

Contemporary Endocrinology
Series Editor: Leonid Poretsky

Leonid Poretsky
Wylie C. Hembree *Editors*

Transgender Medicine

A Multidisciplinary Approach

 Humana Press

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Series Editor Foreword

Transgender medicine, like transgender rights, is a new frontier. Endocrinologists, however, have been inhabiting this frontier for decades because of the patients' need for hormonal therapy. For this reason, I thought it would be appropriate to publish *Transgender Medicine: A Multidisciplinary Approach* in the *Contemporary Endocrinology* series.

Needless to say, comprehensive care of a transgender individual requires much more than hormonal therapy—primary care physicians, mental health professionals, pediatricians, plastic surgeons, specialists in reproductive health, and other medical specialists all have important roles to play. Further, because transgender patients' needs often extend beyond medicine, social workers, legal professionals, and spiritual counselors also may have to be involved. Hence, the interdisciplinary nature of this book.

I am thankful to an outstanding group of accomplished experts passionately devoted to this field who enthusiastically contributed their time and effort to this volume. I realize that there is no publication that can match our transgender patients' perseverance, determination, and courage in their pursuit of a fulfilling and happy life. I hope that this text will make a contribution to the development of the knowledge base sorely needed to help transgender individuals achieve their life goals.

New York, NY, USA

Leonid Poretsky, MD

Preface

Medical and social care of transgender persons require complicated, multidisciplinary efforts with complex strategies and many unknowns. The biology of gender identity, gender dysphoria, and gender incongruence is still incompletely understood. The best medical practice options are often based upon retrospective or empirical studies rather than upon controlled, randomized, double-blind trials common to most other areas of medicine.

Even hormone therapy for transgender individuals is commonly based upon the strategies used for estrogen replacement in menopausal women or testosterone in hypogonadal men—treatment modalities whose goals differ from those of gender affirming hormone therapy in transgender individuals. As a result, treatment may lack consistent standards of care required to ensure an acceptable transition in hormone levels using the best available therapeutic options. To make things even more complex, in addition to hormone therapy, transgender persons have a multitude of coincident needs—medical, surgical, educational, social, and legal—all of which must be addressed.

In planning this volume, we attempted to address as many of these needs as possible. We have engaged a multidisciplinary group of experts and asked them to provide recommendations and advice based upon the best available evidence. Clearly, the important and compelling field of transgender medicine will continue to evolve and the next edition of this text (if and when it comes) may look very different. So, in the meantime, we hope that the reader will find this text a useful guide for safe and efficient care of transgender persons.

We are grateful to all contributors who embraced this project with immense enthusiasm and to our students who keep asking good questions and demanding evidence-based answers. Most importantly, we are indebted to those transgender persons from whom we continue to learn daily and with whom we are proud to share their accomplishments.

New York, NY, USA

Leonid Poretsky, MD
Wylie C. Hembree, MD

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Chapter 1

History and Prevalence of Gender Dysphoria



**Tonia Poteat, Katherine Rachlin, Sean Lare,
Aron Janssen and Aaron Devor**

Introduction

When asked to write about the history and prevalence of gender dysphoria, we carefully considered what that might include. We recognize that the transgender population is vastly diverse throughout the world. The evolution of transgender medicine is intricately connected to cultural attitudes regarding gender, to the evolution of language, to patient identities and narratives, diagnoses, and standards of care, as well as the ways transgender people are identified and counted. A discussion of the history and prevalence includes acknowledgement of all the people impacted by these systems, and how the strong voices and experiences of this population have contributed to the evolution of these systems.

The language used to describe transgender people is evolving. For the purposes of this chapter, we use the words trans, non-binary, and gender diverse to mean

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people whose gender identities do not match or align with their sex assigned at birth. We use these terms in an attempt to be inclusive of all gender identities, though we recognize that over time, trends in language will change. It is important to use the terms most affirming to each person when working with individual people. Of course, as a chapter that includes discussions of historical perspectives, we may use other terms when citing or quoting another source. When we use capitalization for Gender Dysphoria, we are referring to the diagnosis as defined in the *Diagnostic and Statistical Manual (DSM) 5*; when “Standards of Care” is capitalized, we are referring to the World Professional Association of Transgender Health’s (WPATH) Standards of Care (SOC).

Trans and non-binary people throughout time have had rich, complex, and varied narratives about their lived experience that have not always aligned with either the diagnostic criteria laid forth or with the expectations of medical and mental health providers. Over the Past 50 years, in order to access gender-affirming care, trans and non-binary people have been required to undergo evaluations and receive a diagnosis associated with gender diversity. (As we will describe, the diagnostic label and criteria have changed over time). People who did not meet the diagnostic criteria would not get gender-affirming care; therefore, they would sometimes tailor their narratives to fit the diagnosis, even if the description did not accurately or fully reflect their experience. When this happened, providers remained uninformed about the real and varied experiences of their gender diverse patients [16]. The increasing outspokenness and visibility of trans and non-binary people have allowed for clinical decisions, diagnostic categories, and treatment protocols to evolve and to better serve these groups.

We hope to increase readers’ understanding of the history and complexity of this topic and how we got to where we are at the time of this printing, particularly in the treatment of gender dysphoria. The purpose of this chapter is to briefly describe the long history of gender diversity; to address difficulties in estimating the number of gender diverse people worldwide and the challenges for researchers and medical and mental health professionals who wish to define and count this population; to look at the history and utility of Gender Dysphoria as a diagnosis in the *DSM-5* and the *International Classification of Diseases (ICD)*; and to provide some historical perspective on the evolution of standards of care over time.

We recognize that the field of transgender medicine is evolving and will continue to do so after this book is printed. Growing advocacy by, and visibility of, transgender people will also rightfully continue to influence this field and future work. That said, it is important to understand how we got here, how the history of diagnoses has influenced where we are, and how we move forward in the care and management of gender dysphoria. The chapter is divided into four sections: A Short History of Gender Diversity, Being Counted, A Brief Review of Diagnostic Changes over Time, and An Evolution of Guidelines. Each section ends with thoughts on future directions and the need for further work.

A Short History of Gender Diversity

The medicalization of gender diversity is a relatively new historical phenomenon. The word transgender and the concepts that it attempts to convey, are quite new in historical terms, really only becoming widely used in the 1990s. The terms trans, non-binary, and Two-Spirit are even newer, coming into common usage in the early 2000s. Earlier in the twentieth century, the words transvestite and transsexual were more commonly used in Western societies to describe people who cross-dressed periodically, or who pursued complete hormonal and surgical transitions.¹ Prior to the beginning of the twentieth century, however, there were no words in English or European languages specifically to describe what we now think of as trans or non-binary people. Nor were there hormonal treatments or gender affirmation surgeries. Thus, those in Western societies who wished to change gender expression could either present as gender-nonconforming or affect a social transition to the other binary gender and hope to remain undetected. However, evidence of people in the West who were gender diverse is as old as are our historical records.

While it would be anachronistic and/or colonialist to apply today's Western diagnostic or social categories to people of other times and places, it is possible to recognize that people who share some features with those who today might call themselves transgender, transsexual, trans, non-binary, or any of a wide range of related identity terms, have always been part of humanity. The historical evidence of earlier gender diversity that is available must be understood to be far from verifiable in the specifics, but the existence of gender diversity cannot be in doubt.

Often, the evidence comes to us through very incomplete reports made by observers rather than from the people themselves. Such reports can tell us something about people's actions; they can tell us less about their motivations and identities. In all cases, the reports are likely to be difficult to interpret in relation to today's sensibilities. In particular, throughout most of human history, and still quite common today, physical sex, social expressions of identities, and erotic inclinations and behaviors, have all been thought of as a single manifestation of more or less the same underlying factor. In some contexts, such dispositions were thought of as stemming from one's soul, in others, from one's biology. Thus, gender diversity in other times and places might have been interpreted as what today would be understood as differences of sex development, or as homosexuality, or having a soul in the wrong type of body, or as stemming from some combination of these and other factors.

One of the oldest historical records of gender diversity comes to us from a female-bodied pharaoh named Hatshepsut who ruled Ancient Egypt 1478–1458 BCE and was depicted as a king with a beard, standing in a masculine pose [22]. This scant evidence might indicate an individual who today would seek out transgender medicine. From the Roman period, historical records tell of Emperor

¹The term transsexual has fallen out of favor with some due to its association with medicalization. However, there are individuals who embrace transsexual as an identity.

Elagabalus who ruled 218–222 CE. The little that we know about him includes that he was known for his sensuous beauty, his use of cosmetics, and his feminine clothing and mannerisms. Similar to many gender diverse people who seek gender-affirming medical treatment today, he wanted to be known as a female, and he sought a surgeon who could give him female genitalia [65, 93].

Many Indigenous peoples around the world have long had the language to describe gender diversity as it has been understood in their cultures. In many cases, these societies and cultures recognized and embraced three or more gender identities and such people were often seen as special healers or spiritual guides. As the influence of Western culture and medicine spreads, some of the language and attitudes of the West have begun to supplant, or coexist, with more traditional approaches. For example, the Hijra of modern-day India, who trace their lineage back 2000 years, typically start life with male genitalia and later undergo ritual castration, and sometimes penectomy, using traditional methods. They are then understood to be neither male nor female, but, rather, some of both. They dress in women's clothing, do not usually attempt to be seen as women, and exhibit a form of femininity that is both a parody of proper Indian womanhood and a bowdlerization of it [66]. Today, some Hijra also identify as transgender or transsexual and seek hormonal treatments and hospital-based surgical procedures [79].

Over 150 traditional Indigenous cultures of North America had culturally accepted roles for people who were recognized as different from women and men on the basis of their temperament, work roles, clothing, personal habits, spirituality, or sexuality. Today, the English term Two-Spirit functions as an umbrella term that includes lesbian, gay, bisexual, trans, non-binary, intersex, queer, and questioning people. Some Two-Spirit people identify more with specific aspects of gender or sexuality within the Two-Spirit umbrella, and other people prefer to simply identify as Two-Spirit [37, 74].

There are also numerous European historical figures who exhibited traits that, in today's world, might cause them to identify, or lead others to consider them to be trans. The story of Jean D'Arc is well known. Born in 1412 in France, at the age of 17 she had a vision from God that she was to dress in men's clothing and help lead France in the battle against England. Although she prevailed against the English, ultimately, she was burned at the stake, refusing until her death to dress in women's clothes and accept women's traditional gender role [82]. Spaniard Catalina de Erauso, the Lieutenant Nun, born in 1585, exhibited behavior that today might indicate a trans identity. Lacking any alternative for gender expression other than subterfuge, at the age of 15, de Erauso escaped from the convent where she had been deposited as a child and began to live as a young man. De Erauso became a sailor and traveled extensively. By 1626, de Erauso's story had become legendary and the Pope gave de Erauso a choice between living as a woman in a convent, or a man in the secular world. De Erauso chose to embrace manhood for the remainder of his life [25]. The Chevalier/Chevalière d'Éon, born in 1728 in France, demonstrated a gender expression similar to some of today's non-binary people. For the first 49 years of life, d'Éon lived as a man who served as a military Captain and as a spy. However, aspects of d'Éon's gender expression led many people at the time to

believe that d'Éon was really a woman who dressed as a man in order to prove that women could do anything that men could do. Believing d'Éon to be a woman, in 1777, the King of France ordered d'Éon to only wear women's clothing from that time on—which d'Éon willingly did. Upon d'Éon's death in 1810, d'Éon's body was examined by several doctors who reported that d'Éon had male genitalia [56].

While people in earlier centuries might have wished that they could transform their bodies to align them with their gender identities, medicine did not begin to provide the means to do so until the first half of the twentieth century. Toward the end of the nineteenth century, medical professionals started to recognize that some people desired to live as a gender different from the one they were assigned at birth. Krafft-Ebing described a case of a young male who felt “as if I were a real woman,” and referred to this case as an example of “effemination,” which he classified as one of the most diseased forms of homosexuality [57]. In 1910, Magnus Hirschfeld, who established the Institute for Sex Research in Berlin in 1919, published one of the first professional books challenging the view that trans people were necessarily homosexual, *Transvestites: The Erotic Drive to Cross Dress* [47]. In 1930, some of the first experiments with gender-affirming surgeries were conducted on two trans women at Hirschfeld's Institute.

Michael Dillon was probably the first trans man to undergo a medical transition including hormonal treatments and genital surgeries. Born in 1915, Dillon displayed classic childhood and young adult signs of being trans. In 1939, at age 24, Dillon procured testosterone pills, the effects of which enabled him to live socially as a man. Dillon later had his breasts removed and then underwent a 4-year-long series of genital surgeries to create a penis. In 1958, a journalist exposed Dillon as trans, making him one of the earliest trans celebrities. Dillon died in 1962 as a Buddhist monk in India at age 47 [49].

Starting in the 1950s, a number of Americans came to prominence and influenced social and professional perceptions of who might be included under the trans umbrella. Christine Jorgensen (1926–1989) was the first transsexual person to achieve international fame when the story of her gender transition made front-page headlines in the *New York Daily News* on December 1, 1952. Four months later, the *Los Angeles Times* declared her the “most talked about” person in the world. At that time, trans people often had no words to describe how they felt and thought that they were the only ones in the world with their feelings. The news about Jorgensen's gender transition was transformative. It informed the public about the existence of trans people and offered hope to trans people that transition may be possible for them. For many service providers, members of the general public, and trans people themselves, Jorgensen's heteronormative appearance became the standard template for transsexual gender expression [31]. It was not until 1966 that the first major publication appeared that recommended gender-affirming treatments for transsexual people. Harry Benjamin, who had studied with Magnus Hirschfeld, published *The Transsexual Phenomenon*, setting a new direction for the treatment of gender diverse people. Some trans people used this book as a guide for pursuing treatment from a growing number of sympathetic physicians.

Virginia Prince (1912–2009) had a long career as a trans speaker, publisher, editor, and author. In 1960, she founded a very influential magazine, *Transvestia*, was its editor for 20 years, and used it effectively as a mouthpiece to spread her views on gender within trans circles. Prince also attended professional conferences and communicated extensively with leading gender experts of her day, influencing their views on gender diversity. Prince was an early, assertive, proponent of the separation of sex and gender, and of the primacy of gender identity in determining persons' social and legal rights and statuses. She proudly maintained that she was a woman irrespective of her retention of the penis with which she had been born. She coined the word transgenderist to describe how she lived full-time as a woman without the benefit of surgery and identified as neither a transsexual nor a transvestite. During the early 1960s, Prince started a group called “The Hose and Heels Club”, which later evolved into the much larger Foundation for Full Personality Expression (FPE), and then into the even-larger Society for the Second Self (Tri-Ess), which still exists today with chapters across the United States. In the 1960s, Prince was arrested and convicted for sending sexually explicit letters to a heterosexual male cross-dresser through the US Mail. Her probation requirements included that she not cross-dress. However, her lawyer negotiated permission for her to cross-dress if she did it for educational purposes. Thus began Virginia Prince's successful public speaking career advocating for acceptance of heterosexual male cross-dressers. At age 55, Virginia Prince began to live full-time as a woman, which she continued to do until her death at age 96 [32].

Lou Sullivan (1951–1991) was another trans person, who was instrumental in advancing professional thought. Sullivan was androphilic (attracted to men) at the time when the professional opinion was that anyone who claimed to be a trans man and androphilic was not a true transsexual and should be denied hormonal and surgical treatment. Sullivan was a driving force in convincing professionals to provide gender-affirming treatment to gay and bisexual trans men. He wrote and spoke out for years, until he had amassed a group of other androphilic men and garnered the attention of influential professionals who joined him in his advocacy. Shortly before his death from AIDS in 1991, Sullivan commented that he took a certain pleasure in sharing his HIV status with some of the gender clinics that had rejected him because they thought that he could not live as a gay man because “...it looks like I'm gonna die like one” [80].

As trans people began to access the Internet in the 1990s, they built online communities for social support, knowledge exchange, and with strength in numbers necessary to influence medical and social policy. Similarly, social understandings of gender diversity have been expanding. For example, the number of individuals who assert non-binary identities is increasing [63, 73]. Gender non-binary people may eschew the term trans because they feel it implies movement from one point on a gender binary to another, an implication that does not accurately reflect them. Terms that non-binary people may prefer include: genderqueer (political non-binary identity); bi-gender (being both a man and a woman); pangender (being all genders, including more than two); agender, null gender, neutrois (having no gender); and gender creative or gender fluid (continuing to explore and change gender identity

and expression). Current standards and practices of care are generally geared to assisting trans people to achieve binary forms of gender expression and embodiment. The needs of non-binary people may represent the next major challenge for professionals working in the field of transgender medicine.

Being Counted

“If you’re not counted, you don’t count” is an old adage that speaks to the importance of data as a tool to advocate for the needs of marginalized groups. Researchers determine who “counts” by first defining the population. They often use diagnostic criteria or clinical guidelines for this purpose, and individuals who do not fit within these parameters may not be counted as part of the population. Enduring challenges to gathering data on the numbers of gender diverse people include how to ascertain trans and gender diverse identities, identify “representative” samples, and overcome stigma-related barriers to disclosure. The dynamic and evolving nature of gender identity presents additional challenges for counting the numbers of gender diverse people and highlights the inherently reductionist nature of quantitative research [41, 58]. Nonetheless, being counted in health research is necessary to advance understanding of the diverse health needs of trans and non-binary people and to respond to that diversity in clinical care [77]. How researchers determine who “counts” as trans is impacted by, and has an impact on diagnostic criteria, clinical guidelines, and the lives of gender diverse people themselves.

The movement from pathologization toward understanding gender diversity as a normal variation of human existence is reflected in the evolution in ways researchers have attempted to define and describe the numbers of trans people in a given population [64]. Definitions are important, as they determine who is included or excluded from the population of interest and are often used to determine who receives care. For many years, the medical literature focused on counting trans people who sought gender-affirming medical interventions to transition from their assigned sex at birth to another gender [94]. Other studies included individuals who met DSM diagnostic criteria for “Gender Identity Disorder” or “Gender Dysphoria” or who had received an International Classification of Diseases (ICD) code for “transsexualism” [9]. This practice implicitly, or explicitly, excludes gender diverse people who do not seek gender transition services in a medical setting or at all.

Historical reports of population sizes of 1 in 4000 to 1 in 50,000 were based on clinical populations, largely in Europe [27, 28, 95]. While clinic-based data are important for the planning of clinic-based services, they underestimate the size of the broader population of gender diverse people. Nor is it clear from this approach how to determine the denominator for estimates of the population proportion.

In recent years, researchers have adopted population-based methods to estimate the number of trans people. For example, McFarland and colleagues [62] used two population-based methods to estimate the number of trans men living in San

Francisco [62]: the service multiplier method [55] and the wisdom of the crowds method [99]. The service multiplier method calculated the total population size as a count of trans men using a specified community-based organization service in a single year divided by the proportion of trans men in the survey who reported using the service in that same year. The wisdom of the crowds method asked survey participants “How many transgender men do you think there are living in San Francisco?” The median response was used as the population size estimate.

Other strategies include asking a representative sample of people from the general population about their gender identity and extrapolating results to the entire population. One example of this approach is the U.S. Behavioral Risk Factor Surveillance Study (BRFSS). The BRFSS collects data via interviews with more than 400,000 adults in all 50 states as well as the District of Columbia and three U.S. territories each year, making it the largest continuously conducted health survey system in the world [13]. In 2014, 19 states included the question, “Do you consider yourself to be transgender?” In 2016, the Williams Institute began to publish estimates of the transgender population based on these data, providing not only the number and proportion of the U.S. population who identify as transgender but also information on the age and racial distribution. The Williams Institutes estimated that 1.4 million adults (0.6% of the U.S. population) identify as transgender [39] as well as 150,000 U.S. youth, 0.7% of the population ages 13–17 years [46]. The population of adults who identified as transgender was more racially and ethnically diverse than the U.S. general population. Among adults who identified as transgender, 55% identified as White, 16% identified as African-American or Black, 21% identified as Latinx or Hispanic, and 8% identified as another race or ethnicity. Adults who are African-American or Black (0.8%), Latinx or Hispanic (0.8%), and of another race or ethnicity (0.6%) were more likely than White adults (0.5%) to identify as transgender [38].

A recent meta-analysis identified five population-based national surveys with 20 waves of data collection that reported on trans identities between 2006 and 2016 [63]. Questions used to collect data on trans identities varied by survey with questions ranging from “Do you identify as transgender?” to “Are you male, female, or transgender?” to “Which of the following best represents Do you think of yourself” with response options that include “transgender, transsexual, or gender variant.” A meta-regression of these data suggests that the number and proportion of people who identify as gender diverse has been rising and will continue to rise over time. Winter et al. [95] used data from studies in five countries (U.S., U.K., Belgium, Netherlands, and New Zealand) where reported proportions of trans people ranged from 0.5 to 1.2%, and they applied the lower proportion to the global population to estimate 25 million transgender people worldwide [95]. However, global estimates are quite limited by lack of data from several regions, including Sub-Saharan Africa, Middle East/North Africa, and Eastern Europe/Central Asia. Sabin and colleagues [75] found that only 17 size estimates of trans women (not inclusive of trans men or non-binary individuals) had been conducted in all low and middle-income countries, with 6 of those studies having been conducted in 2014, the most recent year of the analysis [75].

The Center of Excellence for Transgender Health (COE) currently recommends using a two-step method that distinguishes sex assigned at birth from current gender [81]. While this is considered a best practice [85], it has limited ability to capture the growing number and complexities of emerging gender identities, particularly among youth. The widespread stigma against gender diverse people has been well documented and may prevent them from sharing their gender identities or gender histories with others, even on anonymous surveys and in confidential medical records [51, 86].

Future directions in trans research will require carefully fitting underlying research questions with sampling and ascertainment methods used to estimate the number of gender diverse people. For example, planning for clinical services would be an appropriate time to use electronic record data or other means to identify the proportion of the practice population that is trans or non-binary, if such data is routinely collected [52]. Questions that seek to describe the broader gender diverse population will need to use population-based, representative methods—which can be a challenge for small and stigmatized populations. As the exponential increase in studies with gender diverse populations indicate, these challenges have not, and should not, deter future and ongoing research to address the health of trans and non-binary people [72].

A Brief Review of Diagnostic Changes Over Time

The story of gender diversity and its relationship to social constructs is one that has undergone tremendous change over the course of the past 100 years. It is a story of controversies and rifts within medical and mental health communities and it is a story that has evolved from one of morality and criminality to one of medical access and self-advocacy. The terms ‘transvestite’ and ‘transsexual’ were first utilized by Magnus Hirschfeld, a leading sexologist and physician practicing in Berlin, Germany in 1910 [47] and in a journal article published in 1923, respectively [48]. Unfortunately, Hirschfeld’s institute and records were destroyed when the Nazis came to power. The study of gender diversity fell into quiescence until the middle of the twentieth century with the work of Michael Dillon [30] and then Harry Benjamin, who went on to advocate for gender diverse individuals [92] to have access to gender-affirming medical care. Dr. Benjamin’s work arose in the context of a history of treatment by the broader medical and mental health community that strove for many decades to define gender diversity as inherently pathological [14].

Within the mental health and medical communities, practitioners have looked to the DSM and ICD for a common language and set of descriptors to define a specific diagnosis. With consistent diagnostic criteria, the field is able to better define, and thus more accurately research the same set of concerns across contexts. Unfortunately, this also means that the inherent bias of those writing the criteria shapes how the diagnosis is described, and also may shape the stories that patients must tell in order to “qualify” for a diagnosis. Over the last several decades, trans

and non-binary individuals have claimed platforms to share their experiences and have enriched the broader conversation about gender in our society. In concert with this change in the broader social context, the descriptions for gender diversity in the DSM and the ICD have been enriched over time.

There are ongoing robust debates about whether gender diversity should have an associated diagnosis. Proponents of a diagnosis point to the need for a diagnosis in order to access reimbursement of medical care and advance research initiatives, and some trans individuals describe a sense of relief that their experience is concretized into a diagnosis. Opponents of a diagnosis point to gender diversity as a normal aspect of human development that is not pathologic and assert that a diagnosis is stigmatizing and unnecessary for seeking care. This debate is beyond the scope of this chapter, but it is important to reflect that trans and non-binary individuals have not been members of the committees that finalize diagnostic criteria in the DSM and ICD until their most recent iterations.

Within the Diagnostic and Statistical Manual (DSM), gender identity was first addressed in the DSM-II (1968) and was classified in the chapter titled “Transvestism or Other Sexual Deviation” [3]. For DSM-III (1980), the term transsexualism was defined as a sense of discomfort and inappropriateness in one’s anatomic sex that was persistent and continuous over a 2-year period [4]. This term was separate from transvestism, which was defined as a paraphilia, marked by “recurrent and persistent crossdressing by a heterosexual male...for the purpose of sexual excitement.” (1980). It was not until the DSM-III-R (1987) that childhood and adolescent gender identity was addressed [5]. In this edition, adults remained within the diagnosis of transsexualism, and children were given the diagnosis of atypical gender identity disorder (GID). Individuals meeting criteria for transvestism in DSM-III would meet criteria for the diagnosis of “transvestic fetishism” in DSM-III-R. The label of GID persisted until the DSM-5 (2013), at which point the diagnoses were changed to: Gender Dysphoria in Children, and Gender Dysphoria in Adolescents and Adults [6] (Tables 1.1 and 1.2).

There are stricter criteria for diagnosing prepubertal youth with Gender Dysphoria than for adolescents and adults. This is in part due to the process of gender development and in part due to the lack of specificity of previous diagnoses. In particular, prior to the DSM-5, the diagnostic criteria focused more on stereotypical, binary gender expression as opposed to gender identification. Much of the diagnostic criteria were focused on how children preferred to play and dress as opposed to how they described their gender identity. For example, in the DSM-IV,

Table 1 Gender identity in the DSM

	DSM-I — 1952	DSM-II —1968	DSM-III-R —1973	DSM-III—1980	DSM-III-R—1987	DSM-IV —1994	DSM-5 —2013
Gender identity	N/A	Sexual deviation	Sexual deviation	Transsexualism (adults); atypical GID (children)	Transsexualism (adults); GID-NOS (children)	Gender identity disorder	Gender dysphoria

Table 2 DSM-IV versus DSM-5 diagnostic criteria [6, 7]

DSM-IV	DSM-5	DSM-5
<p>Gender identity disorder</p> <p>A. A strong and persistent cross-gender identification (not merely a desire for any perceived cultural advantages of being the other sex). In children, the disturbance is manifested by four (or more) of the following:</p> <ol style="list-style-type: none"> (1) Repeatedly stated desire to be, or insistence that he or she is, the other sex (2) In boys, preference for cross-dressing or simulating female attire; in girls, insistence on wearing only stereotypical masculine clothing (3) Strong and persistent preferences for cross-sex roles in make-believe play or persistent fantasies of being the other sex (4) Intense desire to participate in the stereotypical games and pastimes of the other sex (5) Strong preference for playmates of the other sex <p>B. Persistent discomfort with his or her sex or sense of inappropriateness in the gender role of that sex</p> <p>C. The disturbance is not concurrent with a physical intersex condition</p> <p>D. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning</p>	<p>Gender dysphoria in children</p> <p>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):</p> <ol style="list-style-type: none"> (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), 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 and 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 of the other gender <p>B. The condition is associated with clinically significant distress or impairment in social, school, or other important areas of functioning</p>	<p>Gender dysphoria in adolescents and adults</p> <p>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:</p> <ol style="list-style-type: none"> (1) A marked incongruence between one’s experienced/expressed gender and primary and/or secondary sex characteristics (2) A strong desire to be rid of one’s primary and/or secondary sex characteristics, or a desire to prevent the development of the anticipated secondary sex characteristics (3) A strong desire for the primary and 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 (6) A strong conviction that one has the typical feelings and reactions of the other gender <p>B. The condition is associated with clinically significant distress or impairment in social, occupational, or other important areas of functioning</p>

the applicable diagnosis was Gender Identity Disorder (GID) and because the diagnostic criteria were heavily weighted toward gender expression, one could be diagnosed with GID while still having an identity that aligned with birth sex. That is, a natal male who identifies as a boy who happens to prefer girls as friends, enjoys girls' toys and dressing in girls' clothes in play, and avoided more stereotypically masculine play, would still meet criteria for GID. As such, the diagnosis was highly nonspecific and captured both children who would later self-identify as trans and non-binary as well as children who would later identify as cisgender.

The new diagnostic criteria for Gender Dysphoria in the DSM-5 have shifted to focus more specifically on the alignment of gender identity and sex assigned at birth and take a stance that a trans identity in and of itself is not pathological, but the distress felt from Gender Dysphoria can negatively impact functioning. Additional changes include language that provides for more flexibility in recognizing non-binary identities and does not presume that a person whose identity does not align with their sex at birth has a gender identity that does align with a binary identity of female or male. The presence of Other Specified Gender Dysphoria and Unspecified Gender Dysphoria in the DSM-5 (and GID Not Otherwise Specified in the DSM-IV) provides additional opportunities to diagnostically capture the breadth of presentations by gender diverse individuals. These diagnoses allow for individuals who do not meet full diagnostic criteria for Gender Dysphoria to still be able to access gender-affirming care [70].

There have been similar changes in diagnostic classification in the ICD as in the DSM. The current version of the ICD, ICD-10, came into use in 1994. In the ICD-10, "transsexualism" is described as a "disorder characterized by a strong and persistent cross-gender identification (such as stating a desire to be the other sex or frequently passing as the other sex) coupled with persistent discomfort with his or her sex" [53]. The proposed changes for the diagnoses in ICD-11 are twofold: the new diagnostic term will be Gender Incongruence, and it will be moved out of the section on mental and behavioral disorders and into the section on conditions related to sexual health.

As described previously, concretizing a set of experiences into diagnostic criteria that one is required to meet in order to access care may also ultimately shape the stories told by patients to their health care providers [16, 59]. As more gender diverse patients, activists, clinicians, educators, and researchers have been able to advocate and describe their own experiences as separate from the diagnostic criteria, professional service providers have been able to see the diversity of lived experiences of transgender populations and, slowly, the diagnostic criteria have begun to reflect this understanding.

An Evolution of Guidelines

As the field of transgender health has evolved, treatment guidelines [2] and standards of care [55] have developed to meet the needs of transgender people. These guidelines provide direction for professional conduct and decision-making and are intended to ensure that diagnosis, treatment, and research are optimized and standardized across settings. Every medical specialty has standards of care and the most widely accepted standards of care in the field of transgender health are the Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People, Version 7, (SOC) published by the World Professional Association for Transgender Health [21]. The first version of the SOC was published in 1979 and filled one page. The seventh version, published online in 2011 is 112 pages [97]. Since 1979, the SOC have gone through six revisions and the organization has changed its name from The Harry Benjamin International Gender Dysphoria Association (HBIQDA) to the World Professional Association for Transgender Health (WPATH). The renaming of WPATH reflects its broad international constituency and a field that is increasingly focused upon health and well-being and away from diagnosis, dysfunction, and pathologization. Successive versions of the SOC reflect the evolution and development in treatment options, and the burgeoning interdisciplinary transgender movement which constitutes a vocal group of gender diverse people who have had input into the SOC as well as other standards and guidelines.

The overall goal of the SOC is to provide clinical guidance for health professionals to assist transsexual, transgender, and gender-nonconforming people with safe and effective pathways to achieving lasting personal comfort with their gendered selves, in order to maximize their overall health, psychological well-being, and self-fulfillment. [21]

The SOC attempt to walk a fine line by providing both maximum flexibility for a diverse population and tangible and specific guidance for practice and policy. This is evident in the recommendation that when practitioners tailor the guidelines for individual treatment they are encouraged to acknowledge how they have deviated from the standard practice, to inform the patient that they are doing so, and to document this treatment both for legal and research purposes [21].

Within the WPATH SOC, there are several areas that have been most controversial. The first is the role of psychotherapy, mental health evaluation, and diagnosis [43]; related to that, is the potential of informed consent paradigms, the next is the need for a “real life experience” (RLE); and a third is the treatment of children and adolescents. The earliest versions of the SOC required individuals to have a period of psychotherapy prior to hormones and surgery. Version 7 of the SOC does not require people to have psychotherapy but do require a mental health evaluation and a diagnosis (which can be provided by either a medical or behavioral health professional). RLE, the practice of living in one’s affirmed gender for a period of time before hormones or surgery, was a requirement for early versions of the SOC; and it continues to be a recommendation in many treatment protocols (such as those of many insurers and third-party payers in the U.S. which require RLE prior to surgery).

Because of the irreversible nature of the surgery, and to a lesser extent, hormones, individuals have been encouraged or required to live for a time in their affirmed gender prior to undergoing these procedures. Such protocols assume that social transition is more reversible than medical transition. This is often not the case because once a person comes out as transgender, the disruption to family, social life, and professional life may be irreversible. In addition, many people need some medical interventions in order to be able to effectively present in their affirmed gender. A period of hormones, chest masculinization surgery for transmasculine people, or feminizing facial surgery (FFS) for transfeminine people may be necessary in order for people to engage safely in RLE. In that case, it makes sense for medical interventions to precede RLE. There may also be individuals who do not need or want a social transition, but who do want medical interventions, and RLE would be contraindicated for them [33, 69, 91]. The SOC recommend a period of RLE as a criterion prior to genital surgery, though the SOC also say that they are meant to be interpreted as flexible recommendations.

As in all previous versions of the SOC, the criteria put forth in this document for hormone therapy and surgical treatments for gender dysphoria are clinical guidelines: individual health professionals and programs may modify them. Clinical departures from the SOC may come about because of a patient's unique anatomic, social, or psychological situation; and experienced health professional's evolving method of handling a common situation; a research protocol; lack of resources in various parts of the world; or the need for specific harm-reduction strategies. These departures should be recognized as such, explained to the patient, and documented through informed consent for quality patient care and legal protection. This documentation is also valuable for the accumulation of new data which can be retrospectively examined to allow for health care – and the SOC – to evolve. [21]

Guidelines for the treatment of children and adolescents have changed quite dramatically over the course of the last three decades, as more research and clinical work has been done to better understand the trajectories and outcomes of gender diverse youth. Any guidelines for this population will be inherently more controversial given the ethics of medical decision-making for individuals without the legal capacity to consent, and the potential for disagreement between children and their parents. A notable set of guidelines for children and adolescents, created by the Royal College of Psychiatrists [19] focused on four main interventions—a full assessment, ongoing therapy, recognition and acceptance of the “gender identity problem,” and decisions about the extent to which to support gender role transition. The authors described Gender Identity Disorders in childhood as rare and complex phenomena and recommended that any potentially irreversible interventions be delayed until after age 18. Since these guidelines were released, more and more children and adolescents are presenting for gender-affirming care, and because of changes in insurance coverage and a better understanding of the efficacy of medical interventions for youth with Gender Dysphoria, an increasing number of individuals under 18 are seeking medical and surgical interventions, and many children and adolescents are presenting initially for treatment having already socially transitioned.

The guidelines concerning access to care for children, adolescents, and adults have become less restrictive over the course of time so that fewer procedures

require mental health evaluation, fewer recommendation letters are required, and more types of professionals are viewed as capable of providing such evaluations. Over the seven versions of the SOC, there has been increasing recognition that transgender individuals need holistic care—this may include not only provision of puberty blockers, hormones, and surgery, but also primary and preventative health care, reproductive care, vocal therapy, hair removal, support for partners and family, and advocacy in the world outside of medical settings. The SOC have also evolved in response to current conceptions of gender and gender identity, and the inclusion of non-binary identities is one of many core features of the current climate in transgender health.

Though the WPATH SOC are the most widely recognized standards internationally, there are, in fact, many clinical and treatment guidelines for the support of transgender people throughout the world. These guidelines are produced by professional organizations, national health services, human rights organizations, and community, public, and private health organizations. Some are so specific as to describe hormone regimens [23, 36, 44, 45], others are broad enough to apply to all medical specialties and centers serving this population [21, 83, 98]. Some are true treatment guidelines, and some provide general guidance for cultural competence. It is beyond the scope of this chapter to describe every guideline. It is enough to recognize that there have been guidelines of some sort developed for use by organizations operating within Asia, Canada, the Caribbean, Israel, Latin America, Australia and New Zealand, Europe, and the United States as described below.

One of the earliest guidelines to emerge from the transgender rights movement is the Health Law Standards of Care for Transsexualism [40]. These standards are composed of five principles and five standards focused upon depathologization of gender nonconformity, the right to self-determination, and freedom from barriers to care through informed consent as determined by the treating medical provider, and the elimination of the mental health provider as a gatekeeper. These themes have been addressed by all subsequent treatment protocols. By the early 2000s, identity-affirming care had become the primary orientation for specialists in the field of transgender health [21, 24, 33, 34, 54, 60, 78].

Some of the most widely used and influential guidelines have been developed by community-based healthcare centers that deliver care to thousands of transgender people every year. In the United States these centers include the Fenway Center in Boston, the Mazzoni Center in Philadelphia, the Tom Waddell Clinic in Los Angeles, Whitman-Walker Health in Washington, D.C. and the Callen Lorde Health Center in New York City, all of which have developed treatment guidelines and protocols for the provision of healthcare services to transgender people [18, 26, 61, 71]. One of the features of these clinical protocols is an emphasis on removing barriers to care by using an informed consent model for access to hormones [26]. The informed consent model approaches gender-affirming hormones like most other medical treatments and procedures, which require only a consultation with a medical provider to obtain informed consent for treatment. This model has emphatically eliminated any required period of psychotherapy, RLE, and in some cases, the need for a diagnosis of gender dysphoria. Depending upon the program,

individuals may see a social worker or other mental health provider for a one- or two-session psychosocial evaluation, or a patient may meet only with a medical practitioner who discusses the risks and benefits of treatment options and ensures that the patient is fully informed and understands them. If the medical or behavioral health specialist who does the brief screening detects serious physical or mental health concerns or other reasons that an individual may not be ready for hormones, then the person may be referred to a specialist prior to treatment, with the goal being to support the person in becoming ready for the services they need. Most informed consent protocols have been developed in places that provide hormones, and they have documented the success of these programs as measured by patient satisfaction and absence of regret [26].

Increasingly, the development of guidelines is a discipline within itself and the evaluation of evidence that is used in constructing evidence-based guidelines is a specialized practice [8, 11, 29, 35, 84]. Evidence is evaluated using a formal rating system and treatment recommendations are given grades based upon the available evidence used to support them.

One of the most influential guidelines to employ an evidence-based review are the *Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Nonbinary People*, University of California—San Francisco [27, 28]. These guidelines offer a graded review in which each recommendation carries a description of the research which underlies that recommendation and a measure of the strength of that recommendation. They present a comprehensive model of care developed by the Center of Excellence for Transgender Health’s Medical Advisory Board, “a diverse group of expert clinicians from a variety of academic and community based setting” [27, 28] and aim to include every aspect of transgender health and well-being that can be addressed in the context of health care. These guidelines, which attempt to build upon existing guidelines, such as the WPATH SOC v.7, are distinguished by their rigorous empirical basis, the diverse composition of the US consultants and authors, by covering healthcare needs broadly, by being less pathologizing, more inclusive, and removing barriers to care whenever possible.

Some treatment guidelines have been developed by professionals who work with community advisory boards, while other guidelines have been developed with community organizations as first authors. Examples of community-generated guidelines include the *Blueprint for the Provision of Comprehensive Care for Trans People and Trans Communities in Asia and the Pacific* [15], the *Blueprint for the Provision of Comprehensive Care for Trans Persons and Their Communities in the Caribbean and other Anglophone Countries* [67], *Por La Salud de las Personas Trans: Elementos para el desarrollo de la atención integral de personas trans y sus comunidades en Latinoamérica y el Caribe* [68], and *Implementing Comprehensive HIV and STI Programmes with Transgender People: Practical Guidance for Collaborative Interventions* (the “TRANSIT”) [89].

In addition to general guidelines intended to support care across a range of treatment settings, some have been developed for very specific institutions. Guidelines developed to address the needs of transgender people housed in

correctional facilities, detained by the US Department of Homeland Security, and serving in the military, reflect the institutional recognition that transgender people need affirmative care in every setting [10, 17, 20, 50, 76, 87, 88]. In 2011 and 2013, the US Department of Veterans Affairs, part of the US Veterans Health Administration in Washington, DC, approved a document which “established policy regarding the respectful delivery of health care to transgender and intersex Veterans who are enrolled in the Department of Veterans Affairs (VA) health care system or are otherwise eligible for VA care.” This policy includes an introduction to basic terminology and guidance on how to be respectful of transgender patients, as well as what kinds of care are available and guidelines for how to provide that care [20]. Institutional guidelines, such as those of the Boston VA, often concern themselves with accommodations such as room assignments and gender-segregated facilities [90].

As the practice of transgender health and medicine has become more widespread, more specialty associations have published guidelines for working with transgender and gender diverse populations. These specialty areas include: plastic surgery, endocrinology, urology, social work, psychology, psychiatry, nursing, voice and speech pathology/therapy, epidemiology, infectious disease, public health, pediatrics, and family practice. The websites for these professional organizations often display policy statements in support of the health and agency of transgender individuals.

Because of the interconnectedness of medical and social policy, and the specific needs of transgender individuals around the world, most standards of care and healthcare guidelines provide both clinical guidance and discussion of social policy. Writers of such guidelines recognize that it is not enough to offer gender-affirming health care. In response to the stigma and other challenges faced by transgender people, professionals who deliver care also advocate for their patients’ very basic rights to access care, and for the recognition of identity in broader social policy, such as the ability to change gender markers on legal identity documents, to marry, adopt children, and receive protection from violence and from discrimination in employment, health care, and housing [42]. For example, the *Blueprint for the Provision of Comprehensive Care for Trans People and Trans Communities in Asia and the Pacific* states that

The main purpose of the Blueprint is to improve access to competent primary and specialized care for trans people in Asia and the Pacific. A comprehensive evidence-based guide is an essential step in that process. This Blueprint will be a resource enabling health providers, program planners and managers, policymakers, community leaders, and other stakeholders to promote and address the health needs of trans people. At the same time, enhancing trans people’s health and well-being requires a human rights approach that seeks to end discrimination and recognizes the dignity and equality of all. For that reason, the Blueprint builds the case for changing laws, policies, and practices to bring trans people back from the margins of society and ensure their full social inclusion in the life of the community at large. [15]

There are pros and cons to the existence of treatment guidelines. Guidelines are designed to ensure uniformly best care across settings, but once a protocol is

standardized it may lose flexibility [96]. This is especially evident where insurance companies in the United States have instituted policies regarding third-party payment for gender-affirming hormones and surgery. The policy for Aetna Insurance is typical of those that require patients to meet certain criteria for their medical care to be reimbursed [1]. These criteria may be easily met by some patients and be completely inappropriate for others. For example, the insurance guidelines require a “real life experience” of 12 months prior to surgery, they also assume 12 months of hormones prior to surgery. In practice, many people will not want or need hormones before they request surgery, and the definition of “real life experience” may vary widely based on individual needs. As mentioned earlier, individuals who do not fit neatly into diagnostic categories may be forced to misrepresent their experience in order to access treatment.

Transgender medical options are used by a range of gender diverse individuals who fall outside of the better-known trans population of individuals who seek transition across the gender binary. The DSM-5 and SOC 7 both acknowledge the need for flexibility in support of non-binary individuals and others who challenge gender norms. One clear example of a population of individuals who need access to gender-affirming medical treatment are those who identify as Eunuchs—some of whom do not identify as male—and may need surgery and/or hormones in order to bring their bodies into alignment with their gender identities. Research shows that they are at great risk of self-surgery if denied treatment [69, 91]. The WPATH SOC version 8 (in the process) will include a section that addresses the need for recognition of this group and guidance for professionals who can provide for their safe access to gender-affirming care.

In summary, current and developing guidelines reflect trends in transgender health such as a turn away from pathology towards healthy identity, an increased focus on the needs of children and youth, provision of services for non-binary and other gender diverse individuals [12], a shift from strict treatment criteria toward flexible informed consent, and from a focus on hormones and surgery to a focus on whole-person health and well-being. Additionally, many comprehensive guidelines address the negative effects of social stigma and the positive effects of community and peer empowerment, and the increasing involvement of transgender consumers and transgender professionals as designers and consultants in the development of guidelines.

We have provided a brief social history of transgender people; reviewed the challenges and approaches to estimating the number of transgender people; provided an overview of the history of Gender Dysphoria as a diagnosis; and presented an overview of the evolution of the Standards of Care. As the field of transgender medicine continues to evolve, it will be important to remember how we got here and to understand how that historical path has influenced current standards as well as the way we move forward with gender-affirming care for transgender people.

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