

**COMPREHENSIVE RECOMMENDATIONS FOR IMPROVING THE HEALTHCARE
EXPERIENCE OF TRANSGENDER AND GENDER-EXPANSIVE INDIVIDUALS**

by

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ABSTRACT

This paper presents a comprehensive summary of the literature surrounding transgender primary and preventive healthcare and recommendations for professional medical staff and researchers. The public health significance of this issue is that there are an estimated 1.2 million transgender adults living in the United States at the time of this research. Formal epidemiological measurements of the population as well as the incidence and prevalence of gender dysphoria throughout the life course are missing from the literature. Transgender patients face a unique combination of healthcare access barriers and therefore are less likely than the general population to seek treatment. Access barriers include personal attitudes and beliefs, interpersonal interactions resulting in discrimination, and structural barriers such as lack of insurance coverage. Delays in primary and preventive medical care are associated with poorer health outcomes across all populations. Because of their unique vulnerabilities, transgender patients require medical care that is comprehensive and sensitive to the needs of individuals who are transgender. Rigorous research and improved medical practices can offset the minority stress and associated medical concerns faced by this community in the long-term.

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1.0 INTRODUCTION

The purpose of this study is to identify the current research gaps, medical knowledge deficits, and medical practice and policy needs specific to healthcare consumers who are transgender. This will also include identifying current standards of practice, and establishing best practice guidelines for those areas that are less well-developed. This critical literature synthesis focuses on primary and preventive care in a holistic sense, instead of the more well-researched (but still notably insufficient) transition-specific care. It is of note that some deficits extend into the realm of gender confirmation, such as research into hormone therapy and gender confirmation surgery, but these will not be the primary focus of this paper.

It is of note that many practitioners in the field are now using the term “gender-expansive” to describe the entire spectrum of identities incongruent with sex assigned at birth. This term is not currently reflected in the literature, but will be used here during the course of the recommendations section. Since many people do not identify as transgender but may have an identity not congruent with assigned sex, this term is more inclusive of the entire community. When discussing those who identify as gender-expansive, acronyms such as “FTX” or “MTX” will be used. These indicate sex assigned at birth (M for male, F for female), to (“T”), and X for any variation of gender identity. These acronyms are used infrequently in the literature. More common are the acronyms MTF and FTM (male-to-female and female-to-male) to indicate binary transition.

This paper will explore the perceived barriers to quality healthcare identified by both patients and providers as described in the extant literature. Attention will be given to current standards of practice, and how to incorporate them into current medical practice. This will also show how individuals who identify as transgender or gender expansive have been systematically excluded from existing medical studies. Erasure will be discussed in regards to not only medical research, but also medical education and ongoing training. The paper will conclude with recommendations across seven specific categories: staff training, healthcare environment, medical documentation, general care, insurance policies, medical education, and research needed.

1.1 STATEMENT OF NEED

The estimated number of people who identify as transgender has increased over the last several years. This increase may be an artifact based on people's comfort in coming out/identifying as transgender, a broader available vocabulary for the many identities one may experience, and more reliable data-collection through respondent-driven sampling. Information from 2011 suggests a global population of approximately 25 million people who identify as transgender (1). It is of note that this is an extrapolation to a global population of 5.1 billion, and used the lowest reported estimate of people who identified as transgender. This does not directly state inclusion of all gender-expansive identities.

In the United States estimates of the transgender population are provided by The Williams Institute, using the Behavioral Risk Factor Surveillance Survey (BRFSS) (2). The BFRSS provides an optional module regarding gender identity, but is not measured in most

states. This was first implemented in the 2014 survey. Those results showed that there are at least 1.4 million transgender adults living in the United States (2). The numbers also suggested that among younger adults, the prevalence of transgender identity is higher.

It has been well-established through research that the lesbian, gay, bisexual, and transgender (hereafter referred to as LGBT) population experiences poorer health outcomes than the general population (3). In addition, a closer look at the evidence suggests that there are significant within-group disparities between the LGB population and the transgender population in relation to healthcare services, access, and primary care utilization (4, 5).

Surveys of transgender people have yielded numerous concerning statistics regarding healthcare. These individuals report being unable to access trans-inclusive primary and emergency care as a main health concern (6), and even when care is accessed, pervasive discrimination across all healthcare systems has been reported (4). One author summarizes these disparities as a call to action:

“In a recent survey... over 21% [of transgender adults] were denied mental health services, 15% were denied gender-specific care (such as Pap smears for transgender men), and 10% were denied primary health care. Disturbingly, in a national report, over 70% of transgender adults reported harsh or abusive language, blame for their health status, or physical roughness or ^{[[[}abuse from health care professionals. Unsurprisingly, 90% of transgender individuals agree that there are ‘not enough health professionals adequately trained to care for transgender people.’” (7)

1.2 SOCIAL DETERMINANTS OF HEALTH

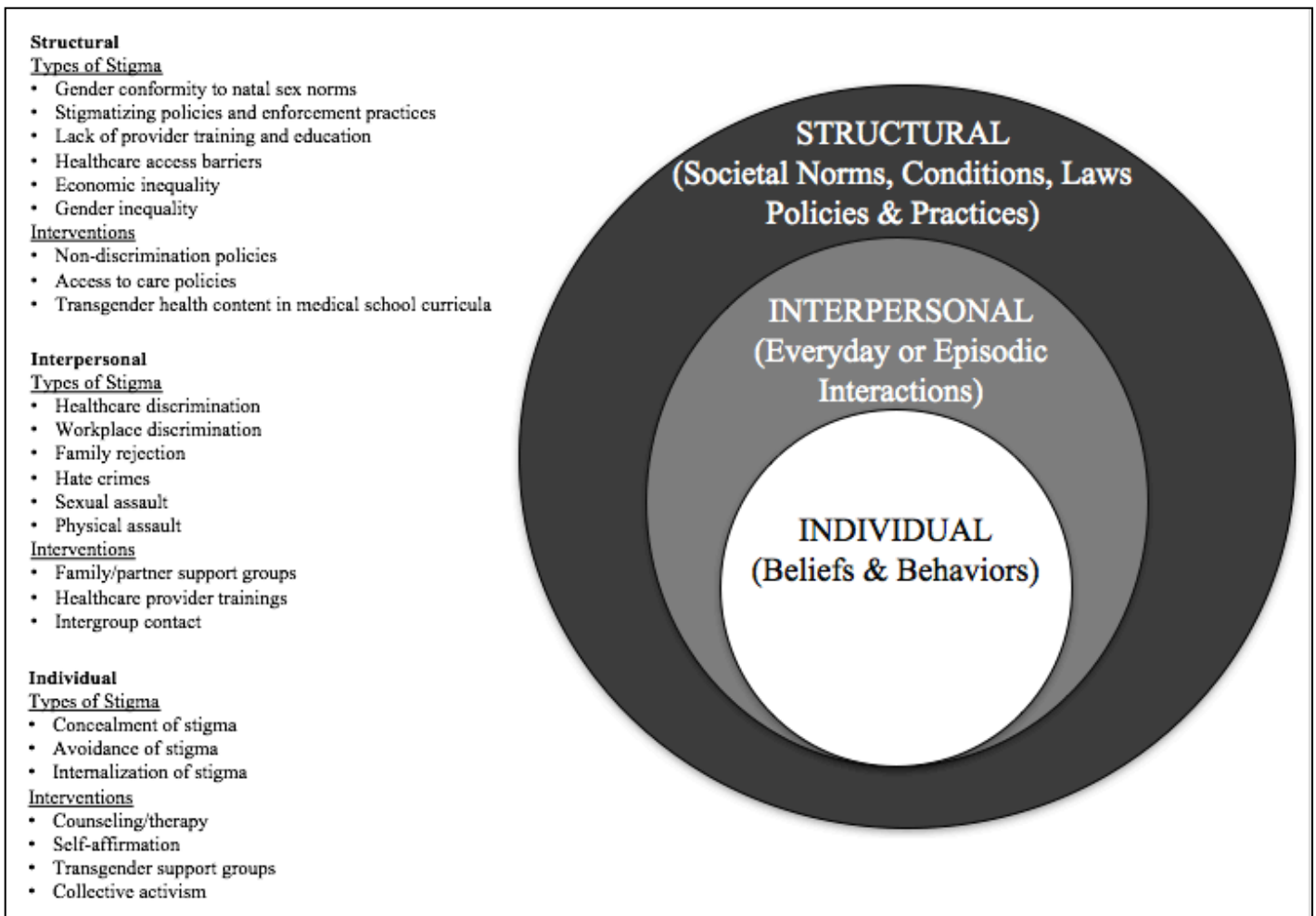
Social determinants and health system determinants both contribute to limited healthcare access. The World Health Organization (WHO) defines determinants of health as a set of circumstances or the combination of environmental, genetic, and social factors that affect an individual's health(8). It is well-documented that the transgender population faces issues with social support, employment conditions, housing conditions, income level, and social status (4, 9-13). Research has shown that “poverty, homelessness, stigma, addiction, violence, untreated mental health problems, lack of employment opportunities, powerlessness, lack of choice, lack of legal status, and lack of social support create an environment in which...illnesses flourish and spread” (6). All of the barriers listed are current challenges faced by the transgender community, as demonstrated in existing literature.

People who identify as transgender have an increased risk of suicide compared to the general population. Percentages of those attempting suicide are 41% and less than 2%, respectively (4). The minority stress model has been used to explain higher rates of suicide attempts among the LGB population (14). This model indicates that people with multiple layers of marginalization (for example, someone who is in the LGBTQ community and is also a racial or ethnic minority) will experience poorer health outcomes than someone in one or more dominant groups (someone who is cisgender, heterosexual, and/or in the racial majority) (3). This model could be further applied to the poor health outcomes of transgender individuals compared to the general population, but has not been rigorously studied to date.

1.2.1 Stigma

Stigma and discrimination are positively associated with suicide attempts in the transgender population (15) and are positively associated with negative health outcomes in other populations (13). Stigma can occur for a number of reasons within the transgender community, including adherence to binary norms (16). Even when one's status as a transgender person is accepted, the individual may still be expected to act "feminine enough" or "masculine enough" to be accepted as their true gender. People with non-binary identities and those who are gender non-conforming experience stigma for challenging the idea that an individual must present as male or female (16). This also manifests in healthcare settings, which will be discussed later in this paper.

Stigma is pervasive, and can be examined at each layer of the social ecological model. White Hughto et al. (12) describe in detail multiple levels of stigma and how each impacts the transgender population (Figure 1). This ranges from individual beliefs and behaviors (including internalized stigma), to interpersonal interactions, and then to structural norms, laws, policies, etc.



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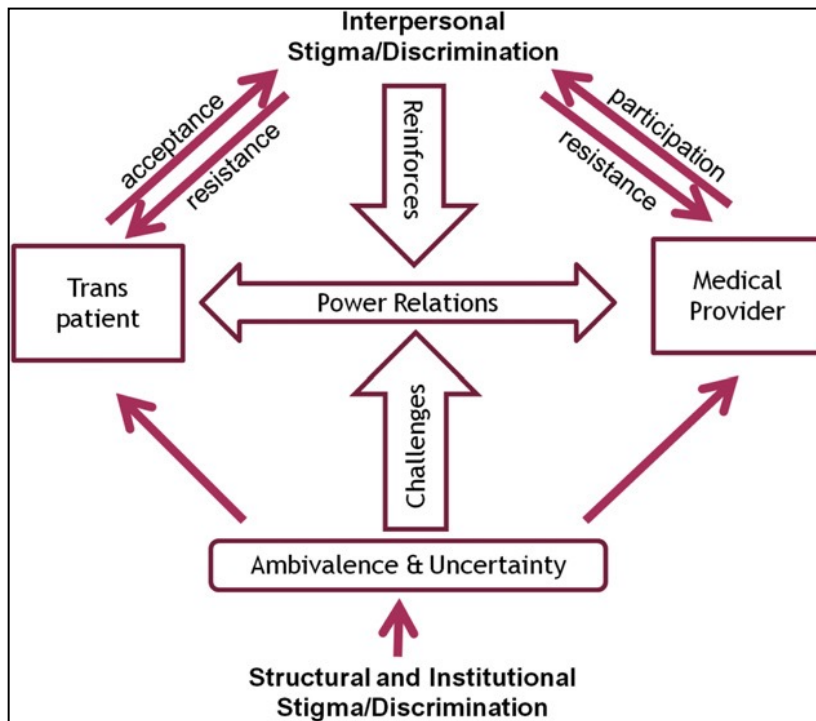
Figure 1. Social Ecological Model of stigma

On an individual level, people often internalize negative associations toward their own group. A person may avoid coming out as transgender due to beliefs that it is unnatural, that it is a phase that they will grow out of, or that others in their life will not accept them as their identified gender.

Interpersonal conflict is something that plagues everyday interactions for transgender people. Some days these may include misgendering microaggressions—other people using the incorrect pronouns to describe a person. Other days it may manifest in rejection from family,

social groups, etc. At the worst, physical and sexual assault are regularly reported by transgender individuals, and experienced at much higher rates than other populations (4).

Structural stigma will be the main focus of this analysis, as it is the most relevant to research gaps and healthcare practices. Multiple studies have reflected the need for people who are transgender to educate their medical providers regarding their unique medical needs (4, 6). The managing uncertainty and establishing authority theory (Figure 2) suggests that this lack of medical knowledge could be a driving force behind negative treatment and stigma among healthcare providers (11). As shown below, the core of interaction between a patient and medical provider rests on power relations. Usually, the medical provider retains power over the patient due to a wider medical knowledge base. Stigma against the patient results in reinforcing the power relations, whereas ambivalence and uncertainty on the part of the provider challenges them. If a provider needs to ask a patient about their medical needs, the provider loses authority. Power shifts to the patient as the patient and provider resist stigma (both internalized and interpersonal), and the provider's uncertainty regarding care increases. This shift in power is proposed to contribute to the medical provider participating in interpersonal discrimination as a way to retain control over the interaction (11). Such interaction jeopardizes the relationship between the two, and may also lead to reinforced stigma on either side (interpersonal stigma from the provider, internalized stigma from the patient) (11).



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Figure 2. Managing uncertainty and establishing authority

The above model is based on the idea of knowledge legitimacy, and how the transgender community simultaneously upholds and challenges current medical knowledge (17). Many medical providers have limited experience in treating transgender clients, and therefore patients have to tell their provider about their transition-related medical needs. This includes but is not limited to information about hormone therapy, one’s gender identity and pronouns, one’s sexual orientation, sexual behavior, and associated risk factors. These patients also challenge current practices and beliefs by educating healthcare professionals about things that are effective or ineffective in their care, regardless of whether they are supported practices by the medical community (17).

Link and Phelan describe the detrimental effect of stigma on overall public health (18). The process of stereotyping culminates in the exercise of power over the stigmatized individuals, leading to stereotyping on both sides of the power dynamic (18); for example, transgender patients may begin to see medical providers as cold, uncaring, close-minded, or even dangerous. Furthermore, when discussing existing health disparities we would be remiss to forget the higher rates of HIV infection among people who are transgender (19). As shown in the Lambda Legal report, those diagnosed with HIV are also likely to experience discrimination based on disease status (5). Herbst et al. showed intersectional disparities within the transgender population, and found that the highest rates of HIV infection were among transgender people of color (19). This further upholds the minority stress model applied to this population. Multiple layers of stigmatization lead to poorer health outcomes, and this is no different within the transgender community (3).

2.0 METHODS OF DATA COLLECTION

Articles were collected through the PubMed database. The focus was to find articles that had measured primary and preventive healthcare concerns for people who identify as transgender or gender expansive. This also included emergency care for general conditions, or conditions not related to transition. The following search terms were used (Table 1).

Table 1. Search Terms

Field 1	"transgender persons"[MeSH Terms] OR ("transgender"[All Fields] AND "persons"[All Fields]) OR "transgender persons"[All Fields] OR "transgender"[All Fields]) OR transsexual[All Fields]	
Field 2	"primary health care"[MeSH Terms] OR ("primary"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "primary health care"[All Fields] OR ("primary"[All Fields] AND "care"[All Fields]) OR "primary care"[All Fields]) OR ("preventive medicine"[MeSH Terms] OR ("preventive"[All Fields] AND "medicine"[All Fields]) OR "preventive medicine"[All Fields] OR ("preventive"[All Fields] AND "care"[All Fields]) OR "preventive care"[All Fields]	
Field 3	"health"[MeSH Terms] OR "health"[All Fields]) OR ("delivery of health care"[MeSH Terms] OR ("delivery"[All Fields] AND "health"[All Fields] AND "care"[All	

Table 1 Continued

	Fields]) OR "delivery of health care"[All Fields] OR "healthcare"[All Fields]	
Additional filters	English language Published within the last 10 years Adult subjects (ages 18+)	= 185 results

Additional content criteria were assessed after the initial search was conducted. The primary focus of the article had to be on primary or preventive healthcare and not specializing in hormones, surgery, or other gender-confirmation procedures. The transgender population also had to be the only focus of the article, or was separated in the analysis from the lesbian, gay, and/or bisexual population. Citation mining was used following collection of articles. Of the initial 185 search results, approximately 12 were included in this paper. The rest were gathered through citation mining and external sources.

3.0 RESULTS

A qualitative study of physicians examined their perceived barriers to providing high-quality care to people who identify as transgender (20). The authors divided these into five categories: healthcare access, health system determinants, medical knowledge deficits, diagnosing vs. pathologising transgender individuals, and ethics of transition-related care (20). In order to address the deficiencies in healthcare faced by this population, this paper will begin by examining each category in detail and explore supporting research.

3.1 HEALTHCARE ACCESS

Healthcare access is a complex topic. Access ranges from being aware of healthcare services, to perceived need for services, to the actual experience of seeking healthcare. Access includes such things as transportation, scheduling, costs of co-pays, and the experience one has when seeking care. There are also multiple factors that may encourage or discourage patients from returning after an initial appointment. The model explored here breaks healthcare access down into provider factors and patient factors, and explores barriers at each stage from both sides of the interaction.

3.1.1 Conceptual model of healthcare access

Levesque, Harris, and Russell define access as “the opportunity to have health care needs fulfilled” (21). They provide a model that describes the path from health care needs to health care consequences, with steps in between indicating perception of health needs, care-seeking behaviors, and utilization of healthcare. The health belief model is nested within this framework, but that model alone cannot explain the full range of a patient accessing healthcare or not. The health belief model encompasses only the patient’s perceived need for care, feelings about accessing care, health literacy, and cues to seek care. As is seen in the model below, this is only a fraction of the full picture; the health belief model covers the first two segments of the process of healthcare access.

The Levesque et al. model (Figure 3) shows the outside forces impacting behavior change, as well as utilization and health outcomes. Based on this model, the authors propose a conceptual framework of access, and discuss the barriers on both the side of the patient and the side of providers. Here we will discuss in detail the specific challenges faced by transgender individuals at all levels of healthcare access.

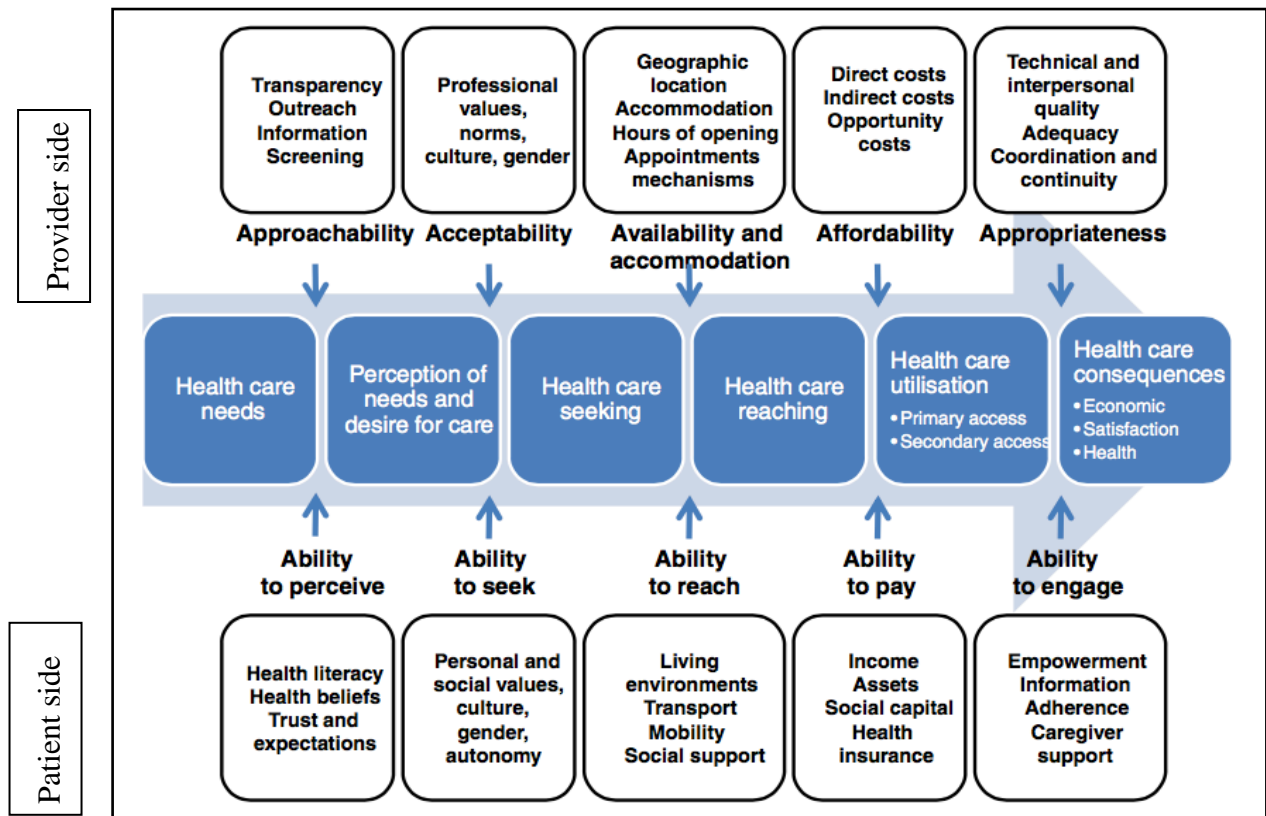


Figure 3. Conceptual model of healthcare access

- Provider (“supply side”)
 - *Approachability.* Approachability refers to public information that the service exists, is able to be utilized, and can provide positive health outcomes to the target population(21). Transgender people often do not know of primary healthcare providers who are knowledgeable and/or nearby. Access to relevant healthcare information is a concern identified by the transgender community (6). Cruz identifies that this may cause patients to delay necessary healthcare until the point at which the health problem becomes severe enough to warrant emergency room treatment (10).

- *Acceptability.* This concept refers to any social/cultural beliefs about providing healthcare, and whether providing care to this population is socially sanctioned. The example given describes the healthcare-seeking behavior for some individuals of the Islamic faith, for whom physical contact between unmarried individuals of opposite genders is socially unacceptable. If the patient is a woman and the doctor a man, this may cause the provider to feel he is not able to provide care due to unacceptability (21). Health care providers may face discrimination from the community or from peers for providing care to gender minorities. This is a risk many providers accept, but could preclude others from providing such services.
- *Availability and accommodation.* Even when healthcare services do exist and are acceptable, they may not be within a reasonable distance from a patient's home or work, have necessary accommodations for those with a disability, employ providers with appropriate knowledge and credentials, or have appointments available within a reasonable amount of time (10, 21).
- *Affordability.* While primary healthcare is often covered under insurance, many gender-affirming procedures and medications are not (22). Insurance policies also fail to cover biological sex-based care for those who have legally changed their gender: for example, a prostate exam for a woman (22). Providers are limited in their ability to offer lower-cost services without reimbursement from insurance providers, government agencies, or private funding streams. To ensure the highest-quality services, providers need to be adequately compensated.

- *Appropriateness.* Appropriateness refers to provider adherence to established standards of care. An example is the circumstance of a transgender man seeking cervical care at a women’s healthcare clinic; the very nature of the health center implies that it is only for biological, cisgender women. Similarly, accepting attitudes and willingness of healthcare providers to learn about how to provide comprehensive trans healthcare play a large role in determining whether people will return for services or not (6). If a transgender man enters the clinic, gets misgendered as a woman, and feels his identity is being invalidated, this would be an example of inappropriate services.

- Patient (“demand side”)
 - *Ability to perceive.* Individuals must first understand the need for preventive, primary, and emergency healthcare, and know that these levels of care exist. Much of this understanding comes from health literacy and is influenced by health beliefs (21). For the transgender population, patients may not be aware of biological screening recommendations (such as Pap smears), immunizations and preventive treatments (PrEP, HPV vaccine), or recommended tests for chronic health conditions that may be impacted by long-term hormone use (cardiovascular disease). Interviewees have reported that many doctors are also unaware of screening recommendations and long-term effects of gender-affirming surgeries (6). Even if the population is aware, they may not know who provides such care, or how to find this information.

- *Ability to seek.* This refers to the patient-side barrier of acceptability. As stated above, transgender people may not feel comfortable seeking care due to fear of mistreatment, or insecurity with their identity. The example of a transman seeking cervical care can be used here. If the individual understands that he should still be receiving regular Pap smears but does not feel comfortable presenting to a women's health clinic or provider, then he would likely not receive the recommended screenings (6). The stigma surrounding an LGBTQ or trans-specific healthcare clinic may prevent patients from obtaining care for fear that they will be "outed" socially, further marginalized, or seen to have a stigmatizing health condition (i.e. HIV).
- *Ability to reach.* As stated above, many transgender individuals do not live within a reasonable distance from knowledgeable healthcare providers. Cruz proposed that transgender individuals may delay care based on inability to easily access care providers who are sensitive to their unique medical needs and trained to provide competent care for people who are gender expansive (10). Survey participants often cite that not enough providers are trained to provide transgender care (5, 23).
- *Ability to pay.* Income instability is cited by transgender survey participants as a main barrier to care (6). In this same small group of participants, 30% reported being unemployed or working poor (6). Based on the findings from the National Transgender Discrimination Survey (4), approximately 14% of the United States transgender population reports being unemployed. Reduced household income is associated in other populations with delaying medical care, as is a lack of

insurance (24). This puts the transgender population at greater risk of delaying medical care due to not having access to funds gained from employment, as well as employer-based insurance plans.

- *Ability to engage.* This refers to an individual's empowerment, information received, natural supports, and adherence to a regimen of treatment. Of course, every individual given healthcare recommendations has the option of declining adherence. However, for the transgender population there is a lower likelihood that they will receive familial support in their choices and treatment plans (4). Since the ability to engage is influenced by the level of support, either from others encouraging initial treatment or supporting the patient in receiving ongoing care, this puts people who are transgender at a disadvantage to continuing care.

3.1.2 Delayed Medical Care

Many transgender people delay medical care, which can enhance risk for future medical conditions, worsen outcomes of existing conditions, and lead to increased cost of medical care (24). While the quantitative percentages are similar, significant qualitative differences exist between the transgender population and the general population when it comes to reasons for delaying medical care. One study showed that 33% of the general population delayed medical care over the last 12 months, due to a variety of factors (25). The top three reported reasons were not being able to take time off work, having to care for someone else, or not having transportation (25). Of the respondents, 3% indicated fear for personal safety. None reported discrimination as a factor.

In contrast, the National Transgender Discrimination Survey stratified respondents by their transgender status and found very reasons for delayed care (4). A quarter of study participants reported that they had delayed care due to fear of discrimination, with many having reported previous experiences of discrimination (Figure 4). Similarly, a report by Lambda Legal found the highest rates of fear among transgender individuals for being denied care or being treated differently due to trans status (Figure 5) (5). Compared with the general population, the reasons for delaying care in the transgender population paint a picture of risks outweighing the benefits of medical intervention.

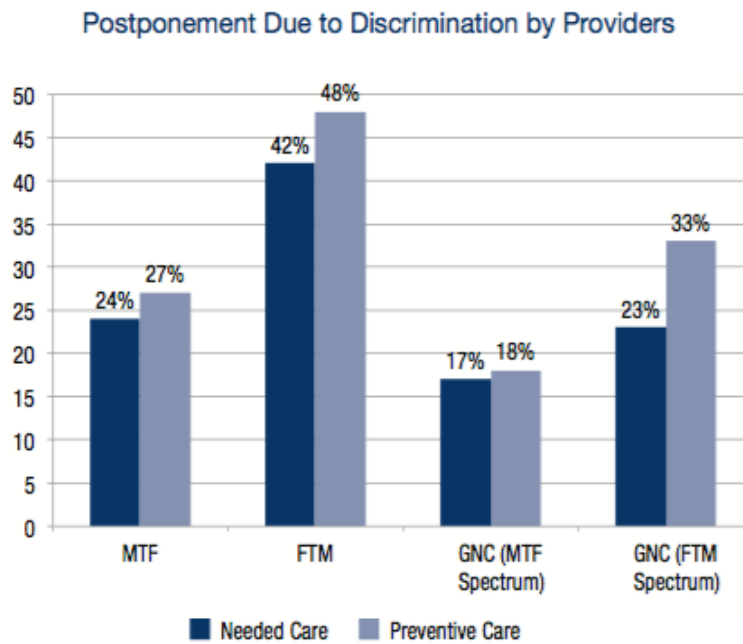


Figure 4. Postponement of preventive and emergency care

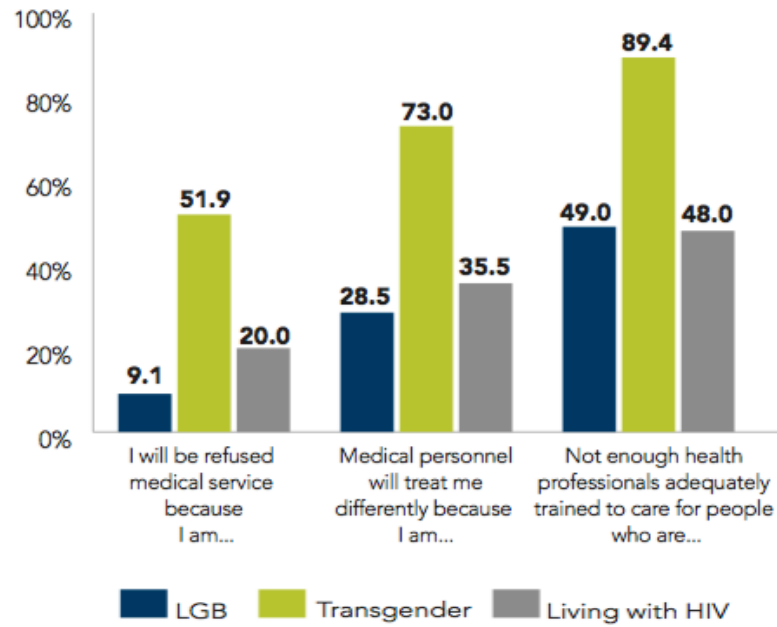


Figure 5. Fears and concerns about accessing healthcare

3.2 HEALTH SYSTEM DETERMINANTS

The World Health Organization defines health system determinants as “the way health systems are designed, operate and financed” (26). For this section, the focus will remain on day-to-day operations of healthcare settings and insurance policies, and how these impact people who are transgender.

Traditionally the healthcare system restricts patients to binary gender (male or female) in medical forms, electronic health records, and research studies (9, 27). This makes it difficult for transgender patients to be recognized in ways that are not only medically relevant, but also socially validating. This is especially true for patients who have not undergone medical treatment and who may still present as their sex assigned at birth. This is important to show patients proper respect of their names and pronouns, but also to understand potential screening recommendations appropriate to someone’s anatomy.

Insurance has historically been a barrier to quality care for transgender individuals. Prior to the Affordable Care Act (ACA), transgender identity, gender identity disorder, or gender dysphoria were all listed as “pre-existing conditions,” which could therefore result in health insurance denial (22). The ACA went into full implementation in 2014, removing the barrier of pre-existing conditions (22). Transgender adults seeking care prior to 2014 may have had a more difficult time accessing care, resulting in poorer health outcomes. Even once an individual has healthcare coverage, transition-related services remain difficult to access. Insurance companies may identify hormones, surgeries, and therapy to address gender dysphoria as “not medically necessary,” which may occur with higher frequency following the passage of the ACA (22). To

this author's knowledge, no research has been conducted to examine the frequency of insurance denials for gender-confirming care and qualitative reasons behind them.

Despite positive changes in transgender healthcare instituted in the ACA, many health insurance providers retain practices that prohibit transgender individuals from obtaining needed healthcare, such as not covering transition-related services (22) or not performing routine screenings because biological sex differs from gender (6).

3.3 MEDICAL KNOWLEDGE DEFICITS

Though transgender people are regular consumers of healthcare services and have been receiving medically complex care for decades, published research and available data do not match the current need for information, as evidenced by persistent health disparities experienced by people who are gender expansive. Pervasive discrimination among healthcare providers results in erasure of transgender people from research, expulsion from clinics not equipped or unwilling to provide care, and denial that transgender health issues are anything more significant than an anomaly among thousands. Indeed many providers adhere to outdated statistics regarding the number of transgender individuals, and in doing so, continue the institutional erasure that impedes quality care (6).

When established practices and treatment recommendations do exist, they are “often not incorporated into textbooks, educational curricula, health care protocols, or other summary documents, or [are] incorporated in a way that conflates gender identity with sexual orientation” (6). As already stated, gender identity is significantly different than sexual orientation, and as evidenced by the NTDS and Lambda Legal reports, much less easily understood (4, 5). These

reports and studies are not readily incorporated into information already being provided to healthcare providers; therefore, in order for a physician or medical professional to access the information, the person needs to know what to look for and where to find it.

Until recently, medical knowledge that did exist regarding transgender healthcare may have lacked accuracy and therefore been a hindrance to proper care. For example, recent evidence has brought to light the idea that estrogen may not protect against prostate cancer as previously believed (28). Historically, a literature review revealed only 10 known cases of prostate cancer in transwomen, which upheld the protective theory of estrogen. However, these 10 cases constitute too small a sample size to support the conclusion of estrogen being protective. To date no known studies have compared prostate cancer rates in transgender women taking estrogen with cisgender men not taking estrogen. The researchers here argued that “patients in this cohort did not undergo regular screening, and therefore it is possible that subclinical cases were overlooked” (28). To have accurate estimates of disease incidence and prevalence, subclinical cases must be included in measures, and therefore anyone at risk for prostate cancer should be screened regularly. It can then be assessed whether transwomen receiving estrogen are at any qualitatively different risk for cancer than cisgender men. This will be revisited in the recommendations section of this paper.

Surveys conducted among OBGYNs indicated that these providers were unable to identify any differences in pelvic examination processes between transgender men and cisgender women (29). The providers surveyed did not identify that a transgender man or non-binary person may experience higher levels of anxiety and discomfort during a pelvic exam, and may require additional supports during a procedure (29).

Other studies show a higher likelihood for unsatisfactory Pap results for people who have been on androgen therapy and also retain a cervix (30). An unsatisfactory Pap is a sample that does not have enough cells or tissue to analyze for abnormalities. The medical assumption here is that the cervix/pelvic region of individuals receiving androgen therapy is qualitatively different than that of cisgender women. One idea postulated is that the cervix and vagina atrophy as the presence of estrogen is reduced within the body; certain treatments for post-menopausal cisgender women have been shown to be effective for collecting more satisfactory samples, but this has not been tested in transgender individuals. Inadequate Pap tests cause significant anxiety among all patients, regardless of gender identity, and this anxiety may cause longer delays between follow-up tests (30). Cisgender women tend to return for follow-up testing well within the recommended 4-month window following an abnormal Pap test, whereas transgender male patients (assigned female at birth, also referred to in the literature as FTM or FTX) wait significantly longer—in many cases, well over a year (30). In the absence of better information, the American College of Obstetrics and Gynecology (ACOG) recommends that patients who are transgender follow the same cervical screening guidelines as cisgender women, a fact that may have to be conveyed with greater importance to both patients and providers. This is especially important considering the higher prevalence of smoking and sexual violence among FTM and FTX individuals, both risk factors for cervical cancer (31). Another study supports this claim due to finding cases of cancer only incidentally when preparing FTM patients for sex-reassignment surgery (32); these cancer cases may have gone undetected without examination for a different medical procedure. At the time of the Urban study, the authors were only able to find 7 case studies over the last 10 years (2000-2010) addressing gynecologic malignancies in FTM patients (32). Such a diagnosis may lead not only to continued dysphoria among patients who retain

female sex organs, but may also cause insurance issues among those who have had their gender legally changed, and result in negative mental health consequences (32). It is of note that these mental health consequences should not deter a person from undergoing regular screenings and any treatment required, but that patients who identify as transgender or non-binary may require additional supports and follow-up compared with the general population (32).

Medical knowledge is based in both ongoing research and education curricula. These are two areas in which representation of transgender people remains inadequate. A recent meta-analysis explored the current trends in research focusing on the transgender population (33). The authors found only 116 studies globally that focused on the transgender population in any meaningful way (33). This study excluded studies that grouped the LGBTQ population into one group and did not stratify based on sexual orientation and/or gender identity. The authors identified 981 unique health outcomes, or data points (for example, diabetes would be one data point, as would be clinical depression). Many studies analyzed more than one health outcome. A thematic analysis separated these data points into six categories, listed in declining order of research density: mental health, sexual and reproductive health, substance use, violence/victimization, stigma/discrimination, and general health. Only 68 out of 981 datapoints (6.93%) related to general health, such as diabetes, heart disease, etc. This is of particular concern due to the dearth of knowledge related to long-term hormone use, different screening guidelines for health issues in transgender individuals, and the higher prevalence of health issues in other populations as a result of minority stress (33).

If we assess the declining research density as a model for the assumptions made about the transgender population, we see an implication that the concerns for people who are transgender are primarily those of substance abuse, mental illness, and what is perceived to be sexual

deviance. Recalling the discussion of stigma, these conditions compound negative connotations and lead to more stigmatizing conditions being assumed for the entire population of transgender people.

Transition-related care such as hormone treatments, masculinizing/feminizing surgeries, and sex-reassignment (also referred to as gender affirmation or gender confirmation surgery) have been studied significantly more in the medical community. Hembree et al. (34) discussed the current research and assessed recommendations along several domains relating to endocrine treatment. The researchers used the GRADE method (Grading of Recommendations, Assessment, Development, and Evaluation), an international method of establishing evidence-based guidelines. The GRADE method uses a 4-point Likert scale, with 4 being the highest-quality research according to systematic reviews conducted by third parties (34). The researchers analyzed two systematic reviews for consistency of findings and strength of evidence. Domains analyzed included service recommendations such as “We recommend that adolescents who fulfill eligibility and readiness criteria for gender reassignment initially undergo treatment to suppress pubertal development” (34). Each domain is a specific action to be taken with a patient meeting specific demographic criteria. Out of 24 domains listed, only 3 domains ranked at a 3 as far as existing research quality; that is to say, only 3 were considered to have “moderate quality” evidence (34). None of the domains were ranked at a 4 (“high quality”). A description of the GRADE method explains that a ranking of 4 would indicate the domain studied has received support in multiple RCTs that are strong and consistent across results. By contrast, a rating of a 2 means that the existing research would have come from observational studies (instead of RCTs) or from RCTs that were flawed in their design (35). Despite the large number of studies further

research was needed across all domains to reach a level of high-quality medical knowledge and standards (34).

A later analysis by the Center for Excellence in Transgender Health at UCSF expanded upon these treatment guidelines for adults and included non-binary people in their recommendations (36). These recommendations, while more comprehensive than the aforementioned study, still continue to focus almost exclusively on transition-related care. This includes important information such as reference levels for hormone injections, and side effects or complications of various surgeries (36). This information is accessible by general practitioners as opposed to only specialists, so in theory primary care providers can provide ongoing health maintenance instead of specialists.

These analyses do not include information regarding conditions that affect the general population for which the transgender population may experience a difference in risk, such as heart disease. More of this will be discussed in the research recommendations section.

3.3.1 Medical Education Deficits

The literature reflects a dearth of education among healthcare service workers, including doctors, nurses, desk staff, emergency responders, and specialty providers. This has been studied most frequently among OBGYNs. One study showed that 80% of OBGYNs did not receive formal training regarding people who are transgender while in their residency, even when latency since residency was considered. Providers who went through residency more recently were no more likely to have had training including transgender clients, indicating that education has not improved over time (29).

Referring back to the healthcare access model (21), this creates a gap in the number of available providers within reasonable distance from people who need care. This means the chain of access may be broken at both the availability/accommodation link and at the appropriateness of services link. Though screening recommendations exist for people with cervixes, it is not clear whether these practices are as effective at detecting cancers or abnormalities as they are in the general population.

Many studies focus only on LGBT sensitivity training, and few address the lack of training specific to people who are transgender. While transgender people are included in LGBT sensitivity training, healthcare experiences suggest that efficacy is significantly less for gender minorities. If the training was equally effective for sexual orientation minorities and gender minorities, the disparities in negative healthcare experiences would likely not exist, or would be significantly smaller than they are. The National Transgender Discrimination Survey and report on healthcare by Lambda Legal indicate that trainings have not been equally effective to ensure quality care (4, 5)

Emergency medicine is also resistant to including diverse populations in their training. Program directors for emergency medicine don't often see a need for LGBT-inclusive residency training, and when they do, don't know any interested faculty who are able to facilitate trainings (37). Indeed emergency medical staff may need to be more competent in treating transgender patients than most, since many transgender individuals delay care until an emergency condition develops (38).

3.3.2 Sensitivity Training and Effectiveness

Evidence shows that there are some positive effects to sensitivity training. Among medical school students given four sessions regarding LGBTQ inclusive healthcare, many were able to provide qualitative feedback indicating that they felt better prepared to interact with this population (39). A Canadian study reported that sensitivity improved patient outcomes up to 1.5 years after implementation of a randomized controlled trial (40). The limitations in this study indicated a need for further research to assess long-term outcomes for patients and providers following sensitivity training. For example, the authors state a lack of cultural diversity within the patient sample, indicating that more representation from minorities would be needed.

3.4 DIAGNOSING VS. PATHOLOGISING TRANSGENDER PATIENTS

Many transgender people seek gender confirmation through medical means. As stated by White Hughto et al., “The medicalization of gender nonconformity represents one form of structural stigma that shapes and reinforces perceptions of transgender people as deviant” (12). Historically these diagnoses have included titles such as gender identity disorder, now listed as gender dysphoria (41).

Gender dysphoria as a diagnosis allows an ICD code to be utilized to bill for treatment. However, it takes the term “disorder” out of the name, thus eliminating some of the stigma attached to a diagnosis. Khan (22) summarizes this debate among the transgender community, within the medical community, and through the entanglement of legal definitions. While some in the transgender community oppose the idea that a medical definition needs to exist, others

identify it as a necessary means to an end—a way for insurance companies to provide compensation for transition-related care (22).

3.5 ETHICS OF TRANSITION-RELATED CARE

Healthcare providers identified ethics of transition-related care as being a barrier to providing quality care (20). Limited literature addresses ethics and those providers who refuse to provide transition-related care. Studies have found that healthcare providers often express discomfort or refusal to perform care for transgender individuals. In one study 11% of doctors stated they were unwilling to perform Pap smears for transmen and 20% were unwilling to perform breast examinations for transwomen (29).

Recommendations from Hembree et al. deny that cross-sex hormones should be administered to pre-pubescent children (34). There are many current practitioners who opt for a reversible treatment known as puberty blockers. The concern of the authors is that many adolescents who experience gender dysphoria will experience remission, and return to gender congruence with sex assigned at birth. Practitioners are concerned about making changes to a child's body, and indeed the recommendations now discourage surgical intervention on anyone under age 18 (34, 36).

Ethics can be extended to the insurance sector as well. It has been noted that the transgender population, in comparison with other groups, is a small group with limited political power on their own. An insurance company is designed to assess risk vs. risk—that is to say, risk of denying coverage to someone vs. risk of covering them for potentially expensive procedures and follow-up (22).

It is unclear what the physicians surveyed were referring to when discussing ethics, and the extant literature does not explore this further. A comprehensive attitudes assessment has not been conducted to determine the ethical dilemmas facing medical providers when interacting with people who are transgender. Further qualitative inquiry is needed to clarify what is meant by ethical considerations.

4.0 RECOMMENDATIONS

Over the past decade, multiple researchers have proposed recommendations for comprehensive care of transgender individuals within integrated healthcare systems. Despite the existence of standards of care published by WPATH and the Endocrine Society, many practitioners fail to incorporate these into their practice. Thus, transgender patients continue to be neglected and abused in healthcare settings, compounding the marginalization experienced within everyday life and causing detrimental health effects that research has only begun to explore. What follows is a synthesis of existing literature that categorizes recommendations and provides concrete action steps for healthcare providers. The need for extensive research is the final building block in creating a comprehensive system of care for transgender individuals. It cannot be emphasized enough how crucial transgender-specific trainings, protocols, and research are to the development of this field. Based on findings of within-group disparities, blanket policies and trainings covering the LGBT community are not enough to protect gender minorities.

4.1.1 Transgender and gender-expansive sensitivity training

Many organizations have adapted LGBTQ sensitivity trainings for their affiliates. These trainings are usually inclusive of the entire LGBTQ community, and very few concentrating only

on the transgender community are to be found. Samuel Lurie is one of the few people in the United States to provide exclusively transgender-specific, in-person training to healthcare providers (S. Lurie, personal communication, 2016). Mr. Lurie also conducted “Train-the-Trainer” sessions in which he provided information to empower others to teach; however, he admitted that he had done few trainings since 2010. This author recommends that these types of trainings be incorporated to standard orientation and ongoing education, as they are a necessary component within the future of transgender healthcare.

Reed (42) recommends face-to-face training for multiple types of professionals, and the model used could easily be applied to healthcare. More research is needed to see whether this approach can be adapted and brought to the United States, as its inception was in the United Kingdom. Research is needed to determine whether sensitivity training will be effective at changing healthcare attitudes and discrimination toward the transgender population (33).

4.1.2 Creating an environment of inclusion

Current standards of practice span the entirety of healthcare, from the initial conversation at the front desk of an office all the way through follow-up and insurance reimbursement. Coren et al. (43) describe a step-by-step approach that aims to address practitioners at all levels of knowledge and comfort with the LGBTQ community. The authors first recommend that providers evaluate their belief system, including any personal and/or religious opposition to transgender patients, and understand under which circumstances they become uncomfortable. These standards exist for transition-related care, but are limited in their recommendations for primary care. Providers should obtain information regarding standards of transition-related care from professional organizations, such as the American Medical Association, the World

Professional Association for Transgender Health, and the Endocrine Society (43). The healthcare provider should set aside the assumption of expertise, and allow the patient to educate them about health matters with which they are unfamiliar.

A provider must recognize their own limitations when it comes to working with individuals and populations, and this should be assessed separately for sexual minorities and gender minorities (43). Until the provider becomes comfortable, the patient should be referred to someone who can treat them without personal bias. Risk factors must be assessed in a non-judgmental way, which can be an uncomfortable conversation for both parties. Therefore providers without the skills and understanding necessary cannot be expected to assess these accurately.

While patients identifying as lesbian, gay, or bisexual are often affiliated with those who identify as transgender, it should not be assumed that a blanket approach will be equally effective for sexual and gender minorities. The use of specific protocols is recommended when interacting with certain minority groups (9, 44). It is universally recommended that gender variant patients should have access to a private, unisex bathroom (9, 43, 45). Patients admitted as inpatients should have the option of a private room for safety reasons, or should share a room with a patient of the same gender identity (9). Offices can also show support by hanging up symbols of advocacy organizations and posters showing diverse patient populations. Ensuring that a practice's non-discrimination policy is visible is also helpful in making patients feel welcome (43). Something as simple as subscribing to LGBTQ magazines can help patients see themselves represented in waiting room literature (43).

4.1.3 Medical Forms and Records

Significant emphasis is placed on medical forms, and the ways in which these can be designed to accommodate any variation of gender and/or sexual orientation (9). There are several examples of appropriately inclusive forms. For example, sex and gender are two separate categories but are not often separated on paperwork according to the literature (43, 46).

Electronic health records still pose a challenge, but intake forms can be modified for each office or organization.

The Institute of Medicine (IOM) and the World Professional Association for Transgender Health (WPATH) have collaborated on developing electronic health record systems that are able to properly record gender identity and transgender status (9). This would allow a patient's accurate gender identity as well as accurate physiology to be present in the medical record. Laboratory information systems should also reflect gender identity, and may be different from other electronic health records. A transgender patient's hormone levels may differ from reference levels for a cisgender patient, and these would be framed in the laboratory information system (9).

Coding and billing are essential to the delivery of medical care in the United States. However, concern has been raised regarding the use of transgender as a diagnosis. Recently, the Diagnostic and Statistical Manual of the American Psychological Association, Fifth Edition (DSM-V) has removed the diagnosis "gender identity disorder" and replaced it with "gender dysphoria." While the former implies that the patient has a disorder because of gender incongruence, the latter implies that societal factors including gendered behavioral expectations result in distress among people whose gender identity does not align with their sex assigned at birth.

Using gender dysphoria as a diagnosis, clinicians could consider using a natural history of disease model to show the outcomes of various presentations and treatments for this specific condition. If we can utilize a medical model like one pictured below, it is possible we can view the various courses of treated and untreated gender dysphoria (including possible outcomes of death and spontaneous remission) the same way we view infections, cancers, depression, etc. This would no longer indicate that being transgender is an illness, but rather show how transition-supportive care can lead to better health outcomes in those with gender dysphoria. The first model (Figure 6) shows the natural history of untreated gender dysphoria. The second model (Figure 7) shows where treatment interventions can lead to positive natural outcomes, or create a new positive outcome as a result of treatment.

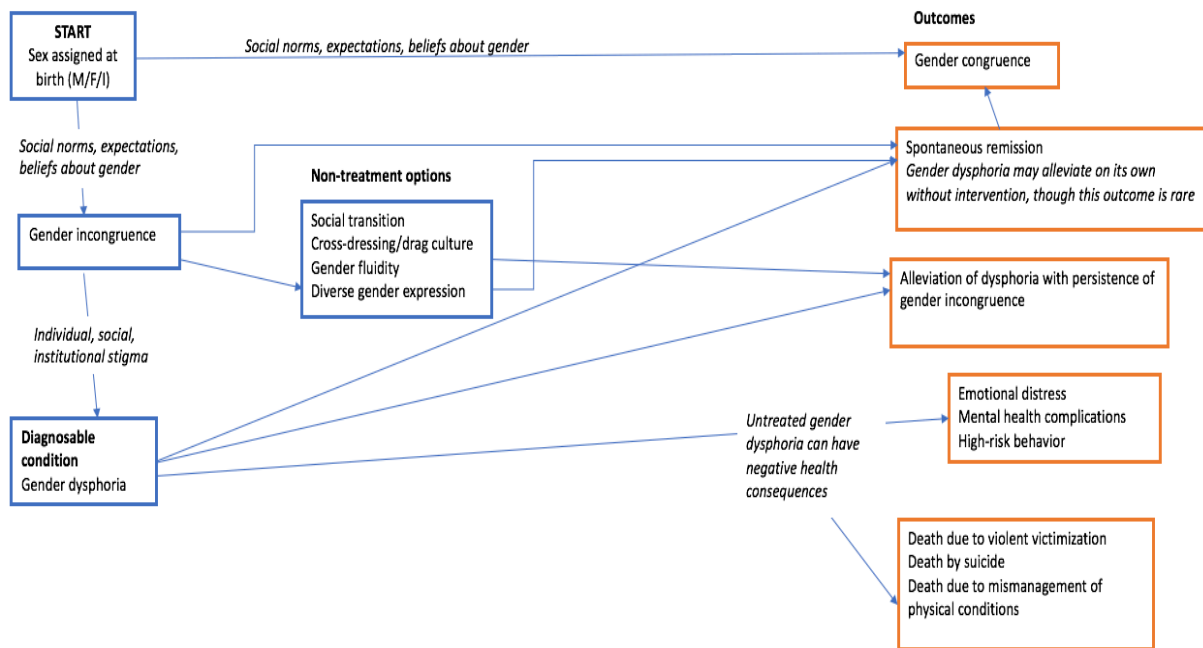


Figure 6. Medical model demonstrating the natural history of untreated gender dysphoria

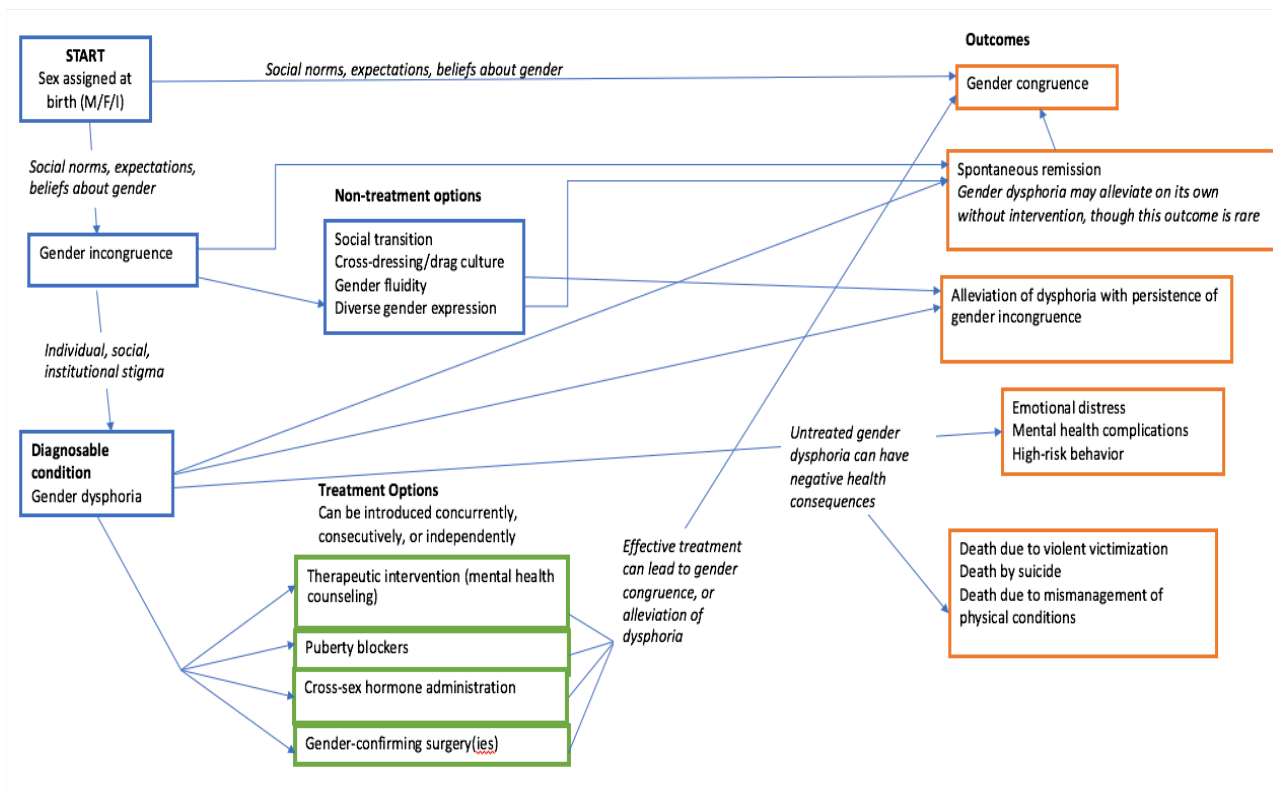


Figure 7. Outcomes of gender dysphoria when treatment is introduced

4.1.4 General Care Recommendations

Transgender patients, like all patients, should be receiving regular primary care, including recommended vaccinations, physical exams, blood work as needed, and any necessary specialty care unrelated to transition-based procedures. Increased risk factors for certain illnesses and conditions make comprehensive, integrated care a necessity. Careful attention should be paid to chronic disease risk, as the levels of risk for these illnesses are largely unstudied in this population (33).

Standard medical screening guidelines apply to all patients regardless of gender identity. Providers must be aware if their patients retain sex organs after surgical intervention, as these are

still at risk for cancers and other conditions that may be overlooked if a patient is unaware of screening guidelines. “Regardless of gender identity, any individual with these organs needs and deserves the same medical care for them, thus the frequent transgender preventative care adage, ‘if you have it, screen it’” (7).

Endocrinologists have concluded that transgender women should be getting breast exams similar to cisgender women, to screen for breast cancer (9). Transgender men should also receive Pap smears and pelvic exams at the same frequency as cisgender women (36, 45).

4.1.5 Insurance policy modification

In reference to billing issues regarding a patient’s legal name vs. chosen name, all insurance companies should have the ability to list a patient’s preferred name first, followed by one’s legal name for payment, identification, etc. This would allow the patient to be properly addressed and feel respected by insurance staff, feel more recognized as their true self, and have flexibility to change their legal name when they have the financial resources, emotional energy, and time to go through the process of doing so. Medical and insurance forms can be flexible and validating, while still adhering to legal standards that bind a patient contractually for payment.

Insurance policies must reflect a commitment to supporting gender-affirming care, and not deny coverage based on “lack of medical necessity” (22). Policies should also include non-discrimination clauses for gender minorities; this has been applied to hospital settings, but should be extended to insurance companies as well (46).

4.1.6 Adding to medical school curricula

Most patients have identified that more providers are needed who are educated in transgender healthcare. Medical students acknowledge the deficits in their education, and find training specific to transgender patients useful and relevant. Many believe this should be incorporated into medical school curricula (33, 39).

There are two ways to incorporate gender variance into medical school curricula. The first method is to have specific courses or training programs relating to the transgender community—a medical competency training at the university level. Medical students are more likely to feel competent, and report improved knowledge, skills, and attitudes (based on self-report), following more than 2 hours of transgender-specific education (47).

The second method, which this author recommends, is the idea of mainstreaming. In this scenario, students would have transgender patients periodically in classroom examples, who may or may not be seeking care related to their status as a transgender person. Even those with a self-identified “conservative” approach to transgender treatment believe that it is essential to incorporate these issues into standard medical education and practice (48).

4.1.7 Research needed

Despite recent efforts by the Williams Institute (2), formal epidemiological measurements of the gender-expansive population have not yet been conducted. This would include incidence and prevalence studies, which would give a more accurate picture of the population demographics (9). Cohort studies should be conducted to determine more in-depth

information. This would supplement a “life course approach” to transgender healthcare that is not currently in practice (9).

It is of note that many existing studies address the LGBTQ community as a whole, and did not separate the transgender portion of the community. Research featuring transgender or gender expansive participants is often lumped in with the rest of the LGBTQ community, and does not always stratify based on orientation vs. identity. This eliminates much knowledge of within-group disparities. Even those studies that do separate based on transgender status often do not acknowledge the differences within the transgender community (49). While one researcher is leading studies of transmasculine individuals through the Fenway Institute in Massachusetts (50), it is unclear whether similar studies are being conducted among other transgender populations or in other geographic locations. This presents an opportunity for research of specific identities, not just transgender people in general. Studies should stratify by binary vs. non-binary identities, and compare health outcomes across these groups. Cruz recommends utilizing the following categories, starting with sex assigned at birth, and ending with current gender identity: female-to-male (FTM); male-to-female (MTF); female-to-other (FTX); male-to-other (MTX) (10). This would indicate whether assigned sex has any bearing on the outcome, but also would show the varying identities of participants. Additional identity categories should be available for participants to self-identify. Other researchers support this two-step method, and emphasize the need to include those not diagnosed with gender identity disorder or gender dysphoria, and those with non-binary identities (16, 33). None of these categories are typically captured within existing research.

Studies of other minority groups shed light on some of the challenges faced by researchers. Majumdar et al. (40) recommend a longer study period to capture more participants

who may utilize healthcare with less frequency than the general population. Studies should also focus on the impact of minority stress on substance use, mental health issues, and other general health concerns (33).

There are specific health conditions that affect the transgender community, but more research is needed to determine risk ratios and associated factors. There have not been formal randomized controlled trials that examine long-term use of hormone replacement therapy (HRT) (9). Some research has suggested differences in blood pressure, cholesterol levels, and BMI as a result of cross-sex hormone administration, but this has yet to be rigorously studied such that clinical guidelines can be developed (13).

While the presence or absence of sexually transmitted infections is often assessed in research, there are limited studies addressing reproductive health issues not related to infectious disease (7, 33, 45). This includes studies involving the incidence and prevalence of cervical abnormalities among FTM and FTX individuals (30). Because of the challenges in collecting cervical samples among these populations, strategies for reducing inadequate Pap results in FTM and FTX patients should also be explored (30).

Much research has focused on suicide and depression risk among transgender people, but other mental health conditions and their prevalence in these populations have received less attention (33). Transgender individuals may be at higher risk for body image disorders and eating disorders due to body dysmorphia, and research should be conducted to determine the level of risk compared to the general population (33). Studies of post-traumatic stress disorder and acute stress disorders should also be conducted due to higher rates of abuse and trauma among these populations (4, 33). Further assessment of the types of abuse and multiple dimensions of such abuse, including verbal and emotional abuse, is also needed (33).

The relationship between providers and patients is a critical element of any healthcare interaction. While some of this has been explored among the general population or other minorities, very little has been conducted with the transgender population. More information is needed regarding trust issues between gender minority patients and their providers (24). Mixed-method research on patient-provider interactions is recommended to accurately capture data regarding what constitutes a welcoming or unwelcoming provider (23).

To date, no studies have been done assessing gender spectrum differences in emergency healthcare experience (44). Alongside this, studies of emergency room experiences must include a full range of positive and negative experiences within emergency department settings (44). Many studies focus only on negative experiences, instead of identifying what creates a positive experience.

Existing models can utilize gender exposure as an independent variable for health outcomes. Current epidemiological frameworks such as a vulnerability matrix would be effective in gauging the impact of various gender identity exposures (as opposed to only sex assigned at birth) in health outcomes, and whether gender experience varies throughout the life course. These models should be certain to include non-binary identities and gender nonconforming individuals, and assess whether binary vs non-binary identities have significant differences in health outcomes (16).

5.0 DISCUSSION

While rigorous research still lacks in many areas, current practitioners support many of the ideas presented in this paper. Additional information was obtained through audio podcasts, conference presentations attended by the author, individual interviews conducted between 2015 and 2018, and networking with local transgender individuals and LGBTQ advocates.

Pubertal hormone blockers are currently being used locally by the Gender and Sexual Development Program at Children's Hospital of Pittsburgh. Per conversation with nurse practitioner Joanne Goodall, a local leader in the transgender health field, this treatment is helpful in blocking the development of irreversible secondary sex characteristics that can lead to extreme dysphoria in individuals who are transgender (51). The advantage of blockers as opposed to cross-sex hormones is that the blockers cause no known permanent effects, except to delay the onset of puberty. While practitioners report that this is not something that is healthy long-term, family members and healthcare consumers agree that this allows the patient some extra time to consider a physical transition without being forced to develop in ways they may not want (52). In the absence of further information, this is considered best practice.

None of the local individuals providing interviews in the Greater Pittsburgh area expressed concerns for their own safety solely for providing care to transgender individuals. However, recently laws in other states such as North Carolina have given practitioners cause for concern. As Dr. Deanna Adkins, a pediatric endocrinologist from the Duke Child and Adolescent

Gender Care clinic pointed out, staff may be a target for violence due to providing care for transgender children. Dr. Adkins made it clear during this interview that her main concern was for the safety of her patients, due to the social determinants of health described earlier in this paper (53).

This paper has not addressed the intersectional concerns of the community. While the challenges facing the transgender population can be consistent across subpopulations, it should not be assumed that people of different racial groups, religions, and socioeconomic statuses share identical experiences. Furthermore the experiences within and across the aforementioned groups may differ based on binary vs. non-binary identities, and gender nonconforming vs. transgender individuals (16).

6.0 CONCLUSION

Safe, reliable, and effective healthcare services are needed for transgender individuals, who face barriers to accessing care at all levels. Specific actions must be taken by the medical community to address the health disparities faced by transgender and gender-variant individuals, and this includes a comprehensive understanding of what those disparities are. While there is much information regarding HIV/AIDS, substance abuse, and mental health disorders, too little research has focused on primary and preventive medicine as a method of health maintenance and disease prevention in this population. Scientifically rigorous studies could help to highlight within-group differences among the transgender population, and aim to find solutions to health disparities faced by this group.

Medical staff at all levels should have the knowledge and skills to treat transgender patients regardless of the point at which healthcare is accessed. These professionals should be granted the opportunity for continuing education focused on the development of sensitivity toward people who are gender expansive. Formal training and research methods should be developed by professionals and thoroughly evaluated throughout implementation. The recommendations shown here serve as a guide for the future of medical care and education to better serve transgender patients.

APPENDIX: TERMS AND DEFINITIONS

These terms and their definitions have been adapted from the literature used in this review

Gender congruence: Condition when gender identity matches sex assigned at birth; these people are known as cisgender individuals

Gender dysphoria: Anxiety, depression, and other distress caused by gender incongruence, social expectations, mental health conditions, and minority stress

Gender expansive:** a way to encompass all non-cisgender identities, including those who do not identify as transgender

Gender non-conforming: Individuals who identify as cisgender, but do not adhere to the typical gender norms or expectations of their assigned gender

Gender incongruence: Condition when gender identity does not match sex assigned at birth

Non-binary: An identity that is neither male nor female, also called **gender-neutral, genderqueer, or agender**

Transgender: For the purposes of research and consistency, this is a term used to describe anyone whose gender identity is incongruent with their sex assigned at birth.

Trans*: (Asterisk included) Sometimes used as an umbrella term to describe the trans spectrum, encompassing non-binary identities and those of fluid gender identity

**Used in practice but not yet seen in literature

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