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Review

Barriers to quality health care for the transgender population

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ABSTRACT

The transgender community is arguably the most marginalized and underserved population in medicine. A special issue focusing on men's health would be incomplete without mention of this vulnerable population, which includes those transitioning to and from the male gender. Transgender patients face many barriers in their access to healthcare including historical stigmatization, both structural and financial barriers, and even a lack of healthcare provider experience in treating this unique population. Historical stigmatization fosters a reluctance to disclose gender identity, which can have dire consequences for long-term outcomes due to a lack of appropriate medical history including transition-related care. Even if a patient is willing to disclose their gender identity and transition history, structural barriers in current healthcare settings lack the mechanisms necessary to collect and track this information. Moreover, healthcare providers acknowledge that information is lacking regarding the unique needs and long-term outcomes for transgender patients, which contributes to the inability to provide appropriate care. All of these barriers must be recognized and addressed in order to elevate the quality of healthcare delivered to the transgender community to a level commensurate with the general population. Overcoming these barriers will require redefinition of our current system such that the care a patient receives is not exclusively linked to their sex but also considers gender identity.

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Introduction

Over the past decade the visibility of the transgender (trans) community has been steadily increasing due, at least in part, to representation in pop culture and the media. Nonetheless, while public awareness of trans issues has been heightened, clinicians, public health researchers, and officials are becoming increasingly aware that trans persons represent one of the most marginalized and underserved populations in medicine. In fact, both the trans community and healthcare providers agree that there are many barriers to healthcare for trans persons that cluster around four main issues: (1) reluctance to disclose, (2) lack of provider experience and resources, (3) structural barriers, and (4) financial barriers [1,2]. This review will focus on these critical issues that create most barriers to care for trans patients as well as potential ways in which they can be addressed. Unfortunately, trans persons are frequently reluctant to disclose gender identity even when receiving medical care because of social stigma and cultural prejudices. While we can be optimistic that such prejudices no longer plague the medical profession,

Abbreviations: APA, American Psychological Association; HT, cross-sex hormone therapy; DSM-5, Diagnostic and Statistical Manual of Mental Disorders 5th edition; EHR, electronic health record; FTM, female-to-male; LIS, laboratory information system; MTF, male-to-female; trans, transgender; WPATH, World Professional Association for Transgender Health.

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the level of proficiency of health care providers in caring for trans patients is very limited [2]. Similar to lesbian and gay populations, trans patients have unique healthcare issues and needs that are often not recognized and a lack of education, training, and resources for providers compounds the problem [3–6]. Lastly, even when gender identity is disclosed to a well-versed and caring provider both financial and structural barriers still exist [7]. It is important that the quality of healthcare delivered to this very vulnerable population is discussed openly so that solutions that can elevate it to equality with other populations can be identified.

It is important to understand that the terms "sex" and "gender", while often used interchangeably, have specific medical and psychological meanings. "Sex" commonly refers to physical characteristics whereas "gender" represents identity and self-image [8,9]. Trans persons experience their gender as being different from the sex that was assigned to them at birth, otherwise referred to as gender nonconformity [1]. Gender dysphoria refers to the distress that can arise from gender nonconformity [10,11]. For some, gender dysphoria may meet criteria for a formal diagnosis that might be classified as a mental disorder. In the DSM-5 these criteria include a strong desire to be treated and identified as the expressed gender, which results in an increased risk of distress leading to significant social and/or occupational impairment [12].

Formal epidemiological studies on the incidence and prevalence of gender nonconformity have not been conducted due to the enormous difficulty of achieving realistic estimates. Over the last several decades, studies from numerous countries have published prevalence data ranging from 1:11,900 to 1:45,000 for male-to-female (MTF) trans persons and 1:30,400 to 1:200,000 for female-to-male (FTM) trans persons [8]. However, these numbers should be considered minimum estimates at best as they are derived from clinics where patients met criteria for severe gender dysphoria and had access to care.

The World Professional Association for Transgender Health (WPATH), an international multi-disciplinary professional association that publishes standards for the care of trans and gender nonconforming persons, released a statement in May 2010 urging the de-psychopathologization of gender nonconformity. The statement noted that "the expression of gender characteristics, including identities, that are not stereotypically associated with one's assigned sex at birth is a common and culturally diverse human phenomenon [that] should not be judged as inherently pathological or negative" [8]. Thus, trans and gender-nonconforming individuals are not inherently disordered; rather, it is the distress of gender dysphoria that might be diagnosable and treatable. This theme was continued in the DSM-5 where gender dysphoria has now its own chapter, separate from sexual dysfunctions [12]. A separate chapter for gender dysphoria is more consistent with familiar clinical sexology terminology and removes the connotation that the patient is "disordered" [12]. In implementing this change, the APA and the DSM-5 affirmed that persons experiencing gender dysphoria need a diagnostic term that removes stigma, won't be used against them in social, occupational, or legal areas, and protects their access to care.

Barriers to care

Reluctance to disclose

The existence of a diagnosis for gender dysphoria often facilitates access to health care and can guide further research into effective treatments. Treatment for gender dysphoria has become more individualized and may or may not involve a change in gender expression or body modifications [13]. The first step in treatment for gender dysphoria is a mental health screening or assessment, which is required to obtain referrals for HT as well as surgery if desired [9]. While not a requirement, psychotherapy is recommended by both The Endocrine Society and WPATH [8,14]. Collaboration between mental health professionals and providers in other health disciplines (e.g. primary care, endocrinology, and surgery) is critical for appropriate patient management. Medical treatment options include feminization or masculinization of the body through HT and/or surgery and are medically necessary for many people [8].

The most common definition of medical necessity is, "health care services that a physician, exercising prudent clinical judgment, would provide to a patient for the purpose of preventing, evaluating, diagnosing or treating an illness, injury, disease or its symptoms, and that are in accordance with generally accepted standards of medical practice" [7]. Generally accepted standards of medical practice are those that are evidence-based and published in peer-reviewed medical literature as well as Physician Specialty Society recommendations [7]. Gender dysphoria can lead to symptoms of clinical depression and the ultimate result is that 41% of trans persons have attempted suicide compared to <2% of the general population in the US [15]. Decades of both clinical experience and medical research have established that HT and/or surgery are effective in treating the symptoms of gender dysphoria and essential to achieving well-being for trans persons [8].

Nonetheless, there is a stigma attached to gender nonconformity in many societies around the world. Such stigma can lead to prejudice and discrimination. For those reasons, many trans persons are reluctant to disclose their gender identity, even in healthcare settings, because of anxiety over the potential negative consequences. The National Transgender Discrimination Survey published in 2010 found that 19% of respondents had been refused care due to their gender identity [15]. The survey also found that 28% of trans people had been verbally harassed and 2% had been physically assaulted while attempting to receive medical care [15]. Negative interactions in health care settings can make an already vulnerable experience unbearable, leading trans persons to delay or avoid necessary services putting their overall health at risk. For example, in order to avoid such interactions the patient might decide to obtain medicines and treatments from nontraditional sources or to forgo care completely. In fact, the prevalence of unsupervised hormone use in urban transgender populations reportedly ranges from 29% to 63%, a behavior that poses significant health risks [16]. Furthermore, even if trans persons are willing to disclose their gender identity, mechanisms to identify and monitor such patients are not in place.

Structural barriers

The structural barriers to care for trans persons are diverse. Based on the 2010 National Transgender Discrimination Survey, a guideline for hospital policies to overcome structural barriers was published by a coalition of civil rights advocacy groups [17]. Some of the barriers are relatively easy to address such as restroom access. Trans persons may be uncomfortable with public restrooms that are restricted by gender and the availability of a private, unisex restroom contributes to a trans affirming environment. Similarly, trans persons should be given the option of having a private inpatient room assignment. If a private room is unavailable or the patient prefers to share a room they should be assigned to a room with a roommate of the same gender identity. In this case, however, it is necessary for the admissions office to ascertain the patient's gender identity usually based on admission and/or registration records, which may not be simple.

The great majority of healthcare IT solutions including electronic health records (EHRs), billing/coding systems, and laboratory information systems (LISs) have implemented a binary male/female identification system. While it accurately captures most of the patient population, this structure impedes the collection of accurate medical information in gender nonconforming populations. In 2010 the Institute of Medicine (IOM) recommended that data on gender identity be collected in EHRs as one component of meaningful use objectives [1]. In response, the WPATH executive committee convened an EHR working group in 2011 comprised of expert clinicians and medical information technology specialists to make recommendations for the development and use of EHR systems with respect to trans patients [18].