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# Barriers to Healthcare for the Transgender Population: A Focus on the Trans Persons' Experience Accessing Healthcare Services

Bryce E. Harrison
*University of Central Florida*

# BARRIERS TO HEALTHCARE FOR THE TRANSGENDER POPULATION: A FOCUS ON THE TRANS PERSONS' EXPERIENCE ACCESSING HEALTHCARE SERVICES

BY

BRYCE HARRISON

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Thesis Chair: Desiree Díaz, PhD, RN-BC, CNE, CHSE-A, ANEF

# Abstract

**Background:** Transgender people face several barriers to healthcare when accessing services. **Purpose**: The purpose of this study was to explore the lived-experience of the transgender person accessing healthcare. **Methods**: Colaizzi phenomenological method was used to delve into the experience. The guiding question was: What is the lived experience (challenges, barriers, and/or difficulties) that the transgender person experiences when accessing healthcare? **Results:** Initial themes were collapsed to create relevant meanings. Five themes emerged from the protocols and were validated by participants. Overall, the transgender person is vulnerable in the healthcare system due to the lack of representation of their identity, which results in their underutilization of healthcare services. **Conclusion**: This study demonstrates the need for changes to our current system of healthcare education and practice to provide competent care to the transgender population.

# Dedications

To my mother and father, who continue to love and support me without waver. Our lives have changed dramatically since I began school, but to this day, I still love you. I hope I can continue to make you proud.

To my big brother, Michael Nunes, your light has inspired me to help our brothers, sisters, and siblings to live as equals with others. You are the voice that will change the world, mine is one that resonates alongside it.

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# Introduction

The transgender population is an emerging population in the United States. A transgender person is broadly defined as an individual with a different gender than the biological sex or sexual anatomy at birth (Hein & Levitt, 2014; Lee, & Kanji 2017). There is an estimated 1.4 million people that identify as transgender in the United States (Flores, 2016; Meerwiik & Sevelius, 2017). This specific population has doubled in the last decade (Flores, 2016). The population of self-identified transgender people has increased while healthcare usage has been underutilized (Lerner & Robles, 2017).

Our study defines transgender man as an individual who was assigned a female (anatomy) gender at birth, but identifies as male (Hein & Levitt, 2014; Lee, & Kanji 2017). A transgender woman refers to an individual who was assigned a male gender at birth but identifies as female. Those who identify as transgender, may or may not be in the process of transitioning their gender expression (outward physical appearance) to match their gender identity. Cisgender is defined as an individual whose gender correlates with the biological sex assigned at birth (Hein & Levitt, 2014; Lee, & Kanji 2017). Transitioning can include: legal name change, hormone replacement therapy (HRT), and gender affirming surgery (Hein& Levitt, 2014; Lee & Kanji, 2017). The process is entirely unique to the individual; no two transgender persons' experiences will be the same.

Previous studies indicated that the lack of knowledge by the provider, denied health services, previous negative experiences, and inability to finance medical expenses were identified as reasons that the transgender population is unable to access healthcare services (Lee

& Kanij, 2017; Giblon & Bauer, 2017; Lerner & Robles, 2017). This study explored the lived-experiences of the transgender patient accessing healthcare services.

## Background

The transgender population faces several stressors related to gender-identity. Stressors include: have a higher prevalence of mental health disparities, including: anxiety, depression, substance abuse, self-injurious behavior, and suicide (Boza & Perry, 2014; Lee & Kanji, 2017; Puri, Shannon, Nguyen, & Goldenberg, 2017; Sutter & Perrin, 2016). Meyer's Minority Stress Model is utilized frequently when comparing the mental health outcomes of a marginalized group to the general population (Meyer, 1995). This theoretical framework highlights areas of distress that may stem from the environment (general stressors), minority status (prejudice, discrimination, violence), and minority identity (expectations of rejection, concealment, and internalized homophobia) (Meyer, 1995). Meyer's Minority Stress Model accounts for marginalized populations and addresses factors that predict the mental health outcomes in this population.

Prevalence of distress equates in the development of positive or negative health outcomes (Meyer, 1995). Bariola reported on the factors that relate to the transgender person's distress and resilience (2015). Forty-six percent of transgender men and women (n=169) surveyed reported high or very high levels of distress, anxiety, depression, or somatization (Bariola, et al., 2015; Bockting, 2010). Significant findings included variables that resulted in lower resilience such as: young age, unable to turn to family for support, and experiences of victimization (Bariola, et al., 2015). Factors that were attributed to higher resilience included: higher income, identifying as heterosexual, and frequent contact with friends, peers, and acquaintances in the LGBT community (Bariola, et al., 2015).

Negative outcomes are prevalent in the transgender population as they experience frequent mental health disparities comparatively to their cisgender counterparts (House, Van Horn, Coppeans, & Stepleman, 2011). A survey, related to LGBT persons experience with interpersonal violence, discrimination, and harassment, assessed how the specific variables can predict suicidal and non-suicidal injury (House, Van Horn, Coppeans & Stepleman,2011). Within the sample of (n=164) transgender participants, 29.9% performed some act of non-suicidal injury such as: cutting, biting, scraping, and hitting oneself without the intent to end their lives (House, Van Horn, Coppeans, & Stepleman, 2011). Approximately 35% of transgender participants have attempted suicide at least once (House, Van Horn, Coppeans, & Stepleman, 2011). Participants reported greater instances of interpersonal trauma (abusive communication and physical violence with their significant other 81.7% compared to cisgender men and women (House, Van Horn, Coppeans, & Stepleman, 2011). An overwhelming majority of the transgender population faces instances of discrimination (96%); there is a need for mental and physical health promotion to improve overall quality of life (House, Van Horn, Coppeans, & Stepleman, 2011). Social support may enhance the quality of life of the transgender person. Contrary, the lack of support can cause the opposite effect by increasing the prevalence of depression and anxiety (Budge, Rossman, & Howard, 2014).

A complete health history and exam provides valuable information for both cisgender and transgender patients. Transgender patients' health history should include specific health and wellness criteria to determine if they qualify for hormone replacement therapy (Chipkin & Kim, 2017; McNamara & Ng, 2016). For example, transgender women who wish to receive estrogen

with a family history of breast cancer or thrombotic disorders are at risk if placed on estrogen (Chipkin & Kim, 2017; Hein & Levitt, 2014; McNamara & Ng, 2016).

Complete physical exams for the transgender patient require the healthcare team to examine all anatomy that remain or is in development over the course of the transition (Chipkin & Kim, 2017; McNamara & Ng, 2016). Transgender men still require breast exams if they have not performed a double mastectomy to affirm their gender identity. Transgender women would require the same breast exam due to the development of breast tissue through hormone therapy (Chipkin & Kim, 2017; McNamara & Ng, 2016).

The transgender person often seeks to further his or her gender affirmation by requesting utilization of hormone replacement therapy. Transgender women may use anti-androgen and estrogen to suppress testosterone production, and increase feminine features (Chipkin & Kim, 2017; McNamara & Ng, 2016). Transgender men may seek the use of testosterone to inhibit estrogen production, and enhance masculine features (Chipkin & Kim, 2017; McNamara & Ng, 2016). Careful and ongoing monitoring of this treatment is mandatory (Chipkin & Kim, 2017; McNamara & Ng, 2016).

Gender affirming surgeries for transgender women include orchiectomy (removal of testes), vaginoplasty (construction of a vagina), penectomy (removal of the penis), and breast reconstruction. Gender affirming surgeries for transgender men include: double mastectomy (breast removal) with reconstruction, hysterectomy (removal of the uterus), metoidioplasty (enlargement of the clitoris), phalloplasty (construction of a penis), scrotoplasty (construction of a scrotum), vaginectomy (removal of the vagina), and urethroplasty (creation of a urethral canal) (Chipkin & Kim, 2017; Hein & Levitt, 2014; McNamara & Ng, 2016). These procedures are

significant changes and assist in aligning the body of the transgender patient to his or her gender identity (Hein & Levitt, 2014). The complexity of the transgender patient's health warrants the need for further research into the disparities he or she faces when accessing healthcare services.

## Problem

Significant themes were identified in the literature regarding healthcare access barriers. The transgender population commonly faces: lack of knowledge by the provider, the provider

refusing to care for the transgender patient, previous negative experiences, and inability to finance medical expenses (Lee & Kanji, 2017; Giblon & Bauer, 2017; Lerner, & Robles, 2017). These barriers prevent the transgender patient from accessing healthcare, therefore, putting them at risk for negative health outcomes.

Knowledge related to transgender health is sparse in the education of medical professionals, which negatively impacts transgender persons' healthcare experiences (Lefkowitz & Mannell, 2017; Chipkin, & Kim, 2017; Lee & Kanji, 2017; Park & Safer, 2018). Clinical knowledge of the transgender patient's needs is necessary to provide safe and effective interventions to improve the overall well-being of the population. (U.S. Department of Health and Human Services, 2018).

Denial of services based on gender identity, transgender patients are at risk for negative health outcomes. Kenagy completed two quantitative studies that investigated the frequency of transgender patients facing issues accessing healthcare (2005). The first study (n=111) revealed that 23% of participants were refused trans-related healthcare, 12% were denied routine medical care, and 9% were denied counseling related to trans-issues (Kenagy, 2005). A second study revealed that 26% of participants (n=154) were denied trans-related healthcare and HIV prevention services (Kenagy, 2005). These issues can increase the psychological distress faced by the transgender population (Eliason, Dejoseph, Dibble, Deevey, & Chinn, 2011; House, Van Horn, Coppeans, & Stepleman, 2011; McCann, & Brown, 2017; Puri, Shannon, Nguyen, & Goldenberg, 2017; Sutter, & Perrin, 2016), and the physical disparities they are at risk for due to the lack of medical interventions (Chipkin, & Kim, 2017; Giblon, & Bauer, 2017; Hein, & Levitt, 2014; Lee, & Kanji, 2017; McNamara, & Ng, 2016).

Discrimination and harassment experienced in the healthcare field by the transgender patient can result in the lack of healthcare they access due to the previous negative experiences (Hein & Levitt, 2014; Lerner & Robles, 2017). This theme extends beyond the provider to other members of the healthcare team as well. A recent study by Shires and Jaffee (2015) (n= 1,711) approximately 40% of transgender participants experienced some form of discrimination: verbal harassment, denial of equal treatment, or physical assault in a doctor's office or hospital (Shires & Jaffee, K., 2015). These acts of discrimination further the psychological distress faced by the transgender population, and the physical disparities they are at risk for due to the lack of medical interventions they will receive (Chipkin, & Kim, 2017; Giblon & Bauer, 2017; Hein & Levitt, 2014; Lee & Kanji, 2017; McNamara & Ng, 2016).

Payment for health services provided can be costly for the transgender patient. These costs typically stem from the health services related to achievement of their transgender identity: hormone replacement therapy and gender affirming surgery (Chipkin & Kim, 2017; Lerner & Robles, 2017, McNamara, 2016, Safer et al., 2016). Often time health insurances do not cover these treatments, resulting in the patient or provider "bending the truth." They will purposely falsify the billing for the insurance to cover the treatment.

## Purpose

Previous studies have investigated the barriers transgender patients may experience when seeking care; however, these consisted of results derived primarily from, quantitative surveys. The purpose of this research was to uncover recurring or new barriers from the lived-experiences of participants through in-depth interviews. Previous literature identified a lack of knowledge by

the provider, provider refusal to care for the transgender patient, previous negative experiences, and inability to finance medical expenses as barriers that this community largely faces. Similar findings are expected from this study; but new barriers within the lived-experiences of these participants were uncovered.

# Methods

## Design

A descriptive phenomenological method by Colaizzi (Sanders, 2003; Valle & King, 1978) was utilized to: explore the lived experiences of our transgender participants accessing healthcare services and to understand their experiences as they relate to the research purpose, and capture the essence of their lived experiences. Colaizzi's method requires the researchers to:

‘‘(1) read all the protocols, (2) review and extract important statements, (3) formulate meaning from statements, (4) cluster meanings into themes, (5) integrate results into a description, (6) create exhaustive description of phenomenon, and (7) ask participants about findings as a validation’’ (Sanders, 2003; Valle & King, 1978). The aim of this study is to confirm previously identified barriers to care for the transgender population and identify new themes that may emerge by utilizing a qualitative phenomenological design. Unstructured interviews with open-ended questions to collect the experiences of the transgender patient accessing healthcare services will be utilized. The open-ended questions were the following:

1. Please try to recall an experience accessing healthcare and the impact that it made on you. Please try to describe the impression: “What is your lived experience, ease and/or challenges, as a transgender person regarding accessing healthcare?”
2. What difference (s) within yourself did you notice after the experience?

## Participants

A convenience sample of transgender men and women were asked to participate in this study. The sample was purposive; therefore, participants were self-identifying as transgender. All participants were required to speak and read in English.

## Data collection

Approval by the University of Central Florida's (UCF) Internal Review Board (IRB) was obtained prior to recruitment and data collection. Recruitment included emails, word of mouth, and flyers. Incentives in the form of gift cards were used once interviews were scheduled and completed. Incentives were given regardless of completing the interview questions in an effort to eliminate coercion. Information regarding the study was conveyed to the prospective participant prior to scheduling an appointment with the primary investigator and faculty advisor.

### Procedure

Consent by the participant was obtained on the day of the interview. The explanation of research was distributed via email prior to the interview and given prior to audio recording. Participants completed the interview with either both the primary investigator (PI) and faculty advisor or solely with the PI. All interviews were conducted with an audio recording device. All recordings were saved onto a password protected computer. Interviews were then sent to a professional transcription agency. Transcribed interviews were then analyzed by both investigators individually and then jointly.

No identifying information was included in the study. The only information that will be included in the study is participant ethnicity, age, education level, biological sex, gender identity, and participant number.

## Results

A total of seven interviews were conducted resulting in saturation of data. Three-hundred and thirty-nine significant statements were identified in the protocols. Statements were

highlighted, numbered, and then clustered into themes. Initially, 11 themes were formulated into clusters and reduced to five key themes.

The investigators developed an exhaustive description: the transgender patient is vulnerable in the healthcare system due to the lack of representation of their identity, which results in their underutilization of healthcare services. It demonstrates the need for changes to our current system of healthcare education and practice to provide competent care to the transgender population. Participants were able to verify the validity of this statement compared to their lived experiences accessing healthcare services as a transgender person.

## Themes

The five themes that were identified in the protocols revealed the difficulties that participants faced when accessing healthcare services through past experiences. Participants were

encouraged to discuss their experiences, easy and/or challenge, with the investigators to provide their unique perspective. These themes were relayed to the participants and were verified as being accurate to their experiences.

## Theme 1 – Limited Preventative Care: Insurance Difficulties

Participants expressed their concerns with financing their healthcare expenses. While this is a relatable theme to many other populations, transgender patients will often be unable to pay for trans-related healthcare services, preventative health management, or primary care physicians. Financial barriers prevent the trans person from receiving care related to their identity, but also preventative health interventions that can increase their quality of life. Participants stated:

> I'd ask, 'is top surgery covered, or is any of the trans surgery covered?', and they said no. It turns out it was covered the whole time, and they were lying to me" (7-12 -72 & 73).

> I do have gynecological-related problems that might inspire an insurance company to pay for a hysterectomy… I feel like I am at a step where its 50/50, whether my ongoing problems are enough to justify a hysterectomy outside of a trans thing (1-7-43 & 44).

> My back has been hurting for a good probably six, seven months. It's got to where I can barely get out of bed in the morning [10/10 pain] (7-3-26).

Participants found that the difficulty for financing their treatment was multifocal; whether it was handling the billing with insurance companies, finding care that is covered by insurance,

or a copay that is affordable. The inability to pay for healthcare can be an arduous task. This is magnified by the transgender population as they transition. They must make the choice to pay for the maintenance of their biological body, achieving their authentic self through trans-related procedures, or not seek care at all to save money.

## Theme 2 – Lack of Knowledge Related to the Standard of Care

The knowledge related to the transgender person's care such as: identity, hormone therapy, mental health, gender affirming surgeries, and maintenance of the biological body, is critical to ensuring they receive positive health outcomes. The healthcare team's inability to properly manage the care of the transgender patient, due to their lack of knowledge, creates risks for negative health outcomes such as: mental health disparities, hormone-related injuries/diseases, and other preventable injuries/diseases (Bariola, et al., 2015; Chipkin & Kim, 2017; Hein & Levitt, 2014; McNamara & Ng, 2016 ) Participants stated:

> She actually didn't abide by the endocrinology guidelines and was transitioning me incredibly slowly. I was on a quarter of the recommended dose (7-1-6).

> Because they didn't know what they were doing, they gave me certain health problems because they game me too high of a dose to start out with, and they weren't effective in teaching me certain things (1-5-37).

> They didn't seem to acknowledge that I was a person in pain (1-6-39).

Participants' expressed their concerns about the lack of knowledge that the healthcare team had when initiating care. They often felt more knowledgeable about their identity, treatment, and plan of care then the providers that were managing their case. Providing care without having the knowledge about the transgender identity, hormone replacement therapy and monitoring puts the transgender person at risk for negative health outcomes.

### Theme 3 – Healthcare Team Bias vs. Willingness to Treat

Participants had various perception of the healthcare team when it came to their willingness to care for a transgender person. Participants were able to find positive and negative experiences relating to healthcare teams' biases or willingness to treat. Participants stated:

> She wasn't really open to talk transitioning [me] faster. Because I wasn't using male pronouns at the time or maybe 'cause I wasn't as trans as she expected, she was discriminating against me in terms of how fast I could transition (7-1-8).

> As I was trying – in the state of Florida, you have to get a letter from a doctor saying you had some sort of gender reassignment surgery to get your license changed, or your birth certificate changed… [Provider's] secretary that signed the letters refused to sign my letter for me to change my gender on my birth certificate (6-6-40).

> She was like, "Absolutely! I'll learn. I'll look into it some stuff. We'll learn together," (6-10-47).

The role of the healthcare team is to provide the best evidence-based practice to those who come into their care; however, each member of the team may have personal biases that may prevent them from treating the transgender person. This creates another barrier that the transgender person must navigate to receive treatment. Our role as providers of a service should be an active partner, along with the transgender person, in initiating, monitoring, and managing treatment regardless of age, sex, ethnicity, class, sexuality, and gender identity.

### Theme 4 – Reinitiating Care After a Negative Experience Related to Outcomes

For those who have been in the healthcare system previously, the transgender person may find it difficult to reinitiate care due to their previous negative experiences navigating it. Participants listed several events that made them weary of the healthcare system and prevented them from continuing any interactions. Participants stated:

> I've been afraid to talk about my back problems from a doctor's sense, and it's been six years. Cause I am worried that I'll have to go through another X-ray again (1-5-34).

> I'm going [out of] my way to make my health better, but then I go there, my identity is ignored or dismissed, and it feels like I'm being disrespected really (2-6-27).

> I only go to the doctor when I [am] absolutely dying (6-3-25).

The goal for providing care to anyone should be to make the experience as comfortable, positive, and safe as possible. When we fail to provide those criteria, we risk that patient not reinitiating care to prevent negative experiences reoccurring.

**Themes 5 – Vulnerability**

The transgender person is consistently having to come out to people, whether it is with family, friends, coworkers, or other members of their community. Being placed in a situation where they may have to disclose their identity, expose themselves, or ask for treatment related to their identity to their provider, nurse, etc. may cause distress, dysphoria, or more in the transgender population. This population will avoid seeking healthcare services, regardless if it relates to their gender identity, due to their feelings of vulnerability in the healthcare system. Participants stated:

> Could you refer to me as this? Could you make it easier for me to exist as this person, rather than this legal name that you have, (1-3-20).

> This is just a way life is for me. It's never easy. It's never going to be easy. Its always going to be a hurdle (6-8-42).

> [I felt] vulnerable 'cause he could have reacted however. I didn't know how he was gonna react. Luckily, he didn't say anything rude, but he could have, and I wasn't in a position to find other care (7-8-51).

Transgender people are constantly put into vulnerable situations, we as a healthcare team should provide an inclusive environment for these people to feel welcomed, unique, and heard. Instances like the ones stated create negative impressions of healthcare in general and con concurrently prevent the trans person from seeking care.

## Discussion

The transgender person's lived-experiences navigating the healthcare system is varied depending on the region, age, identity, presentation, and financial stability of the individual. Investigators were unable to interview a larger variety participant due to financial, time, and participant constraints; however, this study can be used to develop quantitative and qualitative that may be guided using this study. Questions that should guide future research include: what changes can be readily implemented to ensure an inclusive environment for the transgender

person, how can we provide enough education to our future doctors, nurses, technologies etc. to better serve the transgender population, and could we utilize simulations as an effective learning tool in educating healthcare systems to utilize appropriate therapeutic communication for the transgender population?

Progress can be made to provide comprehensive and holistic care to the transgender population by educating current practicing physicians, nurses, and techs, promoting inclusive practices through multi-media, and update hospital informatic systems by recognizing the difference between gender identity and biological sex, and preferred names.

Providing education on the transgender population to the healthcare team can be done by providing education about the transgender identity, medical management of transitioning, and therapeutic communication that can aid in their treatment. Education sessions that inform the providers about the topic and can facilitate an open milieu where they can discuss their biases, experiences, and questions they may have.

Alongside this education, resources located in the local community can be provided to these healthcare facilities to provide further guidance for transgender patients in the future. Information such as endocrinologists, counseling, support groups, and gender-neutral bathrooms can be useful resources for the healthcare team to have to provide services that are not available in the healthcare setting. These resources should be made available to the public and healthcare team through several modes of communications such as websites, information pamphlets, and public announcements.

Informatics should be modified to include identifying material such as gender, biological and preferred name can provide an ease in navigating the healthcare system for the transgender

patient. These updates can provide consistency in the care of the transgender patient throughout their stay in a system. This allows only single visit to be needed to create a patient profile that accounts for their identity, name, and needs; from there, the patient's information is available within any organizational system. Having this information attached to the patient's chart can initiate therapeutic communication which inherently implies respecting one's identity.

These interventions can assist the transgender patient to navigate through the healthcare system by validating and understanding their identity and how it correlates to their health outcomes.

## Conclusion

Transgender persons' currently experience several factors that inhibit their ability to seek healthcare services. These barriers range personal neglect to seek care due to the previous negative experiences they have with the provider's lack of knowledge or biases, to issues paying for procedures that may/may not relate to their transgender identity. Overall, further research should be conducted to provide adequate data on the education needed for healthcare providers to competently care for the transgender person.

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