Gender Nonconforming, Transgender, and Transsexual Patient Navigation of the American Health Care System: Locating a Primary Care Provider

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Gender Nonconforming, Transgender, and Transsexual Patient Navigation of the American Health Care System: Locating a Primary Care Provider

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science at Virginia Commonwealth University.

By

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Master of Science
Virginia Commonwealth University, August 12, 2016

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Abstract

GENDER NONCONFORMING, TRANSGENDER, AND TRANSSEXUAL PATIENT NAVIGATION OF THE AMERICAN HEALTH CARE SYSTEM: LOCATING A PRIMARY CARE PROVIDER

By Justin Michael Vinneau, M.S.

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science at Virginia Commonwealth University

Virginia Commonwealth University

Major Director: Dr. Susan Bodnar-Deren, Assistant Professor, Sociology

This study explores the experiences of gender nonconforming (GNC), transgender, and transsexual (trans) people in the search for a primary care provider in the United States. The current body of literature on transgender health often discusses HIV rates, substance use, mental health/suicide, and few studies have studies primary care seeking behaviors; this study seeks to provide new insight into the primary care (pcp) seeking behaviors of GNC and trans people. The primary theoretical perspectives utilized in this study were West and Zimmerman’s (1987) “Doing Gender” and the Health Beliefs Mode (Ayers et al., 2007; Connor and Norman, 2005; Green and Murphy, 2014). In order to explore the pcp seeking behaviors among GNC and trans individuals, I designed a 45 item survey. The survey was posted on-line on three separate “sub-reddits” between March and April of 2016 and was open to all individuals who self-identified as gender nonconforming, transgender, and/or transsexual. Of 96 responses, 68 were included. Although the sample is small, the results showed that structural barriers were significantly associated with having a PCP. Those with health insurance \( (p=0.031) \) and those with at least one chronic illness \( (p=0.037) \) were more likely to have a regular primary care provider. Descriptive findings support the role of socio-
economic factors, geographic location, and past experiences of discrimination as predictors of primary care status.

**Keywords:** Gender nonconforming; Transgender; Transsexual; Trans; Health; Health care; Primary care; PCP; Patient Navigation; Health Beliefs Model; American Healthcare

**Abbreviations and Acronyms:** PCP – Primary care provider; GNC – Gender Nonconforming; HBM – Health Beliefs Model; Trans – Transgender/Transsexual; MtF – Nataly male to female; MtX – Nataly male to other gender; FtM – Nataly female to male; FtX – Nataly female to other gender
Introduction

The current study is an exploratory, primarily quantitative analysis of the experience of gender nonconforming, transgender, and/or transsexual people in their search for a primary care provider within the United States. The goals of this study are two-fold. First to establish an understanding of what variables, if any, are deterring or preventing gender nonconforming, transgender, and/or transsexual people from seeking out primary care. The second is to identify what characteristics are present in those who have successfully located a primary care provider. This research is being done in response to a gap in the current body of literature and will serve as step towards identifying and analyzing barriers in primary care accessibility among the gender nonconforming, transgender, and transsexual population.

Background

Gender Nonconforming, Transgender, and Transsexual

Traditionally, the United States, like many other Western nations, has maintained a socially expected gender binary – in which gender identity necessarily aligns with natal sex, or the sex one is assigned at birth (e.g. male, female; Hendricks and Testa, 2012; West and Zimmerman, 1987). The term “transgender” refers to a person whose gender identity, gender expression, and/or sexual expression does not align with their natal sex (Alegria, 2011; Hendricks and Testa, 2012; Miller et al., 2015; Porter et al., 2016; Vance, Ehrensaft, and Rosenthal, 2014). While “transgender” is certainly the most recognizable term used to describe this population, it does not always accurately describe a person’s identity. Although not necessarily separate from transgender, “transsexual” has been used to refer to individuals who have undergone sex reassignment surgery and now phenotypically present as their intended gender (Alegria, 2011). “Gender nonconforming” (GNC) is another commonly used term to describe a person’s gender
identity that does not normatively align with the binary (Hendricks and Testa, 2014; Porter et al., 2016; West and Zimmerman, 1987).

However, no one term can accurately describe all gender identities. For example, cross-gender individuals often identify within the gender binary but as the opposite gender – “trans men” (FtM) for those who identify as male and “trans woman” (MtF) for those who identify as female (Hendricks and Testa, 2012; Nadal et al., 2012). There are, however, GNC and trans individuals who do not maintain identities within the binary. These identities may include, but are certainly not limited to: androgynous, genderqueer, third gender, and two-spirit (Hendricks and Testa, 2012; Nadal et al., 2012).

**GNC and Trans Health**

Since the 1990s, there has been an increasing body of literature specific to GNC and trans health. Although there is little to no literature regarding primary care seeking behaviors in the GNC and trans population specifically, the available literature provides insight into extremely important aspects of healthcare: HIV prevalence and prevention, substance overuse and abuse, mental health and suicidality, barriers to care, and standards of care for GNC and trans people. A number of studies have found that GNC and trans individuals face disproportionately high infection rates of HIV, often as a result of unprotected sex and/or the sharing of needles during intravenous drug use or hormone use; HIV rates are particularly high among the male-to-female (MtF) population (Bradford et al., 2013; Clements-Nolle et al., 2001; Garofalo et al., 2006; Herbst et al., 2007; Kenagy and Bostwick, 2005; Nemoto et al., 2004). Substance abuse is also a common health concern among GNC and trans individuals; often, feelings of marginalization, stigma, and mental health disorders (depression, anxiety, etc.) are attributed as the reason for an
increased rate of substance abuse in this population (Bentosch et al., 2013; Hughes and Eliason, 2002; Jordan, 2000). Mental health disorders and suicidality, as mentioned in regards to substance abuse, are quite prominent (Burgess et al., 2007; Clements-Nolle, Marx, and Katz, 2006; Grossman and Augelli, 2007; Haas et al., 2011; Mathy, 2002; Mustanski, Garafalo, and Emerson, 2010; Walter et al., 2013). Although it may be difficult to say with complete certainty, the root of many of these disorders is often thought to be societal stigma, marginalization, and isolation.

Although there have been improvements in healthcare accessibility and utilization for GNC and trans people, the healthcare system in the United States does not fully accommodate GNC and trans people, thus leaving the population underserved and unable to receive comprehensive healthcare (Feldman and Bockting, 2003; Rublin, 2015). GNC and trans individuals report a consistent inability to access adequate healthcare due to a lack of appropriately trained medical professionals, episodes of discrimination and refusal of service on the part of medical professionals, social stigma surrounding gender identity, fear of violence or abuse as a result of gender identity, and the like (Bradford et al., 2013; Cruz, 2014; Hatzenbuehler, 2009; Kmietowicz, 2015; Miller and Grollman, 2015; Poteat, German, and Kerrigan, 2013; Safer et al., 2016; N. Sanchez, J. Sanchez, and Danoff, 2007; Witten, 2014; Witten, 2016; Witten and Eyler, 1999; Witten and Eyler, 2012). In response to this, a growing body of literature has begun to provide resources for healthcare professionals that are designed to help combat stigma and discrimination while simultaneously increasing quality of care in GNC and trans people (Coleman et al., 2012; Lombardi, 2001; Poteat, German, and Kerrigan, 2013; Safer et al, 2016; Vance, Ehrensaft, and Rosenthal, 2014).
Theory

Doing Gender and Doing Heteronormativity

American society typically maintains gender as a binary phenomenon and those who do not normatively align with this binary are seen as nonconformist (West and Zimmerman, 1987). The United States has historically not offered social space, public recognition, or support for those who deviate from normatively assumed gender identities and, as a result, GNC and trans people are often met with confusion, hostility, and, in extreme cases, violence (West and Zimmerman, 1987). West and Zimmerman’s (1987) proposition challenges the normative assumption of gender and offers the argument that gender is a socially constructed phenomenon rather than being inherently linked to natal sex. This position challenges the foundation of the gender binary and attempts to remove all traits assumed to be inherent with masculinity and femininity. A major problem, however, is that social institutions serve as vessels in the replication of traditionally dichotomized gender identities while simultaneously devaluing those of gender minorities or nonconformists. This is done through the process of “doing gender” (West and Zimmerman, 1987).

One “does gender” on the daily basis – simple behaviors, clothing choices, speech patterns, and how others perceive you all factor into gender (West and Zimmerman, 1987). This interpretation of gender is contrary to the biological understanding of gender, which asserts that there are inherently masculine or feminine behaviors. This perspective posits that gender is a wholly social and psychological construct and that it is maintained and replicated through social interaction and social institutions (e.g. media, legal statute, etc.). In this context, GNC and trans individuals, as well as individuals who maintain “normative” gender identities, are constantly acting in ways to maintain gender expression and identity. The difference, however, is that GNC
and trans population must navigate a system that expects conformity and does very little to cater to anything but the norm.

Expanding on West and Zimmerman’s concept of “doing gender”, Schilt and Westbrook (2009) introduce the idea of “doing heteronormativity”. This perspective seeks to address the issue of gender nonconformity alongside the concept of heteronormativity. As with normative gender identities, heterosexuality is often assumed to be the norm in the United States. The gender binary creates a power struggle that favors both masculinity and heterosexuality; those who identify and possess these qualities often have more “class status, power, and privilege than others,” (Schilt and Westbrook, 2009). Societal preferences and assumptions such as these maintain an atmosphere of heterosexism, homophobia (the irrational fear or hatred of homosexuals), and transphobia (the irrational fear or hatred of transgender and/or gender nonconforming individuals) (Schilt and Westbrook, 2009). Conflict then arises when the normative assumptions of gender and sexuality are perceived to be challenged or interrupted. These interruptions disrupt the mainstream, heterosexist logic which may, and often does, lead to adverse reactions from normatively gendered individuals (Schilt and Westbrook, 2009). These reactions can range from personal disdain or confusion to overt expressions of anger or violence directed at transgender or gender nonconforming people (Schilt and Westbrook, 2009).

An interesting and important point to remember is that in most interactions and social encounters, traditionally gendered people and gender nonconforming or transgender people are indistinguishable (Schilt and Westbrook, 2009). One situation in which a high likelihood of risk occurring is in sexual encounters; in these instances, the physical body is presented in its entirety and any differences between gender identity and natal sex can be observed (Schilt and Westbrook, 2009). The overt presentation of the exposed body can be paralleled to the medical
encounter (Witten, 2014 (a); Witten, 2014 (b)). Dissimilar to sexual situations, medical
encounters often occur in professional environments with certain expectations and regulations in
place. The potential conflict is that, while medical professionals receive specialized training and
are often viewed as unbiased, they are still subject to the same reaction as any other traditionally
gendered individual. Experiences or the expectation for experiences such as these can be
deterrents for GNC and trans people who are considering seeking out primary care (Witten, 2014
(a); Witten, 2014 (b)).

Health Beliefs Model

The Health Beliefs Model (HBM) (Ayers et al., 2007; Connor and Norman, 2005; Green and
Murphy, 2014) is a useful lens through which to think about trans health seeking behavior. Since
the mid-1900’s the (HBM) has been one of the most often used psychosocial approaches to
explaining health-related behaviors (Ayers et al., 2007; Connor and Norman, 2005; Green and
Murphy, 2014). This model is intended to explain and predict health-related behaviors based
upon individual beliefs and attitudes (Ayers et al., 2007; Connor and Norman, 2005; Kirscht,
1974; Schnall, Rojas, and Travers, 2015). Often, this model seeks to examine two types of
behaviors: (preventative) health behaviors and illness behaviors. Health behaviors are those that
a person does in order to prevent disease or to detect a disease in its asymptomatic stage (Kasl
and Cobb, 1966; Rosenstock, 1974). Contrarily, an illness behaviors are those that a person does
in order to diagnose an illness and discover a suitable treatment (Kasl and Cobb, 1966;
Rosenstock, 1974).

The health belief model suggests that an individual’s health behaviors are impacted by
their: beliefs about a health concern (perceived susceptibility and severity); perceived benefits, as
well as barriers to action; and perceived self-efficacy, or one’s perceived ability to succeed in a situation and/or accomplish a desired task (Schnall, Rojas, and Travers, 2015). All of these factors are then considered in context – individual demographic characteristics, racial identity, sexual and gender identity, physical access to healthcare treatment, health insurance status, peer behavior, etc. These characteristics are known as “modifying factors” (Schnall, Rojas, and Travers, 2015).

![Health Beliefs Model](image)

*Figure 1: Health Beliefs Model – Adapted from Melina Butterworth’s Explanation of the HBM*

In the context of the current study, the HBM can be used to explain many of the reasons why GNC and trans individuals do not utilize preventative and comprehensive primary care. Studies have shown that, even if GNC and trans people are able to receive healthcare, many feel reluctant to and will postpone doing so, often due to discrimination (Bradford et al., 2013; Cruz, 2014; Grant et al., 2011; Kidd & Witten, 2008; Jackson, Johnson, and Roberts, 2008; Redman, 2011; Witten, 2014 (a); Witten, 2014 (b); Witten, 2016; Witten and Eyler, 1999; Witten and Eyler, 2012). While discrimination is a clear deterrent for many individuals, there may be other variables that impact GNC and trans decision-making. This population is at a disproportionately high risk of employment discrimination and poverty (thus affecting income and insurance status; Bradford et al., 2013; National Transgender Discrimination Survey, 2009; Witten, 2014; Witten,
2016), as well as social and psychological abuse and violence (Bradford et al., 2013; Grant et al., 2011; Jauk, 2013; Lombardi et al., 2001; Merry, 2006; National Transgender Discrimination Survey, 2009; Nuttbrock et al., 2010; Nuttbrock et al., 2013; Witten, 2014 (a); Witten, 2014 (b); Witten and Eyler, 1999; Witten and Eyler, 2012). While it may not be the case in every situation, past experiences such as these could serve as current barriers to seeking primary care.

**Methodology**

**Instrument**

The survey instrument consisted of an information and consent form, a preliminary questionnaire to determine eligibility to participate, and a 45-item survey. The items of the survey were developed based upon the exploratory goals of this study; many questions utilized from previous studies on patient access to primary care and/or transgender health research. The survey was primarily quantitative in nature, but often allowed participants to elaborate or provide further detail to their answers. I am not classifying this study as wholly mixed-method as the qualitative component was not substantial enough and was not heavily examined in analysis. The purpose of including open-ended questions was two-fold. The primary purpose was to allow participants to elaborate upon answers that would otherwise be reductive, while a secondary purpose was to ensure that all aspects of a phenomena could be captured, as the study is exploratory in nature.

The survey was broken up into 6 sections. Section 1 dealt with questions regarding the participants’ gender and sexual identity, as well as presentation to others. Section 2 requested demographic information from participants (e.g. educational attainment, employment status, household income, etc.). Section 3 asked specifically about health insurance status and insurance provider. Section 4 focused on points regarding primary care. Section 5 asked whether the
participant utilizes specialty medical care. Section 6 asked more general questions about the American health care system and participants’ past experiences within this system.

Data Collection Sources

Data were collected through the use of an online, forty-five item, self-administered survey (see Appendix I). The survey was posted to the website www.reddit.com. Specifically, a short call for participants was posted along with a link to the following “subreddits”: reddit.com/r/samplesize, reddit.com/r/asktransgender, and reddit.com/r/transhealth. While each of these “subreddits”, or “subs”, are hosted through reddit.com, it is important to note that each acts as an independent blog with a specialized focus. Reddit.com/r/samplesize is specifically designed for individuals to post questionnaires and surveys of any kind for the subscribers of this “sub” to see. Similarly, reddit.com/r/asktransgender is a space designed for anyone to pose questions to the trans community, while reddit.com/r/transhealth is dedicated to discussing and sharing information regarding anything relating to the health of the trans community. In order to ensure proper etiquette, the moderators of each sub were contacted prior to posting the call for participants. Six “subs” were contacted, and three responded with messages allowing me to post. The original posts were made on February 8, 2016 and were reposted to reddit.com/r/samplesize and r/transhealth on March 23, 2016 and March 25, 2016 respectively. The survey remained active until April 2, 2016. I would like to note that this period of time was extremely short and may have contributed to the small sample size used in this study. Time constraints due to academic calendars and timeframes were the primary reason for the short timeframe for data collection.

Eligibility Criteria
The eligibility of potential participants was based on the following four criteria: that the respondent 1) be at least age 18, 2) be able to speak and understand English, 3) be an American citizen, and 4) self-identified as gender nonconforming, transgender, and/or transsexual. To insure confidentiality, participants were not asked any identifiable information and were reminded on several occasions to refrain from disclosing any details that could in any way identify them (i.e. geographic location, last names, phone numbers, physician names, etc.). Also, participants were not asked to sign any documents; instead, an electronic consent form was presented to all participants prior to beginning the survey. In order to begin the survey, the participant was told to read the form in its entirety and then check a box indicating that they had read the consent form and agreed to participate in the study. Respondents were not provided compensation for this study and participation was wholly voluntary.

Measures

*Gender and Sexual Identity.* The first section in the survey instrument inquired about the respondents’ gender and sexual identities as they perceive them and as how they feel others perceive them. As respondents could select multiple identities, the categories were collapsed for practical analytical purposes. In the case of the respondent’s gender as perceived by others, the categories were collapsed into four options – 1. Transgender (if transgender was marked), 2. Transsexual (if transsexual was marked), 3. Neither transgender nor transsexual (if neither transgender nor transsexual was marked), 4. Both transgender and transsexual (if both transgender and transsexual were marked). Gender self-perception was also recoded in a similar fashion with five categories – 1. Transgender (if the individual marked transgender but did not mark their natal sex or their gender presentation), 2. Trans-man/Man of trans experience (if the
individual marked a transgender identity and also noted a masculine/male gender identity), 3. Trans-woman/Woman of trans experience (if the individual marked a transgender identity and also noted a feminine/female gender identity), 4. Genderqueer/Gender Nonconforming (if the individual did not mark transgender in any way, but did mark genderqueer or another gender nonconforming identity), 5. Other. No disrespect was intended towards any participants who may not maintain any of these identities; the GNC and trans population is diverse and identities do not always fit into analytical boxes. This section also included a question about “outness” (how aware others are of respondent’s gender identity), sex shown on driver’s license, and sex assigned at birth.

**Demographics.** Demographic characteristics included educational attainment (high school or less, some college/vocational, bachelors or higher), employment status (full-time, part-time, unemployed, student), annual household income (<$15,000, $15,000-$54,999, $55,000<), relationship status (single, long-term relationship, cohabitating, married, other), living status (alone, with significant other, parent, child/relative, friend/roommate), whether or not they have a child under the age of 18, and geographic region (city, suburbs, or rural). Racial identity, which initially included six categories was recoded to the dichotomous variable 1. White and 2. Non-white; the purpose of this was to ease analysis and was in no way meant to offend any individuals whose identity does not align with these categories.

**Health Insurance Status.** Respondents reported their health insurance status and, if they had health insurance, what kind of policy it was: employee based (private), individual plan (private), Medicare/Medicaid (public), other.
**Primary Care Provider Status.** Respondents were asked if they currently have a primary care provider and if they had ever had difficulty locating a primary care provider. For this study, primary care provider was defined as “the person that you see for your regular medical care”. If they responded that, yes, they do have a primary care provider, they were prompted with question regarding: how they located their primary care provider, how comfortable they are with discussing their gender/sex status with their primary care provider (recoded to the dichotomous variable: very uncomfortable/uncomfortable or very comfortable/comfortable), how knowledgeable their primary care provider is about their gender/sex-related health concerns, and if they had any fears or concerns about discussing their health with their primary care provider.

**Specialty Care Status.** Participants were asked to report any specialty care that they receive (e.g. endocrinologist, gynecologist, etc.). If they did report utilizing specialty care, they were asked what type of specialty care and if this specialist was their primary care provider. The purpose here is to be as inclusive as possible as some GNC or trans individuals may be undergoing hormone therapy or sex reassignment surgery, which may lead them to having a specialist primary care provider.

**General Health.** The survey also sought to examine self-assessed health, particularly in relationship to the health beliefs model. In this section, participants were asked if they had any chronic illnesses and, if so, what they were – this was recoded into three categories for analytical purposes: 1. No chronic illness, 2. One or two chronic illnesses, and 3. Three or more chronic illnesses. In this section, participants were also asked if they had any difficulties receiving care in
the last calendar year, general difficulty receiving health care, whether or not they had ever experienced discrimination on the part of health care providers, and if they have ever had to educate medical professionals about their health care needs as a GNC or trans person.

**Data Analysis**

I used IBM SPSS statistical software 23 to perform my analysis. Chi-square tests for significance were utilized to determine if there were any significant associations between participant characteristics and primary care status. All tests for significance were done at a $p<.05$ level.

1. **Demographic Characteristics.** I analyzed all demographic variables to examine their association with primary care provider status. In these bivariate analyses, primary care provider status (survey item 27) was the independent variable. Dependent variables included in this analysis were: recoded gender self-perception, recoded gender perception to others, age, recoded racial identity, recoded employment status, recoded household income, regional location, relationship status, living status, and child status. These variables were included in analysis due to the body of literature regarding employment/housing discrimination, high rates of poverty, and fear of abuse or rejection of care due to GNC or trans gender identity (Bradford et al., 2013; Grant et al., 2011; Jauk, 2013; Lombardi et al., 2001; Merry, 2006; National Transgender Discrimination Survey, 2009; Witten and Eyler, 1999). Analysis of regional location is based on literature discussing accessibility of healthcare based on urban, suburban, or rural location (Arcury et al., 2005; Arcury et al., 2005; Fields and Briggs, 2001; Martinez-Donate et al., 2013).
2. Health Care. Health-related variables were also analyzed in order to examine their relationship with the independent variable “primary care provider status”. The dependent variables in these bivariate analyses were: self-assessed health, chronic illness status, insurance status, insurance type, whether or not they had difficulties locating a primary care provider, how they located their primary care provider, their comfort in discussing gender/sex-related health concerns with their primary care provider, and whether or not they have had to educate their primary care provider about their health needs. Questions regarding self-assessed health, chronic illness status, and perceived ability to receive healthcare were included based on literature regarding health trends in the GNC and trans population, as well as literature regarding the HBM (Ayers et al., 2007; Bradford et al., 2013; Connor and Norman, 2005; Cruz, 2014; Kirscht, 1974; Schnall, Rojas, and Travers, 2015). Patients educating medical professionals was also included as it has been reported to be an exhausting process and serve as a barrier to care seeking (Bradford et al., 2013).

Results

Out of an original sample of 96 responses, 68 were usable for the purposes of this study. 22 of the 28 responses excluded did not provide answers for sections 3, 4, and 5; the remaining 6 did not answer any questions following section 1. The exclusion of these answers meant that there was little to no information regarding their experience in the healthcare system.

Demographic Characteristics

The mean sample age was 27.78 years (SD = 7.069 years). The majority of the sample self-identified as sexual minorities (4.4% gay, 19.1% lesbian, 29.4% bisexual, 7.4% asexual, 17.6%
Gender Nonconforming, Transgender, and Transsexual Patient Navigation

pan/omni sexual, 10.3% questioning, and 2.9% queer); approximately two-thirds (66.2%) of respondents self-identified as transgender (4.4% transgender, 14.7% transmen/men of trans experience, 47.1% transwomen/women of trans experience) while 11.8% self-reported genderqueer or gender nonconforming identities; nearly the entire sample (91.2%) reported White racial/ethnic identities; just over half (52.9%) of respondents report being single. In terms of educational attainment, 41.2% of participants reported having some college or vocational training and 45.6% reported having a Bachelor’s degree or higher; 20.6% were unemployed, 35.3% reported being students, 4.4% maintain part-time work schedules (not including students), and 39.7% maintain full-time work schedules; one quarter (25%) of respondents reported annual household incomes below $15,000. In terms of geographic location, the majority of the sample reported living in a city (69.1%) while 11.8% lived in rural regions and 19.1% in suburban regions.

**Healthcare Access and Primary Care Characteristics**

The majority of respondents self-reported having a current health insurance policy (85.3%). Of those who reported having health insurance, 91.3% reported holding private insurance policies (employer policy 60.3% and individual policy 31%), and 8.7% held public insurance policies (Medicare/Medicaid). Roughly half of the respondents self-reported previous difficulty locating a primary care provider (52.9%) and over half reported currently having a primary care provider (69.1%); 38.2% report utilizing specialist care (primarily endocrinologists, gynecologists, and mental health professionals), and of those utilizing specialist care, 10.3% of respondents use these specialists as primary care providers.
In terms of comfort among those who currently have primary care providers (n=47), 34% reported being “very uncomfortable/uncomfortable” when discussing gender/sex status and related health care needs with their primary care providers; in this same group, 64.4% of people said that their current primary care provider is either “knowledgeable/very knowledgeable” about their gender/sex-related health care concerns and needs; the majority of respondents (55.9%), however, reported ever having to educate their doctor or health care provider about their needs as a GNC or trans person. The majority of respondents (63.2%) have never experienced discrimination by a doctor or other health care provider due to their gender or sex status/expression and 57.5% either said they “strongly disagree/disagree” with the following statement: “Medical professionals treat gender nonconforming/transgender/transsexual patients with the same amount of respect as their other patients.”

**Health and Illness Characteristics**

36.4% of respondents reported having a “very difficult/difficult” experience receiving health care when they needed it, and 72.1% of said that, in the past 12 months, they have not had any difficulties accessing medical care. The majority of respondents self-reported having no chronic illnesses (67.6%), while 14.7% reported having one or two chronic illnesses and 17.6% having three or more.

**Bivariate Analysis**

Finally, as illustrated in tables 1 and 2, bivariate analyses between sociodemographic, health care access, and health/illness characteristics and the presence of having a PCP, revealed only two statistically significant relationships: health insurance status and PCP status (p=.031) and chronic
illness status and PCP status \((p=0.037; \text{see Table 1})\). The closest any other associations approaching significance were: household income and PCP status \((p=0.056)\) and past difficulties obtaining care and PCP status \((p=0.055)\). There are, however, notable points to consider from descriptive analysis.

**Discussion**

The results of this study provide some insight into the experiences of GNC and trans individuals. Consistent with the HBM, participants who had health insurance were more likely to have a primary care provider; the presence of health insurance removes a prominent fiscal barrier to receiving healthcare (Ayers et al., 2007; Connor and Norman, 2005; Kirscht, 1974; Schnall, Rojas, and Travers, 2015). Also, participants who had at least one chronic illness were more likely to have a primary care provider; this behavior falls more clearly in-line with illness behaviors, that is, behaviors that come in response to an illness/disorder (Kasl and Cobb, 1966; Rosenstock, 1974).

In line with research on primary care access in the general population, GNC and trans individuals reported having economic barriers to care (Afilalo et al., 2008; Cheung, Willer, and Ginde, 2011; Cheung, Willer, and Ginde, 2011; Cheung et al., 2012; D’Avolio et al. 2013; Newacheck et al., 1998). As mentioned, a statistically significant relationship existed between health insurance status and primary care provider status; another near significant relationship existed between annual household income and primary care status. These findings suggest that if an individual has a valid health insurance policy, regardless of type, as well as an income level above $15,000 per year, then they are more likely to have a primary care provider. The GNC and trans population is at a disproportionately higher rate of poverty, which may be extremely
important in understanding primary care-seeking behaviors and barriers (National Transgender Discrimination Survey, 2009). Socio-economic variables and characteristics appear to be key factors in primary care seeking.

Another important aspect to primary care access is geographic location. While there was no clear statistical relationship between geographic region and primary care status, there were responses that made it clear that access to care was impeded by their distance to a reliable, trained care provider. For example, respondents reported that they had difficulties finding providers because they were “living in an area with a lack of trans-knowledgeable/friendly providers,” “in an extremely rural area and looking for LGBT-friendly coverage,” “[in an area where] many local physicians are not comfortable with transgender patient treatment,” “[in a] very rural area. . . [and] the next closest doctor that they could refer me to is 4 hours away.” As with standard medical care, lack of transportation or nearby medical care is a barrier to access (Arcury et al., 2005; Arcury et al., 2005; Fields and Briggs, 2001; Martinez-Donate et al., 2013). An added dimension to this situation is that many of the respondents reported that there were, in fact, primary care providers nearby; however, they did not feel comfortable seeking them out and/or were not welcome in their offices due to trans-related discrimination.

Fear of discrimination, feeling uncomfortable with certain physicians, and outright refusal of services were also reported as reasons for why respondents had difficulty accessing primary care identity (Bradford et al., 2013; Grant et al., 2011; Jauk, 2013; Lombardi et al., 2001; Merry, 2006; National Transgender Discrimination Survey, 2009; Witten and Eyler, 1999). Not only this, respondents also report many situations in which the physician was willing to provide care, but had not received the appropriate training to provide appropriate care for them as a GNC or trans person. These findings show that policy-level changes must occur within the
medical system – physicians and other healthcare providers need to be receiving training on how to appropriately treat GNC and trans individuals.

Respondents who have successfully located primary care providers often reported having support from peers or their community, hearing about the provider through word-of-mouth, or staying with a provider that they have had since childhood/adolescence.

**Limitations**

There are several limitations to consider for this study. The current sample study is probably non-representative. Participants were recruited via the use of non-probability sampling methods, only participants who had access to a working computer with internet access and a knowledge of www.reddit.com could participate in this study, and the sample size is quite small. Because of this, the findings are not generalizable; the sample was not large enough and was probably non-representative. Additionally, being that the sample was small and non-probability, inferential statistics were not practical, limiting my ability to examine associations.

Secondly, by hosting the study through reddit.com, the participants’ demographic characteristics are probably not representative of the GNC and transgender populations as a whole. The quantity of White, college student/college educated respondents is much higher than one would expect in a representative sample. To give some insight, the demographic makeup of reddit.com looks something like this: male, White, non-Hispanic, 18-29 years, have some college or a college degree, and live in an urban/suburban region (Duggan and Smith, 2013). Income levels are equally distributed based on descriptive analysis (Duggan and Smith, 2013). Although this is likely not representative, it does align with other, more large-scale research done on the trans population. Witten (2014; 2016) conducted online research and found that, much like the
current study, most respondents were White, health literate, and educated. These results likely do not provide clear insight into the rest of the trans population, but remain consistent.

Due to the nature of the study, participants were allowed to leave any question unanswered. This was a major problem in terms of inclusion in the study and analysis. If a participant failed to answer vital questions, even if it was one or two, they were excluded from the study entirely. Another inherent limitation with this study is that all responses were self-reported and, thus, are open to interpretation. Unfortunately, there were no methods available for participants to ask questions or clarify any concerns they may have with the instrument.

Conclusion

Limitations notwithstanding, this study serves as an entry into the untapped study of primary care-seeking behaviors among the GNC and trans populations and provides insight into some of the reasons GNC and trans people do not seek primary care, as well as what characteristics are often present in those who have done so successfully. In this sample, the variables that primarily impacted primary care status were structural and traditional health.

I would like to mention that this research is likely the “best of the worst”. What I mean is that, based on this sample and the online samples of other research on trans health, the participants were educated, health literate, and, more often than not, financially secure (Witten, 2014; Witten, 2016).

This research adds to the body of literature surrounding GNC and trans healthcare and supports the notion for structural changes and policy implications for the improvement of care and access to care. Future research in this field should utilize a larger, more diverse sample in order to provide more clear insight into the true experiences of the population as a whole. Online
research may be a good way to reach participants; however, posting should be done on multiple venues in an effort to increase the reach of the study.

**Human Participation Protection**

This study was reviewed and approved by the institutional review board of Virginia Commonwealth University (Appendix II, III).
References


Gender Nonconforming, Transgender, and Transsexual Patient Navigation


D’Avolio, Deborah, Strumpf, Neville E., Feldman, James, Mitchell, Patricia, and Rebholz, Casey M. 2013. “Barrier to Primary Care: Perceptions of Older Adults Utilizing the ED for Nonurgent Visits”. *Clinical Nursing Research* 22(4): 416-431

Duggan, Maeve and Aaron Smith. 2013. “6% of Online Adults are Reddit Users”.


Witten, T. M. 2014 (a). “It’s Not All Darkness: Robustness, Resilience, and Successful Transgender Aging”. *LGBT Health, 1*


Image Reference

Figure 1. Retrieved From:

https://www.researchgate.net/profile/Melinda_Butterworth/publication/236709187/figure/AS:299290829312021@1448367902686/Figure-31-The-Health-Belief-Model-Flow-diagram-of-the-major-predictors-Source-Adapted.png
Appendix I

Data Tables
Table 1
Characteristics of sample by presence of primary care provider (N=68)

<table>
<thead>
<tr>
<th>Identity/Perception</th>
<th>Total N (%)</th>
<th>No PCP N (30.9)</th>
<th>Has a PCP N (69.1)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sexual Orientation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gay</td>
<td>3 (4.4%)</td>
<td>1 (4.8%)</td>
<td>2 (4.3%)</td>
<td>.846</td>
</tr>
<tr>
<td>Lesbian</td>
<td>13 (19.1%)</td>
<td>3 (14.3%)</td>
<td>10 (21.3%)</td>
<td></td>
</tr>
<tr>
<td>Bisexual</td>
<td>20 (20.4%)</td>
<td>8 (38.1%)</td>
<td>12 (52.5%)</td>
<td></td>
</tr>
<tr>
<td>Heterosexual</td>
<td>6 (8.8%)</td>
<td>1 (4.8%)</td>
<td>5 (10.6%)</td>
<td></td>
</tr>
<tr>
<td>Asexual</td>
<td>5 (7.4%)</td>
<td>1 (4.8%)</td>
<td>4 (8.5%)</td>
<td></td>
</tr>
<tr>
<td>Pan/Omni Sexual</td>
<td>12 (17.6%)</td>
<td>4 (19.0%)</td>
<td>8 (17.0%)</td>
<td></td>
</tr>
<tr>
<td>Questioning</td>
<td>7 (10.3%)</td>
<td>3 (14.3%)</td>
<td>4 (8.5%)</td>
<td></td>
</tr>
<tr>
<td>Queer</td>
<td>2 (2.9%)</td>
<td>0 (0.0%)</td>
<td>2 (4.3%)</td>
<td></td>
</tr>
<tr>
<td><strong>Identity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transgender</td>
<td>38 (55.9%)</td>
<td>10 (47.6%)</td>
<td>28 (59.6%)</td>
<td>.792</td>
</tr>
<tr>
<td>Transsexual</td>
<td>2 (2.9%)</td>
<td>1 (4.8%)</td>
<td>1 (2.1%)</td>
<td></td>
</tr>
<tr>
<td>Neither Transgender/sexual</td>
<td>22 (32.4%)</td>
<td>8 (38.1%)</td>
<td>14 (29.8%)</td>
<td></td>
</tr>
<tr>
<td>Transgender and Transsexual</td>
<td>6 (8.8%)</td>
<td>2 (9.5%)</td>
<td>4 (8.5%)</td>
<td></td>
</tr>
<tr>
<td><strong>Gender Self Perception</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transgender</td>
<td>3 (4.4%)</td>
<td>1 (4.8%)</td>
<td>2 (4.3%)</td>
<td>.578</td>
</tr>
<tr>
<td>Transman/Man of trans exp.</td>
<td>10 (14.7%)</td>
<td>1 (4.8%)</td>
<td>9 (19.1%)</td>
<td></td>
</tr>
<tr>
<td>Transwoman/Woman of trans exp.</td>
<td>32 (47.1%)</td>
<td>12 (57.1%)</td>
<td>20 (42.6%)</td>
<td></td>
</tr>
<tr>
<td>Genderqueer/GNC</td>
<td>8 (11.8%)</td>
<td>2 (9.5%)</td>
<td>6 (12.8%)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>15 (22.1%)</td>
<td>5 (23.8%)</td>
<td>10 (21.3%)</td>
<td></td>
</tr>
<tr>
<td><strong>How “Out” Are You?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>1 (1.5%)</td>
<td>0 (0.0%)</td>
<td>1 (2.1%)</td>
<td>.253</td>
</tr>
<tr>
<td>Slightly (Only closest friends)</td>
<td>12 (17.6%)</td>
<td>6 (28.6%)</td>
<td>6 (12.8%)</td>
<td></td>
</tr>
<tr>
<td>Somewhat (Close friends and family)</td>
<td>25 (36.8%)</td>
<td>10 (47.6%)</td>
<td>15 (31.9%)</td>
<td></td>
</tr>
<tr>
<td>Mostly (Nearly everyone)</td>
<td>17 (25.0%)</td>
<td>3 (14.3%)</td>
<td>14 (29.8%)</td>
<td></td>
</tr>
<tr>
<td>Completely (Everyone)</td>
<td>11 (16.2%)</td>
<td>2 (9.5%)</td>
<td>9 (19.1%)</td>
<td></td>
</tr>
<tr>
<td>Unsure</td>
<td>2 (2.9%)</td>
<td>0 (0.0%)</td>
<td>2 (4.3%)</td>
<td></td>
</tr>
<tr>
<td><strong>Sociodemographic Variables</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex on Driver’s License</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>40 (60.6%)</td>
<td>12 (57.1%)</td>
<td>28 (62.2%)</td>
<td>.694</td>
</tr>
<tr>
<td>F</td>
<td>26 (39.4%)</td>
<td>9 (42.9%)</td>
<td>17 (37.8%)</td>
<td></td>
</tr>
<tr>
<td>Sex Assigned at Birth</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>45 (67.2%)</td>
<td>15 (71.4%)</td>
<td>30 (65.2%)</td>
<td>.616</td>
</tr>
<tr>
<td>Female</td>
<td>22 (32.8%)</td>
<td>6 (28.6%)</td>
<td>16 (34.8%)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (s.d.)</td>
<td>27.78 (7.069)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>62 (91.2%)</td>
<td>18 (85.7%)</td>
<td>44 (93.6%)</td>
<td>.288</td>
</tr>
<tr>
<td>Non-White</td>
<td>6 (8.8%)</td>
<td>3 (14.3%)</td>
<td>3 (6.4%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total N (%)</td>
<td>No PCP N (30.9)</td>
<td>Has a PCP N (69.1)</td>
<td>p-value</td>
</tr>
<tr>
<td>---------------------------</td>
<td>-------------</td>
<td>-----------------</td>
<td>-------------------</td>
<td>---------</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full Time</td>
<td>27 (39.7%)</td>
<td>4 (19.0%)</td>
<td>23 (48.9%)</td>
<td>.115</td>
</tr>
<tr>
<td>Part Time</td>
<td>3 (4.4%)</td>
<td>1 (4.8%)</td>
<td>2 (4.3%)</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>14 (20.6%)</td>
<td>5 (23.8%)</td>
<td>9 (19.1%)</td>
<td></td>
</tr>
<tr>
<td>Student</td>
<td>24 (35.3%)</td>
<td>11 (52.4%)</td>
<td>13 (27.7%)</td>
<td></td>
</tr>
<tr>
<td><strong>Annual Household Income</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$15,000</td>
<td>17 (26.2%)</td>
<td>9 (42.9%)</td>
<td>8 (18.2%)</td>
<td>.056</td>
</tr>
<tr>
<td>$15,000 - $54,999</td>
<td>24 (36.9%)</td>
<td>8 (38.1%)</td>
<td>16 (36.4%)</td>
<td></td>
</tr>
<tr>
<td>$55,000&lt;</td>
<td>24 (36.9%)</td>
<td>4 (19.0%)</td>
<td>20 (45.4%)</td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School or Less</td>
<td>9 (13.2%)</td>
<td>1 (4.8%)</td>
<td>8 (17.0%)</td>
<td>.142</td>
</tr>
<tr>
<td>Some College/Vocational</td>
<td>28 (41.2%)</td>
<td>12 (57.1%)</td>
<td>16 (34.0%)</td>
<td></td>
</tr>
<tr>
<td>Bachelor’s Degree or Higher</td>
<td>31 (45.6%)</td>
<td>8 (38.1%)</td>
<td>23 (48.9%)</td>
<td></td>
</tr>
<tr>
<td><strong>City Size</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Large City (&gt;100,000 people)</td>
<td>29 (42.6%)</td>
<td>8 (38.1%)</td>
<td>21 (44.7%)</td>
<td>.620</td>
</tr>
<tr>
<td>Small City (&lt;100,000 people)</td>
<td>18 (26.5%)</td>
<td>5 (23.8%)</td>
<td>13 (27.7%)</td>
<td></td>
</tr>
<tr>
<td>Suburbs</td>
<td>13 (19.1%)</td>
<td>6 (28.6%)</td>
<td>7 (14.9%)</td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>8 (11.8%)</td>
<td>2 (9.5%)</td>
<td>6 (12.8%)</td>
<td></td>
</tr>
<tr>
<td><strong>Relationship status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>36 (52.9%)</td>
<td>13 (61.9%)</td>
<td>23 (48.9%)</td>
<td>.406</td>
</tr>
<tr>
<td>Long Term Relationship</td>
<td>13 (19.1%)</td>
<td>5 (23.8%)</td>
<td>8 (17.0%)</td>
<td></td>
</tr>
<tr>
<td>Living Together</td>
<td>8 (11.8%)</td>
<td>1 (4.8%)</td>
<td>7 (14.9%)</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>11 (16.2%)</td>
<td>2 (9.5%)</td>
<td>9 (19.1%)</td>
<td></td>
</tr>
<tr>
<td><strong>Do you have children?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7 (10.3%)</td>
<td>1 (4.8%)</td>
<td>6 (12.8%)</td>
<td>.206</td>
</tr>
<tr>
<td>No</td>
<td>60 (88.2%)</td>
<td>19 (90.5%)</td>
<td>41 (87.2%)</td>
<td></td>
</tr>
<tr>
<td>Unsure</td>
<td>1 (1.5%)</td>
<td>1 (4.8%)</td>
<td>0 (0.0%)</td>
<td></td>
</tr>
<tr>
<td><strong>Do you have any children under 18 living with you? (Of those with children)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>6 (85.7%)</td>
<td>1 (100%)</td>
<td>5 (83.3%)</td>
<td>.659</td>
</tr>
<tr>
<td>No</td>
<td>1 (14.3%)</td>
<td>0 (0.0%)</td>
<td>1 (16.7%)</td>
<td></td>
</tr>
<tr>
<td><strong>Living status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>12 (17.6%)</td>
<td>2 (9.5%)</td>
<td>10 (21.3%)</td>
<td>.206</td>
</tr>
<tr>
<td>Partner/S.O.</td>
<td>16 (23.5%)</td>
<td>2 (9.5%)</td>
<td>14 (29.8%)</td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>19 (27.9%)</td>
<td>8 (38.1%)</td>
<td>11 (23.4%)</td>
<td></td>
</tr>
<tr>
<td>Child/Relative</td>
<td>6 (8.8%)</td>
<td>3 (13.4%)</td>
<td>3 (6.4%)</td>
<td></td>
</tr>
<tr>
<td>Friend/Roommate</td>
<td>14 (20.6%)</td>
<td>6 (28.6%)</td>
<td>8 (17.0%)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>1 (1.5%)</td>
<td>0 (0.0%)</td>
<td>1 (2.1%)</td>
<td></td>
</tr>
</tbody>
</table>

Notes: Chi-Square and used for bivariate analyses (Fisher’s Exact test used for cell sizes less than 6). For continuous variable (age), t-test was used. Column percentages shown.
Table 2
Health characteristics of sample by presence of primary care provider (N=68)

<table>
<thead>
<tr>
<th></th>
<th>Total N (%)</th>
<th>No PCP N (30.9)</th>
<th>Has a PCP N (69.1)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Insurance status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has insurance</td>
<td>58 (85.3%)</td>
<td>6 (28.6%)</td>
<td>4 (8.5%)</td>
<td>.031*</td>
</tr>
<tr>
<td>Does not have insurance</td>
<td>10 (14.7%)</td>
<td>15 (71.4%)</td>
<td>43 (91.5%)</td>
<td></td>
</tr>
<tr>
<td><strong>Type of Insurance</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private – Employer Provided</td>
<td>35 (51.5%)</td>
<td>10 (47.6%)</td>
<td>35 (53.2%)</td>
<td>.174</td>
</tr>
<tr>
<td>Private – Individual Policy</td>
<td>19 (26.5%)</td>
<td>4 (19.0%)</td>
<td>14 (29.8%)</td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td>5 (7.4%)</td>
<td>1 (4.8%)</td>
<td>4 (8.5%)</td>
<td></td>
</tr>
<tr>
<td>No Insurance</td>
<td>10 (14.7%)</td>
<td>6 (28.6%)</td>
<td>4 (8.5%)</td>
<td></td>
</tr>
<tr>
<td><strong>Trouble finding a PCP</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>36 (52.9%)</td>
<td>14 (66.7%)</td>
<td>25 (53.2%)</td>
<td>.130</td>
</tr>
<tr>
<td>No</td>
<td>32 (47.1%)</td>
<td>7 (33.3%)</td>
<td>22 (46.8%)</td>
<td></td>
</tr>
<tr>
<td><strong>How did you find PCP</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you use a specialty care provider?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>26 (38.2%)</td>
<td>5 (23.8%)</td>
<td>21 (44.7%)</td>
<td>.102</td>
</tr>
<tr>
<td>No</td>
<td>42 (61.8%)</td>
<td>16 (76.2%)</td>
<td>26 (55.3%)</td>
<td></td>
</tr>
<tr>
<td><strong>Self-Rated Health</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>2 (3.0%)</td>
<td>1 (5.0%)</td>
<td>1 (2.2%)</td>
<td>.917</td>
</tr>
<tr>
<td>Fair</td>
<td>15 (22.7%)</td>
<td>5 (25.0%)</td>
<td>10 (21.7%)</td>
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</tr>
<tr>
<td>Good</td>
<td>21 (31.8%)</td>
<td>7 (35.0%)</td>
<td>14 (30.4%)</td>
<td></td>
</tr>
<tr>
<td>Very Good</td>
<td>21 (31.8%)</td>
<td>5 (25.0%)</td>
<td>16 (34.8%)</td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>7 (10.6%)</td>
<td>2 (10.0%)</td>
<td>5 (10.9%)</td>
<td></td>
</tr>
<tr>
<td><strong>Very Good Self Rated Health</strong></td>
<td></td>
<td></td>
<td></td>
<td>.421</td>
</tr>
<tr>
<td>Yes</td>
<td>28 (42.4%)</td>
<td>7 (35.0%)</td>
<td>21 (45.7%)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>38 (57.4%)</td>
<td>13 (65.0%)</td>
<td>25 (54.3%)</td>
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</tr>
<tr>
<td><strong>Chronic Illness</strong></td>
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<td></td>
<td></td>
<td>.037</td>
</tr>
<tr>
<td>Yes</td>
<td>22 (33.3%)</td>
<td>3 (15%)</td>
<td>19 (41.3%)</td>
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</tr>
<tr>
<td>No</td>
<td>44 (66.7%)</td>
<td>17 (85%)</td>
<td>27 (58.7%)</td>
<td></td>
</tr>
<tr>
<td><strong>Number of chronic illness condition</strong></td>
<td></td>
<td></td>
<td></td>
<td>.098</td>
</tr>
<tr>
<td>None</td>
<td>46 (67.7%)</td>
<td>18 (85.7%)</td>
<td>28 (59.6%)</td>
<td></td>
</tr>
<tr>
<td>One/Two</td>
<td>10 (14.7%)</td>
<td>1 (4.8%)</td>
<td>9 (19.1%)</td>
<td></td>
</tr>
<tr>
<td>Three or more</td>
<td>12 (17.6%)</td>
<td>2 (9.5%)</td>
<td>10 (21.3%)</td>
<td></td>
</tr>
<tr>
<td><strong>Was there a time in the last year where you needed medical help and could not get it?</strong></td>
<td></td>
<td></td>
<td></td>
<td>.081</td>
</tr>
<tr>
<td>Yes</td>
<td>17 (25.8%)</td>
<td>8 (40.0%)</td>
<td>9 (19.6%)</td>
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<tr>
<td>No</td>
<td>49 (74.2%)</td>
<td>12 (60.0%)</td>
<td>37 (80.4%)</td>
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<tr>
<td><strong>How difficult has it been to receive health care when you needed it?</strong></td>
<td></td>
<td></td>
<td></td>
<td>.055</td>
</tr>
<tr>
<td>Very Difficult</td>
<td>5 (7.6%)</td>
<td>4 (20.0%)</td>
<td>1 (2.2%)</td>
<td></td>
</tr>
<tr>
<td>Difficult</td>
<td>19 (28.8%)</td>
<td>6 (30.0%)</td>
<td>12 (28.3%)</td>
<td></td>
</tr>
<tr>
<td>Easy</td>
<td>28 (42.4%)</td>
<td>8 (40.0%)</td>
<td>20 (43.5%)</td>
<td></td>
</tr>
<tr>
<td>Very Easy</td>
<td>14 (21.2%)</td>
<td>2 (10.0%)</td>
<td>12 (26.1%)</td>
<td></td>
</tr>
</tbody>
</table>
Table 2, Continued

<table>
<thead>
<tr>
<th></th>
<th>Total N (%)</th>
<th>No PCP N (30.9)</th>
<th>Has a PCP N (69.1)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experienced discrimination by a doctor or health care provider based on gender/sex status?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>23 (34.8%)</td>
<td>7 (35.0%)</td>
<td>16 (34.8%)</td>
<td>.986</td>
</tr>
<tr>
<td>No</td>
<td>43 (65.2%)</td>
<td>13 (65.0%)</td>
<td>30 (65.2%)</td>
<td></td>
</tr>
<tr>
<td>Have you ever had to educate a doctor about your health care needs as a gnc/trans person?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>38 (57.6%)</td>
<td>11 (55.0%)</td>
<td>27 (58.7%)</td>
<td>.780</td>
</tr>
<tr>
<td>No</td>
<td>28 (42.4%)</td>
<td>9 (45.0%)</td>
<td>19 (41.3%)</td>
<td></td>
</tr>
</tbody>
</table>

Notes: Chi-Square used for bivariate analyses (Fisher’s Exact test used for cell sizes less than 6). * Refers to $p<.05$
Appendix II

Survey Instrument
Thank you for participating in this study on gender nonconforming, transgender, and transsexual people’s experiences locating a primary care provider. Participants please take note that this questionnaire does ask questions that may cause discomfort and/or stress. If, at any point, you become upset, uncomfortable, or anything of the like, please use the following resources: “Trans Lifeline” for the United States: 1-877-565-8860 (24 hour) or GLBT National Hotline: 1-888-843-4564 (limited hours).

Your participation in this study is voluntary. You do not have to answer any questions you do not want to and you may stop taking the questionnaire at any point. However, the more answers that you provide, the better we can create a report that helps the gender nonconforming, transgender, and transsexual communities. As a reminder, please refrain from including any identifiable information in your answers (geographic location, names, phone numbers, etc.).

Please keep in mind that, for the purposes of this study, primary care refers to the patient’s first point of entry into the health care system and as the continuing focal point for all needed health care services (AAFP, 2015). In other words, a primary care provider is the person that you see for the majority of your medical needs.

Section i: Qualifying Information. These questions assess the eligibility of participants’ inclusion in the study.

1. Please identify your birth year (YYYY):

2. Are you an American citizen?
   - Yes
   - No

3. Do you speak and understand English?
   - Yes
   - No

SECTION 1: In this section I am going to ask you some questions about how you identify yourself.

4. Given the list below, and thinking from where you are in your life right now, how would you identify yourself with respect to your sexual orientation (Check all that apply):
   - Heterosexual
   - Gay
   - Lesbian
   - Bisexual
   - Asexual
   - Pan-sexual
   - Questioning
   - Omni-sexual
   - Refuse to be labeled
   - Other [ ]
5. What term do you use most often to describe yourself to others (Check all that apply):
   - Heterosexual
   - Homosexual
   - Bisexual
   - Gay
   - Lesbian
   - Dyke
   - Queer
   - Straight
   - Transgender
   - Transsexual
   - Cross-dresser
   - Queen
   - Genderqueer
   - Other [ ]
   - Not sure

6. Which of the following most clearly describes your gender self-perception (how you see yourself) (Check all that apply):
   - Masculine
   - Feminine
   - Androgy nous
   - Gender queer
   - Transgender
   - Transman
   - Transwoman
   - Two-spirit
   - Questioning
   - Other [ ]

7. In general (thinking of your life as a whole), how “out” are you:
   - Not at all – attempting to be under cover
   - Slightly – only the closest people to me know
   - Somewhat – close friends and relatives know
   - Mostly – nearly everyone knows
   - Completely – everyone knows
   - Unsure

8. If there is anything you would like to clarify or elaborate on regarding your gender self-perception, please do so here:
   [ ]

9. What sex is shown on your driver’s license?
   - M
   - F

10. What sex was assigned to you at birth?
    - Male
    - Female
    - Intersex
    - Other [ ]
11. If you were asked to describe your current sex status to me, how would you describe it:

[ ]

SECTION 2: In this section I am going to ask you some questions about yourself so that I can create an understanding of the population responding to the survey.

12. What is the highest education that you have completed?
   o Less than High School
   o GED
   o High School Degree
   o Trade School/Specialty School Certificate/Degree
   o Some College
   o Associate's Degree
   o Bachelor’s Degree
   o Graduate Degree
   o Other [ ]

13. What is your racial background? (Check all that apply)
   o Native American
   o Black/African American
   o Asian/Pacific Islander/Filipino(a)/Asian Indian
   o White/European
   o Arab/Middle Eastern
   o Other [ ]

14. Do you consider yourself to be Spanish, Hispanic, or Latino/Latina?
   o Yes
   o No

15. With which particular religious/faith tradition would you currently identify yourself?
   o Christianity
   o Judaism
   o Islam
   o Hinduism
   o Buddhism
   o Agnosticism/Atheism
   o Spiritual but do not identify with a religious/faith tradition
   o Other [ ]
   o None of the above
16. Which of the following best describes your current employment status? (Check all that apply):
   o Working: Full-time
   o Working: Part-time
   o Working: Full-time as well as part-time
   o Working: Multiple part-time jobs
   o Unemployed, laid off, or looking for work and receiving public assistance
   o Unemployed, laid off, or looking for work and not receiving public assistance
   o Keeping house
   o Retired
   o Student
   o Other [ ]

17. Into what group did your total household income last year fall?
   o Below $15,000
   o $15,000 - $24,999
   o $25,000 - $34,999
   o $35,000 - $44,999
   o $45,000 - $54,999
   o $55,000 - $64,999
   o $65,000 - $74,999
   o $75,000 - $84,999
   o $85,000 - $94,999
   o $95,000 - $99,999
   o $100,000 - $149,999
   o $150,000 or more

18. Which of the following best represents where you currently live?
   o Large city (100,000 or more people)
   o Small city (Less than 100,000 people)
   o Suburbs
   o Rural area

19. How would you describe your current relationship status? (Check all that apply)
   o Not in a relationship/Single
   o In a long-term committed relationship
   o Living together
   o Legally married
   o Civil union/Domestic partnership
   o Divorced/Separated
   o Widowed
   o Other [ ]

20. Do you have any children?
   o Yes
   o No
   o Unsure

21. Do you have any children under the age of 18 currently living with you?
   o Yes
   o No
22. With whom do you currently live? (Check all that apply)
   - Alone
   - Spouse/Partner
   - Parents
   - Children
   - Relative
   - Friend/Roommate
   - Other [

SECTION 3: In this section I am going to ask you questions about your current health insurance status.

23. Do you have health insurance or other health care coverage?
   - Yes
   - No

24. What type of health insurance or health care coverage do you have?
   - Coverage provided through a current or former employer or labor union (excluding military coverage)
   - Coverage through an individual plan
   - Coverage through Medicaid
   - Coverage through Medicare
   - Coverage through the military (e.g. CHAMPUS or Tri-Care)
   - Coverage through the Indian Health Services
   - Other [
   - Unsure

SECTION 4: In this section I am going to ask you about your primary care provider (the person that you see for your regular medical care).

25. Have you ever had trouble finding a primary care provider?
   - Yes
   - No

26. Please explain why you had trouble:
   [ ]

27. Do you currently have a primary care provider?
   - Yes
   - No
28. How did you find your current primary care provider? (Check all that apply)
   o Word of Mouth
   o Friend
   o Provider Website
   o LGBT Newsletter/Magazine
   o Gender Nonconforming/Trans Outreach Worker(s)
   o Physician Referral
   o Health Clinic/Community-Based Organization
   o Other [ ]

29. How would you describe your experience locating your current primary care provider?
   [ ]

30. How comfortable are you discussing your gender/sex status and related health care needs with your current primary care provider?
   o Very Uncomfortable
   o Uncomfortable
   o Comfortable
   o Very Comfortable

31. How knowledgeable is your current primary care provider about your gender/sex-related health care issues?
   o Not at all Knowledgeable
   o Somewhat Knowledgeable
   o Knowledgeable
   o Very Knowledgeable

32. Do you have any fears or concerns when discussing your health with your primary care provider? If so, please describe them.
   [ ]

SECTION 5: In this section I am going to ask you questions about your specialist care.

33. Do you currently utilize any specialty care providers (endocrinologists, gynecologists, etc.)?
   o Yes
   o No

34. Please tell me what type(s) of specialist(s) you use:
   [ ]
35. Is the specialist you use most often your primary care provider?
   o Yes
   o No

SECTION 6: In this section I am going to ask you about your health and your experience within the American health care system.

36. How would you rate your overall health?
   o Poor
   o Fair
   o Good
   o Very good
   o Excellent

37. Do you have a chronic illness?
   o Yes
   o No

38. Please mark all that apply:
   o Arthritis
   o Anxiety
   o Cancer (please specify): [ ]
   o Depression
   o Dermatitis
   o Diabetes
   o Eczema
   o Epilepsy
   o Frequent Headaches
   o Heart Disease
   o High Blood Pressure
   o HIV
   o Irritable Bowel Syndrome
   o Migraines
   o Respiratory Diseases (e.g. Chronic Bronchitis, COPD, and Emphysema)
   o Schizophrenia
   o Strokes/History of Strokes
   o Other [ ]

39. Was there a time in the past year (12 months) that you needed medical care but could not get it?
   o Yes
   o No

40. Please explain what prevented you from getting the care you needed:
   [ ]

41. How difficult has it been for you to receive health care when you needed it?
   o Very Difficult
   o Difficult
   o Easy
   o Very Easy
42. Have you ever experienced discrimination by a doctor or other health care provider due to your gender/sex status or expression?
   o Yes
   o No

43. Have you ever had to educate any doctor about your health care needs as a gender nonconforming/transgender/transsexual person?
   o Yes
   o No

44. Based on your experiences, how strongly do you agree or disagree with the following statement: medical professionals treat gender nonconforming/trans patients with the same amount of respect as their other patients:
   o Strongly Disagree
   o Disagree
   o Neutral
   o Agree
   o Strongly Agree

45. Please provide any closing thoughts, comments, suggestions, and/or ideas here.

Participants please take note that this questionnaire does ask questions that may cause discomfort and/or stress. If, at any point, you become upset, uncomfortable, or anything of the like, please use the following resources: “Trans Lifeline” for the United States: 1-877-565-8860 (24 hour) or GLBT National Hotline: 1-888-843-4564 (limited hours). As a reminder, this questionnaire is completely voluntary; you may stop participating at any point.”

Thank you for taking this survey.

I realize that your time is valuable and I very much appreciate the effort that you have made in completing this survey. This work will continue to add to the body of documentation concerning the needs of the gender nonconforming, transgender, and transsexual communities.

If you wish to receive a copy of the final report, once it is released, please send an email to Justin M. Vinneau at the following email address: vinneaujm@vcu.edu and indicate where you would like the report sent.
Appendix III

Consent Form
RESEARCH SUBJECT INFORMATION AND CONSENT FORM

TITLE: Gender Nonconforming, Transgender, and Transsexual Patient Navigation of the American Health Care System: Locating a Primary Care Provider

P.I.: Dr. Susan Bodnar-Deren
Student Researcher: Justin M. Vinneau

VCU IRB NO.: HM20005503

PURPOSE OF THE STUDY

The purpose of this research study is to explore the experiences of adult, English-speaking gender nonconforming, transgender, and transsexual individuals while searching for a primary care provider. Please keep in mind that, for the purposes of this study, primary care refers to the patient's first point of entry into the health care system and as the continuing focal point for all needed health care services (AAFP, 2015).

The input received from this study has the potential to bring attention to an otherwise overlooked issue amongst the transgender community.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

After reading this document, you will be asked to complete a forty-five item survey consisting of multiple-choice, yes/no, and open-ended questions. It is important to remember that no identifiable or personal information should be shared in the completion of this survey (e.g. geographic location, any names, phone numbers, etc.).

This questionnaire asks about things like gender identity, your employment status, how much money is made by the people in your house, if you have health insurance, your experience finding a primary care provider, how healthy you think you are, and your past experiences in the American health care system.

All answers will remain anonymous. Any and all identifiable data will remain confidential and unreleased in the final stages of analysis and reporting. Participation in this study is completely voluntary and you may stop the survey at any time before hitting the “submit” button. Once your answers have been submitted, however, there will be no way of identifying which submission is yours and, thus, no way to remove your submission.

RISKS AND DISCOMFORTS

Please be aware that this study has the potential to be uncomfortable for many individuals. In the event that you become uncomfortable or upset in any way, I have attached the contact number of the following resources.

- “Trans Lifeline” for the United States: 1-877-565-8860
  - 24 hour hotline
  - Information about Trans Lifeline from their website: “Trans Lifeline is a 501(c)3 non-profit dedicated to the well-being of transgender people. We run a hotline staffed by transgender people for transgender people. Trans Lifeline volunteers are ready to respond to whatever support needs members of our community might have.”
- **GLBT National Hotline**: 1-888-843-4564
  - **Monday-Friday**: 1pm – 9 pm Pacific Standard Time (PST)
  - **Saturday**: 9 am – 2 pm PST
  - **Monday-Friday**: 4 pm – Midnight Eastern Standard Time (EST)
  - **Saturday**: Noon – 5pm EST
  - Information about GLBT National Hotline from their website: “The Gay, Lesbian, Bisexual and Transgender (GLBT) National Hotline provides telephone, online private one-to-one chat and email peer-support, as well as factual information and local resources for cities and towns across the United States.”

**BENEFITS TO YOUR PARTICIPATION**

You will not experience a direct benefit from completing this questionnaire. As previously stated, this study is intended to explore the experiences of gender nonconforming, transgender, and transsexual individuals as they seek primary care providers. The knowledge gathered from the data will provide another source of insight into the experiences of individuals within these populations with the hopes of improving conditions.

**COSTS**

There are no costs for participating in this study other than the time you will spend completing the questionnaire.

**ALTERNATIVES**

There are no alternatives to completing this survey. Your participation in this study is voluntary. You may choose to not participate in this study at any point.

**CONFIDENTIALITY**

You will not be prompted for and are urged not to disclose any personal or identifiable information. Any information that could identify you in any way will be stored in a secure computer database and disregarded in analysis. Every effort will be made to ensure that you will remain anonymous and all personal information confidential.

The questionnaire will be administered in Virginia Commonwealth University’s REDCap survey host. REDCap ensures the confidentiality of all identifiable information including inadvertent identifiers such as I.P. address and maintains the anonymity of participants.

**VOLUNTARY PARTICIPATION AND WITHDRAWAL**

You do not have to participate in this study. If you choose to participate, you may stop at any point without penalty. You may also choose not to answer any questions that are asked in the study.

**By completing this questionnaire, I am agreeing to participate in this study.**
VCU IRB Contact Information:
804-828-0868 or ORSP@vcu.edu
900, East Leigh Street, Suite 3000
BioTech One Building
Box 980568
Richmond, VA 23298

Study P.I. Contact Information:  
Dr. Susan Bodnar-Deren  
Phone: 804-827-0523  
Email: smbodnar@vcu.edu

Student Researcher Contact Information:  
Justin Vinneau  
Email: vinneaujm@vcu.edu
Appendix IV

Call for Participants (Posting to the sub-reddits)
Title: Research Study: “Gender Nonconforming, Transgender, and Transsexual Patient Navigation of the American Health Care System: Locating a Primary Care Provider”

Body: I am currently conducting research for my Masters of Sociology at Virginia Commonwealth University. This questionnaire seeks to explore the experiences of gender nonconforming, transgender, and transsexual individuals within the United States in their search for a primary care provider. Please note that this study only seeks data from individuals who are 18 years or older, American citizens, and self-identify as gender nonconforming, transgender, or transsexual. All information gathered in this questionnaire will be kept anonymous and all identifiable information will be kept confidential. The questionnaire contains 45 items and will take approximately 30 minutes to complete. There is no compensation for completing this survey.