible to address as a single entity. However, the attitudes of health care providers, can and should be addressed from within the health care profession. This can be accomplished through community groups and advocacy organizations that support transgender patients' rights, and through the inclusion of transgender individuals in local, state, and federal anti-discrimination laws that will carry legal consequences for providers whose personal attitudes result in systemic anti-trans discrimination in their health care practices. Laws protecting against anti-trans discrimination in employment and health insurance must be passed if we expect transgender individuals to benefit from positive changes in the attitudes and behaviors of health care providers. Passage of the Employment Nondiscrimination Act currently sidelined in the Senate should be a priority.

The damage is done, so to speak, for transgender individuals who have already developed suspicious or fearful attitudes about the health care system, and one need only look back as far as the Tuskegee syphilis trials to understand the long shadow that abuses of the health care system trails behind. Although health care providers trained in recent years and those who will be trained in the future may well learn to respect gender identity as an unalterable personal attribute rather than a debilitating pathology, the history of anti-trans discrimination is not yet in the past, and extraordinary efforts must be made by the medical professions, public health educators, and

lawmakers in order to reach out to transgender individuals who have come to the conclusion that it is unhealthy to seek health care in this country.

During the focus group discussions, participants occasionally gave each other health information which was inaccurate. The powerful influence of social support networks like the Knox Boyz and Girlz, the T-Men, and the T-Vals should be harnessed as a target of community health interventions that provide correct and appropriate health information as well as information about local resources for transgender individuals who need health care. These interventions should also serve the purpose of introducing transgender individuals to supportive and knowledgeable health care providers. These should be providers who do not insist on providing services behind closed doors, but who advertise their services in LGBT (or just T) community spaces and who engage the community at these events to answer questions about health and local resources that might encourage some transgender individuals to seek health care who have previously declined to do so.

These findings are probably most relevant to the communities from which they originate, where they may serve as a record of lived experiences and assist in focusing the communities' activities to address the barriers to health care that are described in this thesis. The implications of this study may also be of use to health care providers and community organizers who intend to address transgender health care issues, and researchers who study transgender health, rural health care access, or other related fields may find this paper useful background for future research. The facilitators to health care which were developed by individuals within the transgender communities represented in this paper should be attended to and used to model similar strategies in future interventions; these successful strategies have been tested and accepted within the population and should be respected as important "grass-roots" interventions.

6.2 STUDY LIMITATIONS

There are a number of limitations to this research study. First and foremost, the experiences of the individuals who participated in the focus group discussions are unique and therefore are not generalizable. The perspectives of and statements made by participants represent only the opinions and experiences of the transgender individuals who attended these discussions and did not take into account the perspectives of other individuals who are involved in the health care process, including health care providers and the friends and families of transgender individuals. These focus groups discussed individuals' personal experiences with health care; thus, the study data are very much connected to the locations in which focus groups were conducted and where participants lived.

Due to financial and time constraints, the author spent only two weeks in Tennessee collecting data. Therefore, recruitment relied largely on existing networks of transgender individuals who were connected with either political and advocacy or social support organizations, or both. The vast majority of participants were well-connected with other transgender people in their region, indicating that this study did not represent those individuals who are significantly cut off from any social support system.

Recruitment was based on convenience sampling and did not yield racial/ethnic or gender identity diversity, with the sample being heavily white or Caucasian and primarily individuals who identified along the trans-masculine spectrum (FTM or male, in this sample). The sample was more diverse in age of participants, but there were significant gaps in this demographic characteristic of the study sample as well. A longer recruitment period and use of other non-network based recruitment venues, such as posting flyers in clubs and businesses and advertising on websites such as www.craigslist.com and those with content specific to trans-folks might

have yielded more diversity in participation. However, safety for both participants and the author was a concern; and the decision was made that the yield would probably not be worth the gain for this small, exploratory study.

Use of focus group discussions as the primary method of data collection did have some limitations. In almost every focus group, the majority of participants were already acquainted with, or friends with other participants. While this may have made some participants feel more comfortable, alternatively, some participants might have been reluctant to share personal health information with their peers and acquaintances. In addition, because the participants were often well acquainted and therefore inclined to chattiness, it was sometimes difficult to keep the discussion on track, and within the dedicated time-frame. Finally, focus group participants may have tried to answer questions as they believed the facilitator wanted them to answer.

6.3 CONCLUSION

Health care access is a factor significant to understanding nearly all health disparities in the transgender population, and for that reason, it is the focus of this thesis. The existing research suggests that discrimination against transgender individuals plays a large role in many of the barriers to health care access, including geographic location^{2,6-8}. This study explored health care access for transgender Tennesseans. Participants from focus group discussions in two cities, Nashville and Knoxville, were invited to talk about where they lived, what kind of health care they had sought and received, and how to assess their ability to access health care.

The experiences described by participants indicate that they feel discrimination and stigma lead to significant barriers to their health care access. Participants explained that how

they are treated by health care professionals impacts their willingness to seek health care. Misuse of names and gendered pronouns by providers led to significant discomfort of participants, who believed that they were not only disrespected but given substandard or inadequate health care by providers. The lack of legitimacy surrounding transgender identity affected providers and insurance companies who were unwilling to recognize and provide for trans health needs. Furthermore, participants described the discrimination and stigmatizing attitudes present in their towns as exacerbating their fears of discrimination in health care. They described the importance of educating health care providers about trans health issues, and self advocacy as well as social support among the most important facilitators to improving their health care access.

The trans population has not waited for outside assistance nor do they demand anything more than respect and equal ability to address their health needs.

Faith: It's a problem we've all had for a long time; I've had for a long time. I want to solve the problem.

INTERVIEWER: Anything else anybody wants to say?

Daniel: I think that education is also very important. We need people to be our advocates. And a big issue is nobody is speaking for us and sometimes we hide and we're scared to speak for ourselves. And if, you know, somebody who's not in our world won't speak for us, then we need to speak for us and go to these hospitals... We need to show them that we're human beings and we deserve basic human rights, even if it's just basic health care for a heart condition or diabetes. We shouldn't be treated like animals or less than human. It's not our responsibility per se, but I think somebody needs to make sure that somebody is out there telling all these health professionals who say that they care about human beings and the health of human beings to show them that we're humans and we deserve to be treated fairly (Faith, Daniel).

As researchers and health care providers we must find a way to partner with the trans population to meet needs that are beyond the scope of individual ability.

Health care facilities, including hospital, private practices, and public health departments, must address the needs of transgender individuals in their communities. Trans cultural

competence as well as basic trans health education must be the minimal requirements for the accreditation of health care facilities. Organizations such as the American Public Health Association and the American Medical Association should follow-up public statements of support for accreditation requirements with action, lobbying the Accreditation Council for Graduate Medical Education and the Liaison Committee on Medical Education to amend accreditation requirements for medical schools and residency programs. These changes should be made in educational programs for all health care providers, including physicians, nurses, technicians, and others. This process must include a significant research component as well as collaboration with organizations that have already developed recommendations for trans health care and trans cultural competencies, such as the Gay and Lesbian Medical Association, the National Center for Transgender Equality, and the National Coalition for LGBT Health. Foremost, the development of new standards for health care provider education should consult transgender individuals and health care providers who have served this population.

APPENDIX A

INSTITUTIONAL REVIEW BOARD APPROVAL LETTER



University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508 (fax)
<http://www.irb.pitt.edu/>

Memorandum

To: Katherine Buchman
From: Sue Beers, PhD, Vice Chair
Date: 2/18/2010
IRB#: [PRO10020200](#)
Subject: Health Care Access Among Rural and Urban Transgender Individuals in Tennessee:
Identifying Barriers and Resilience

The above-referenced project has been reviewed by the Institutional Review Board. Based on the information provided, this project meets all the necessary criteria for an exemption, and is hereby designated as "exempt" under section 45 CFR 46.101(b)(2).

The IRB has approved the advertisement that was submitted for review as written. As a reminder, any changes to the wording of the approved advertisement would require IRB approval prior to distribution.

Please note the following information:

- If any modifications are made to this project, use the "**Send Comments to IRB Staff**" process from the project workspace to request a review to ensure it continues to meet the exempt category.
- Upon completion of your project, be sure to finalize the project by submitting a "**Study Completed**" report from the project workspace.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

APPENDIX B

NOTICE OF CONFIDENTIALITY

Focus Group Discussion with Transgender Individuals About Health Care Access: March 2010

The purpose of our discussion today is to learn about the experiences that transgender individuals have with health care access, and the general challenges and barriers as well as the strengths for transgender individuals in accessing health care. I am not going to ask you about your personal medical history, but rather about general experiences you have had with health care access, or that you have heard about from others. I asked you for your zip code because I am interested in how your experiences differ between those who live in rural and urban areas. I will not ask you to use your real name during the discussion today, nor will I record your contact information.

Everything which is said during this focus group discussion should be considered confidential. Please do not repeat anything you hear in this room today. This discussion will be taped, and after the tape has been transcribed it will be destroyed. All notes and tapes from our discussions will be kept locked or in password protected files. I, Katherine Buchman, will be the only person with access to those files.

If you have any concerns about the study or would like more information you are encouraged to contact me at Katherine Buchman kjb39@pitt.edu or (615) 668-8649. You may also contact my academic advisor, Dr. Thomas Guadamuz at teg10@pitt.edu.

APPENDIX C

EMAIL RECRUITMENT SCRIPT

Katherine Buchman, a native Tennessean who is a graduate student in Public Health at the University of Pittsburgh is looking for transgender Tennesseans to participate in a research study. As part of her master's thesis she is asking you to talk about your experiences and opinions about accessing health care as a transgender individual, and she is very interested in hearing from people in both rural and urban parts of Tennessee.

Katherine will be conducting focus groups during the week of March 1-7 and would like it very much if you would participate, or pass on this information to friends of yours who are transgender, and might be willing to participate. Female-to-male, male-to-female, or transgender individuals who identify another way are all encouraged to participate.

For the convenience of those who plan to attend the Advancing Equality on the Hill event being sponsored by Tennessee Equality Project on March 2, there will be several focus groups in Nashville the days before and after the event. We will also hold focus groups in other parts of Tennessee so that people who are not able to travel to Nashville can have their opinions and experiences heard.

Your voice matters! Participating in this research gives you the opportunity to help public health researchers and community organizers address the concerns affecting you and your community. **Your participation will be completely anonymous and you will not be asked to provide any personal information about yourself or your health.**

Participants will be given incentives and snacks will be provided.

If you are interested in participating in a focus group or would like more information please contact the researcher, Katherine Buchman at kjb39@pitt.edu or by phone at 412-383-7591. You may also contact her faculty advisor, Dr. Thomas E Guadamuz, at teg10@pitt.edu.

For local character references for Katherine please ask and she will direct you toward LGBT individuals in Nashville who can confirm her trustworthiness and goodwill.

Thank you!

APPENDIX D

FOCUS GROUP DISCUSSION QUESTIONS

1. Tell me about the town/area where you live, and the people who live there.
2. Describe your experiences getting health care in your area/ being able to get health care.
3. I want to know what the barriers or challenges are that make it difficult to get the health care you want or need. ...or those of someone you know.
4. Sometime we hear about trans men and women being denied care or discriminated against- tell me about any experiences you've had with discrimination, or things you've heard about from friends or others.
5. How do you decide where to go for health care? ...in your community or out of town?
6. We've talked about what makes it difficult to access care. Tell me what makes it easy, or how you and others get around these barriers.
7. How could we improve your access to health care- generally, and trans-care specifically?
How much do you feel like your voice would/should be heard in that process?

APPENDIX E

ANONYMOUS DEMOGRAPHIC QUESTIONNAIRE

Focus Group on Health Care Access

What is your home zip code? _____

What gender or sex do you identify with? _____

How old are you? _____

What is your race or ethnicity? _____

What is the highest level of education you have completed? _____

What is your profession? _____

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