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## Transcending Barriers: Understanding the Prevalence and Drivers of Healthcare Avoidance Among the Transgender Community

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**Abstract**

Transgender people encounter barriers to healthcare access on many levels that contribute to their delay or complete avoidance of healthcare, which can lead to poor physical and mental health outcomes. The recent uptick in both scientific and public interest towards transgender individuals has brought up concerns about their mental health and well-being, as current research suggests that they may be at an increased risk for discrimination, prejudice, various forms of psychopathology and lower quality of life. As a result of social stigma, minority stress, and interpersonal problems, transgender individuals experience elevated rates of anticipated and enacted stigma, thus furthering their odds of healthcare avoidance. In this review, the practical role of gender affirming healthcare is discussed, as well as the benefits of having access to competent medical professionals and social support. The conclusion of this review leads to an outline of possible implications of healthcare avoidance, including suggestions for healthcare professionals and relatives or friends of a transgender individual.

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## I. INTRODUCTION

In recent years, the LGBTQ+ community has become the target of increasingly exclusionary political legislation, as well as harmful rhetoric in the media. The negative attention has grown so much that the scientific community has begun assessing the psychological features of transgender individuals and has found an increased risk factor for various kinds of psychopathology (Dhejne et al., 2016). Despite this evidence, transgender people face many barriers when trying to access reliable healthcare, which often result in the delay of, or complete avoidance of, any needed medical care. In this paper, the term “transgender” relates to anyone with an incongruence between the sex they were assigned at birth and their current gender identity. Table 1 (see p.9) proposes a summary of the transgender-related glossary encountered in the review.

On the surface, seeking affirming medical care seems intuitive, but some transgender people choose to avoid healthcare altogether, due to fear of exclusion or discrimination in medical settings. Despite the frequency of healthcare avoidance in the transgender community, very little research has been done on the exact reasons why transgender people avoid healthcare, and what affects healthcare avoidance may have on their health, both mentally and physically. This paper aims to discuss the patterns of healthcare discrimination amongst transgender patients and why they lead transgender people to avoid seeking medical care.

## **I.I Transgender Terminology**

“Cisgender” refers to a person whose gender identity is aligned with the sex they were assigned at birth. Conversely, “transgender” (additionally referred to as “trans”) refers to a person whose gender identity does not match with the sex they were assigned at birth, and is most frequently used as an umbrella term when discussing different gender identities, such as female-to-male, male-to-female, and non-binary. People who identify as transgender may experience “gender dysphoria” (Table 2), which is defined by the American Psychiatry Association as “psychological distress that results from an incongruence between one’s sex assigned at birth and one’s gender identity” in the Diagnostic and Statistical Manual of Mental Disorders, otherwise known as the DSM-5-TR (American Psychiatry Association, 2022). While it is true that transgender people can experience gender dysphoria, it is a diverse and subjective feeling, with differences in intensities and manners depending on the person. Because of their gender dysphoria, transgender people may seek out gender-affirming care, which may include “any single or combination of a number of social, psychological, behavioral or medical (including hormonal treatment or surgery) interventions designed to support and affirm an individual’s gender identity” (World Health Organization, n.d.). In the case of transmasculine patients, the hormone administered would be testosterone, whereas for transfeminine patients, the hormone administered would be oestrogen (also known as estrogen) and/or antiandrogens.

**Table 2 Gender dysphoria – diagnostic criteria by DSM-5-TR (APA, 2022)****Gender dysphoria in children (F64.2)**

- A.** A marked incongruence between one's experienced/expressed gender and assigned gender, of at least 6 months' duration, as manifested by at least six of the following (one of which must be Criterion A1):
1. A strong desire to be of the other gender or an insistence that one is the other gender (or some alternative gender different from one's assigned gender).
  2. In boys (assigned gender<sup>1</sup>), a strong preference for cross-dressing or simulating female attire; or in girls (assigned gender), a strong preference for wearing only typical masculine clothing and a strong resistance to the wearing of typical feminine clothing.
  3. A strong preference for cross-gender roles in make-believe play or fantasy play.
  4. A strong preference for the toys, games, or activities stereotypically used or engaged in by the other gender.
  5. A strong preference for playmates of the other gender.
  6. In boys (assigned gender), a strong rejection of typically masculine toys, games, and activities and a strong avoidance of rough-and-tumble play; or in girls (assigned gender), a strong rejection of typically feminine toys, games, and activities.
  7. A strong dislike of one's sexual anatomy.
  8. A strong desire for the primary and/or secondary sex characteristics that match one's experienced gender.
- B.** The condition is associated with clinically significant distress or impairment in social, school, or other important areas of functioning.

Specify if: with a disorder/difference of sex development (e.g., a congenital adrenogenital disorder such as E25.0 congenital adrenal hyperplasia or E34.50 androgen insensitivity syndrome).

Coding note: Code the disorder/difference of sex development as well as gender dysphoria

**Gender Dysphoria in Adolescents and Adults (F64.0)**

- A.** A marked incongruence between one's experienced/expressed gender and assigned gender, of at least 6 months' duration, as manifested by at least two of the following:
1. A marked incongruence between one's experienced/expressed gender and primary and/or secondary sex characteristics (or in young adolescents, the anticipated secondary sex characteristics).
  2. A strong desire to be rid of one's primary and/or secondary sex characteristics because of marked incongruence with one's experienced/expressed gender (or in young adolescents, a desire to prevent the development of the anticipated secondary sex characteristics).
  3. A strong desire for the primary and/or secondary sex characteristics of the other gender.
  4. A strong desire to be of the other gender (or some alternative gender different from one's assigned gender).
  5. A strong desire to be treated as the other gender or some alternative gender different from one's assigned gender).
  6. A strong conviction that one has the typical feelings and reactions of the other gender (or some alternative gender different from one's assigned gender).
- B.** The condition is associated with clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Specify if: with a disorder/difference of sex development (e.g., a congenital adrenogenital disorder such as E25.0 congenital adrenal hyperplasia or E34.50 androgen insensitivity syndrome).

Coding note: Code the disorder/difference of sex development as well as gender dysphoria.

7. Specify if: posttransition: the individual has transitioned to full-time living in the experienced gender (with or without legalization of gender change) and has undergone (or is preparing to have) at least one gender-affirming medical procedure or treatment regimen—namely, regular gender-affirming hormone treatment or gender reassignment surgery confirming the experienced gender (e.g., breast augmentation surgery and/or vulvovaginoplasty in an individual assigned male at birth; transmasculine chest surgery and/or phalloplasty or metoidioplasty in an individual assigned female at birth).

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<sup>1</sup> Sex assigned at birth.

## **I.II Sexual Identity**

A person's gender interacts with their sex, but they are two distinct terms and should not be used interchangeably. The term sex refers to a set of biological attributes, mainly associated with chromosomes, hormones, and reproductive and sexual anatomy (World Health Organization, 2021). Infants are traditionally assigned either male or female sex based on the appearance of their external anatomy/genitalia. In the past, biological sex in humans has been reported as strictly male-female binary, but in more recent research, this division of sexes into male and female has been called into question, and in its place, a more fluid understanding of sex has been suggested (Štrkalj & Pather, 2021).

Conversely, the term gender is much broader and refers to socially constructed characteristics of men and women. These can include the norms, roles and relations of women and men, such as the view that men are supposed to be the provider of the family and women the caretaker. When we talk about gender, we are mainly referring to a person's "gender identity", or a person's intrinsic sense and individual experience of gender. How they express their gender identity is referred to as their "gender expression", such as their dress and speech. However, gender expression is not always indicative of a person's gender identity, and in some cases a person may not fit into either "male" or "female." It is important to note that a person's sex and gender are not influenced by their sexual or romantic orientation (whoever a person feels romantic and or sexual attraction to). Every aspect of an individual's sexual identity (their biological sex, gender identity, gender expression and sexual orientation) is highly personal, individual, and can be expressed as a spectrum. Table 1 describes the most commonly used transgender-related terminology and what they mean.

**Table 1** Definition of transgender-related terms

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Cisgender ( <i>adj.</i> )	A person whose gender identity matches sex assigned at birth
Transgender ( <i>adj.</i> )	A person whose gender identity differs from sex assigned at birth
Transmasculine ( <i>adj.</i> )	Umbrella term to include AFAB transgender people that identify on the male side of the gender spectrum
Transfeminine ( <i>adj.</i> )	Umbrella term to include AMAB transgender people that identify on the female side of the gender spectrum
Intersex	Umbrella term for individuals born with natural variations in biological or physiological characteristics (including sexual anatomy, reproductive organs and/or chromosomal patterns) that do not fit traditional definitions of male or female
AFAB	Assigned Female At Birth
AMAB	Assigned Male At Birth
Gender identity	A person's internal sense of their own gender
Gender expression	Way of expressing oneself through clothes, hairstyle, mannerism, etc.
Hormone replacement therapy (HRT)	Hormone therapy with the purpose of aligning the sex hormone profile and therefore secondary sex characteristics to one's gender identity
Passing	Getting perceived from others as one's own gender identity
Misgendering	Referring to someone using language (e.g. pronouns, gendered compliments, etc.) that does not align with their gender identity
Transphobia	Negative attitudes, feelings or actions towards transgender people, discrimination specifically directed to transgender people

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### **I.III Healthcare Avoidance**

Access to healthcare is defined as the “timely use of personal health services to achieve the best personal outcomes” (Institute of Medicine, 1993). Healthcare access is characterized as the ability and ease of the consumer to seek and obtain needed services from providers or institutions as well as the cost of healthcare (Kcomt et al., 2020). Healthcare avoidance can be defined as a kind of patient disengagement that impedes an individual’s health behaviors or causes them to delay obtaining health care, and thus can negatively influence an individuals’ well-being (Byrne, 2008). The social and organizational barriers that transgender people encounter on a regular basis can hinder their access to healthcare. When interviewed, one transmasculine individual stated that the biggest barrier to seeking care in the medical field related to his gender identity was “the lack of providers you can trust to give you competent care” and, due to a short list of providers that he felt safe going to, he was “often going to be subjected to long wait times or commutes” in order to get an appointment (Darden, 2022). Transgender patients’ general health, of which mental health plays a crucial role, is significantly related to fear of discrimination from a medical provider. The mental health needs of transgender patients are undoubtedly substantial, and research shows that if transgender patients are expecting stigma and discrimination from healthcare professionals, they are less likely to seek out any type of care, negatively impacting their overall health and well-being (including their aforementioned mental health) (Kattari et al., 2017).

## **II. Literature review on healthcare avoidance among transgender populations**

### **II.I Research Approach**

A literature review was conducted on articles reporting transgender subjects dealing with discrimination or prejudice in the medical field, especially instances where they delayed or avoided seeking medical treatment due to fear of discrimination. The literature search was conducted using search engines such as *PubMed* and *Google Scholar*. To obtain relevant papers, a number of the following search terms were used: “transgender,” “healthcare avoidance,” “discrimination,” “healthcare access,” “healthcare discrimination,” “healthcare avoidance,” “cisnormativity”. Due to their accuracy and recency, web pages on human rights and LGBTQ+ associations were also used as references in order to ensure the use of up-to-date, non-discriminatory language so as not to offend or go against any members of the transgender community. Furthermore, reviewing the references of selected papers has been used to gather additional reference material, and a podcast titled *In My Queer Body* was conducted as a way to gain personal, qualitative accounts of healthcare avoidance and discrimination among transgender and gender non-conforming interviewees (Darden, 2022).

### **II.II Inclusion and Exclusion Criteria**

The papers referenced in this review were not taken into consideration unless they met the inclusion criteria. Papers were only considered if they were published between the years of 2013 and 2023, and were written in English to avoid translation errors or misinterpretations. The inclusion criteria were inclusive to all people who identify as

transgender, including those who identified as gender non-conforming, non-binary, and agender. When screening participants for *In My Queer Body*, participants were not required to have an official diagnosis of gender dysphoria, but were expected to identify as either transgender or gender non-conforming, and have previous negative experience when seeking healthcare related to their gender identity or medical transition.

## **II.III Results**

### **II.III.I Prevalence**

The exact prevalence of avoidance within the transgender population is difficult to estimate, due largely in part by how many transgender people do not disclose their identity if possible when seeking medical care, as well as how many transgender patients fail to report instances of discrimination/prejudice. There are also large discrepancies on which groups within the transgender community are more often subjected to discrimination within the healthcare industry, and therefore experience more healthcare avoidance. Race, ethnicity, socioeconomic status, and a person's assigned sex at birth have all been found to show varying degrees of impact on a transgender patient's likelihood of experiencing healthcare discrimination and avoidance. For example, McCabe et al. (2020) utilized the 2015 U.S. Transgender Survey results ( $N = 19,157$ ) to examine avoidance of healthcare due to anticipated discrimination among transgender adults (aged 25 to 64) and found that transgender men face a larger risk of healthcare avoidance due to fear of discrimination than transgender women. Contrarily, a study by Clark et al. (2022) analyzed data collected from the 2018 Annual Questionnaire of The Population Research in Identity and Disparities for Equality (PRIDE) Study (an online, national, longitudinal cohort study on the health of sexual and gender minority people) and found that transgender women had the highest odds

of experiencing healthcare avoidance, especially if they lived in a state where there were no protective state-level policies in place for gender affirming healthcare services. The inconsistencies between the results of these two studies further illustrates the discrepancy between which groups within the transgender community are more often subjected to discrimination and healthcare avoidance.

One of the most largely considered explanations for why transgender patients avoid seeking healthcare is fear. Kattari et al. (2017) conducted a study on how fear of anticipated discrimination, or non inclusive healthcare, increased transgender patient's chances of avoiding healthcare and negatively impacted their physical and mental health. By analyzing data from a survey of 417 transgender adults in the Rocky Mountain region of the United States, they suggested a significant association between delaying healthcare because of fear of discrimination and worse physical and mental health among transgender adults. Their research states that transgender individuals who delayed healthcare had 3.08 percent greater odds of having current depression, 3.81 percent greater odds of a suicide attempt in the past year, and 2.93 percent greater odds of suicide ideation within the past year (Kattari et al., 2017).

Unfortunately, the current research available that discusses the driving reasons behind or the implications of healthcare avoidance within the transgender community have limitations that may impact their credibility. Oftentimes, research studies are done using one-time surveys with random sampling, which may result in the prevalence of bias, affecting how researchers interpret certain causalities.

### **II.III.II Barriers blocking effective healthcare for transgender people**

For the transgender community, discrimination and prejudice in the world of healthcare are quite extensive. Recent research has found that even when compared with the amount of hostility and discrimination that transgender people face in other settings, such as housing and employment, healthcare is still the most common place for transgender people to experience non inclusive treatment. These odds of discrimination rise even higher when considering those who have a lower socioeconomic status, those who disclose their gender identity to healthcare service providers, and persons of color. In some cases, studies have found that 28% of transgender participants reported postponing needed medical care because of fear of discrimination, 19% reported being refused care because of their gender identity, 28% reported being subjected to verbal harassment, and 2% reported being victims of physical violence in medical settings (Kattari et al., 2017). Furthermore, many respondents indicated that they had to teach their medical provider about basic transgender information, emphasizing the lack of overall knowledge that healthcare providers have in regard to medical transitioning, and underscoring the lack of trust that transgender patients may feel when seeking competent caretakers.

### **II.III.III The minority stress model and public opinion**

The minority stress model is a conceptual model used to further understand the rates of poor mental health in a specific disadvantaged population, first utilized in a study of suburban gay men (Feinstein, 2019). Reisner et al. (2015) argue that there are two main types of discrimination in public experienced by trans people that increase their odds of poor emotional and physical health as well as postponing needed and/or preventative

healthcare: (1) anticipated stigma, the fear of discrimination; and (2) enacted stigma, experienced discrimination. Based on these definitions, current research speculates that experiencing non inclusive healthcare, as well as delaying healthcare because of fear of discrimination, not only contributes to stressors that transgender people encounter, but can also be an indicator for worse mental and physical health. During an interview on *In My Queer Body*, one respondent reported that he “spent years [avoiding] any medical examination”, especially gynecological, for “fear of suffering transphobia” (Darden, 2022). The respondent went on to report that, at times, healthcare providers could not offer him the help he was seeking, and he often had to explain to them how hormone therapy affects a person’s body, describing how the providers did not “have parameters to take into consideration the changes [his] body is going through when assessing [his] health” (Darden, 2022).

Along with the Minority Stress Model, the overall attitudes that society holds towards transgender people (otherwise referred to as public opinion) have a significant impact on how trans people interact with the world around them, including avoidant behaviors. Transgender people face an increasingly volatile and uncertain political climate in the United States, with the majority of developing legislative processes directly involving the public’s opinion. Unfortunately, there is a lack of published research that analyzes the impact of the general population’s opinion on transgender people and their civil rights, leaving attitudes about transgender people left to anecdotes and rendering the transgender population nearly invisible in the world of research. This further underlines the importance of recognizing that, due to anticipated stigma, enacted stigma, and an awareness of general attitudes towards trans people, many trans people fear for their safety and will modify their behavior in order to avoid being the subject of discrimination or prejudice.

#### **II.III.IV Gender affirmation**

Gender affirmation, or being recognized as the gender with which one identifies, can include many factors, such as gender and name congruence on legal documents, undergoing surgical transition, having received hormonal treatment, and having received familial support regarding social or medical transitioning. Lelutiu-Weinberger et al. (2020) found that gender affirmation was crucial to mitigating the association between discrimination and past-year suicidal ideation, and attest that by not removing (or at the very least acknowledging) the complex barriers to gender affirmation and gender affirming care, healthcare providers are contributing toward loss of transgender lives. A recent study found that 43.9% of transgender participants needed, but did not receive care, versus only 10.7% of cisgender participants (Giblon & Bauer, 2017). Findings such as these accentuate the direct negative effect that rejection of care and experienced discrimination have on suicidal behaviors and attempted suicides.

Comprehensive gender affirming care is a multidisciplinary issue and involves many different types of healthcare service providers, some of which include plastic surgeons, endocrinologists, mental health professionals, and primary care physicians, among others. One study surveyed 101 transgender females and found that, despite improvements to other barriers to competent healthcare, the lack of knowledgeable healthcare providers was the most prevalent and persistent barrier to finding gender affirming care (Korpaisarn & Safer, 2018). Unfortunately, many healthcare providers do not feel adequately equipped to deal with transgender patients. One survey, conducted by Thomas and Safer (2015) on 20 internal medicine and family medicine resident physicians, found that only one out of the 20 respondents felt sufficiently knowledgeable to be able to assist transgender patients with

hormonal therapy. While a few disciplinary areas of healthcare have training regarding transgender care, there are other fields with no training whatsoever, rendering healthcare providers unable to treat transgender patients who come to their clinics. There are not many surveys currently published on this topic, but one survey conducted on gynecologists discovered that, out of 141 respondents, 80% received no training in transgender health during medical residency (Unger, 2015). All of this information combined only emphasizes the importance of gender affirmation and gender affirming care.

### **II.III.V Implications for healthcare providers and family members**

Positive and affirming healthcare is critical in order to improve the health of transgender people. Healthcare avoidance within the transgender community and its consequences is not something that should be taken lightly, both by the general public and healthcare professionals. There is a critical necessity for an increase in skilled and knowledgeable caregivers, as well as regulatory frameworks that protect transgender people's rights and provide a clear and secure pathway to obtaining the healthcare they need. Health professionals, both practicing and studying, should be required to learn about what it means to be transgender, what the current concerns and relevant issues are to transgender individuals, and fundamental skills such as the proper language and communication skills needed for gender-affirmation. Changes like the ones previously listed are especially needed in states with little to no current protections in place for transgender healthcare, as well as more rural areas where, even if statewide protections exist, educational resources may be limited.

While family support is typically understood to have a beneficial role in the lives of children, parents who have a transgender child have greater possibility of counteracting the

negative mental and physical health issues that may arise as a result of the harassment and discrimination their children may receive due to their gender identity. One survey of 66 transgender youth asked participants to report on parental support (defined as help, advice, and confidante support), and found that parental support was significantly associated with higher life satisfaction, fewer depressive symptoms, and less perceived burden of being transgender (Simons et al., 2013). Snapp et al. (2015) conducted another study of sexuality-related social support affecting measures of adjustment in young adulthood, and found that while family, friend, and community support were all strongly associated with positive outcomes, family acceptance had the overall strongest impact. These findings corroborate with previously published studies and offer guideposts for future research, such as efforts to educate parents and families about how to be supportive of their LGBT child, school sponsored peer-based support groups, and ways parents and guardians of transgender children play a role in mitigating the barriers that the healthcare system presents.

The healthcare system also poses another barrier to transgender people that may influence their decision to avoid utilizing health services: economic costs. In the past, the healthcare system (more specifically insurance policies and healthcare plans) have excluded gender affirming care for transgender and gender nonconforming patients. More currently, due in part to the Affordable Care Act (ACA), there has been a shift of third party payers expanding access to treatment for transgender patients (Padula et al., 2015). Unfortunately, the federal regulations are not always enough to combat the rate of healthcare avoidance in the transgender population. Ehrenfeld et al. (2018) points out that even in situations where transgender patients do have access to health insurance, there are additional barriers they may face that make it harder for them to seek the care they need, such as unstable housing,

lack of transportation, and prioritizing basic living costs (such as food, rent, or utilities) over the cost of medical care or medications. According to the 2015 U.S. Transgender Survey, 29% of transgender people live in poverty and 15% are unemployed, in comparison to the 5% unemployment rate for the general U.S. population (James et al., 2016). These percentages are invariably larger for transgender people of color, and for those transitioning from male to female.

There is an exceptional need for the healthcare system to become a more inclusive and accessible environment. One respondent, when asked how they believe the healthcare system needs to change, stated that “there is a world in which non-queer medical professionals are thoroughly educated about how to provide competent trans care, but I believe there’s a ceiling to how effective that care might be” and suggested that even if healthcare institutions properly educate and train medical professionals on how to interact with and treat transgender patients, “the more effective and long-term solution is the medical field looking to further diversify itself with trans and queer people in it” (Darden, 2022).

### III. Conclusion

Transgender people face much greater obstacles when seeking healthcare than the general population, and are often forced to navigate through systems that, until recently, were designed to keep them out. Understandably, transgender individuals often opt to avoid healthcare altogether due to a fear of expected or experienced discrimination.

Primary care physicians and other healthcare providers interested in better serving transgender patients may need to actively seek them out and provide communication about their staff's expertise and previous training in working with transgender patients and/or the availability of transgender or gender affirming care, such as hormone therapy or sex reassignment surgeries.

The integration of gender-affirming approaches in healthcare is essential in widening the support available for transgender healthcare seekers. Research opportunities are abundant, and are strongly needed to further contextualize the healthcare experiences of transgender adults. Nurse scientists in particular have the capacity to assist in prioritizing future research directions, developing interventions, and overseeing current and future initiatives and policies addressing the health of the transgender population.

Presently, research alludes to the necessity of proper education and training for healthcare providers in trans-competent and gender affirming care, as both knowledge on transgender issues and competent caregivers are insufficient. Given the convoluted web of motivations behind healthcare avoidance, it is important to assess all of the issues together when thinking of solutions, placing emphasis on social support and gender-affirmation to enhance the quality of care and address the needs of the transgender population.

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