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What the Past Suggests About When a Diagnostic Label Is Oppressive

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Abstract

Terminology describing transgender and gender diverse identities has evolved over the past 80 years, becoming progressively less pathologizing and less stigmatizing. While transgender health care no longer uses terms such as *gender identity disorder* or classifies gender dysphoria as a mental health condition, the term *gender incongruence* continues to be a source of oppression. An all-encompassing term, if one can be found, might be experienced by some as either empowering or abusive. This article draws on historical perspectives to suggest how clinicians might use diagnostic and intervention language that is harmful to patients.

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Linguistic Pathology

As the field of transgender health care has transitioned from pathologizing patients to a gender-affirming and patient-centered model and from an understanding of gender as binary to a fuller picture of gender as a spectrum, its associated diagnoses have similarly evolved.¹ Nevertheless, although the field seeks to affirm transgender and gender diverse individuals' identities and to avoid pathologization, there is an ever-present need for clinicians to give a diagnosis in order to justify treatment for insurance and billing purposes.² While a diagnosis might be seen as clinical recognition of an individual's experience, requiring that an individual be diagnosed in order to access needed medical and surgical services that facilitate gender-affirming embodiment and selfhood could also be viewed as perpetuating the oppression of transgender and gender diverse patients.² Although these concerns are legitimate and worrisome, the practical need for a term to be utilized for reimbursement purposes is not likely to disappear in the foreseeable future, and it is up to the field to determine what the most affirming version of that diagnosis can be and under what circumstances it should be used.

A Brief History of Terminology

Prior to the mid-1960s, there were no diagnoses related to gender expression and identity in classification manuals. However, this changed when the World Health

Organization's eighth edition of the *International Classification of Diseases (ICD)* and the American Psychiatric Association's second edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* described a form of gender role expression as transvestism under the parent category of sexual deviations.³ It was not until 1975 that the first diagnosis related to gender identity appeared in the ninth edition of the *ICD* as transsexualism, this time under the parent category of sexual deviation and disorders. At that time, gender was understood in binary terms; an individual coming for care could either remain congruent with the sex they were assigned at birth or wholly transition to the "opposite" gender.³

Four years later, in 1979, the Harry Benjamin International Gender Dysphoria Association, later known as the World Professional Association for Transgender Health, published the first edition of Standards of Care (SOC), wherein the term *gender dysphoria* was utilized.⁴ However, the third edition of the *DSM* in 1980 and the tenth edition of the *ICD* in 1990 instead began using the term *gender identity disorder*, and the fifth edition of the SOC changed its terminology to fall in line with the *DSM* and *ICD* as well.⁴ The word *disorder* being in the official diagnosis is telling of the attitude toward gender identity at the time, with gender identity incongruent with sex generally being considered a psychiatric condition that needed treatment.⁵

Although the term *gender identity disorder* remained in the SOC through the sixth edition, the seventh edition in 2011 reverted to the term *gender dysphoria*, concomitant with **psychotherapy** no longer being a prerequisite for treatment and a reconceptualization of gender as existing on a spectrum.⁶ The fifth edition of *DSM* in 2013 also opted to use the term *gender dysphoria* in an effort to depathologize its terminology.⁷ A sea change came with the eleventh edition of the *ICD* in 2019, which saw diagnoses related to gender identity and sexual orientation moved from the chapter titled "Mental and Behavioural Disorders" to the chapter titled "Conditions Related to Sexual Health," with *gender incongruence* being the new term utilized in the classification system.² This term was chosen in an effort to further depathologize gender diversity and to reduce barriers to gender-affirming care and allow for increased flexibility in treatment options.

Ethics and Diagnostic Labels

Although the terminology describing transgender and gender diverse identities has evolved over the preceding decades with the intention of reducing stigma and broadening care options, the existence of a diagnosis at all can be seen as controversial. A further discussion of the benefits and risks of utilizing a diagnosis for these purposes draws on the ethical principles of beneficence and nonmaleficence.⁸

A diagnosis as affirming. Some individuals might feel that the existence of a term to describe their experience is validating and lends credibility to their feelings.⁹ Hence, having a diagnosis available to these individuals can be seen as affirming of their experience. Additionally, the very practical reason for having a diagnosis available is that clinicians need a diagnosis to bill for their services, and patients need to have one to be eligible for potential reimbursement from their health insurance companies.⁹

Furthermore, as people continue to express and embody their gender identities in ways that differ from the gender corresponding to their sex assigned at birth, the benefits available from a formal diagnosis will be more easily realized. Eventually, gender diversity, like pregnancy, could come to be understood as a condition that individuals

can experience but that is not a disorder or illness. From this standpoint, the provision of a diagnosis can be seen as upholding the principles of beneficence (by enabling access to health care) and nonmaleficence (by reducing the risk of harm as the diagnostic labels becomes less stigmatizing over time). However, because destigmatization of diagnosis is not likely to occur in the near future (though it will likely lessen), other benefits will still need to be present to outweigh the risks of harm. Another benefit of the existence of a formal diagnosis is that it can help with tracking outcomes from treatments on a large scale, which can inform state or national health policy decisions, although tracking is made more difficult with a wide array of diagnosis strategies.

When is a diagnostic label oppressive? Although a diagnosis can be affirming to some, many might think that they now must “achieve” a diagnosis in order to receive needed care.¹⁰ That is to say, patients might feel that rather than simply trying to convey to medical professionals how they feel about their gender identity, they must focus more explicitly on manifesting the characteristics that professionals desire to see in order for a certain medical diagnosis to be entered in their chart, which opens the door to receiving treatments for said diagnosis.

Furthermore, despite the diagnostic term *gender identity disorder* having been replaced in the *ICD* and *DSM*, any new term that contains the word *disorder* implies that what the term describes is a disease, and acceptance of gender diversity has not yet become sufficiently widespread that these associations can be overlooked. No matter how far the field comes in altering the terminology of gender identity and expression, a diagnosis can be stigmatizing, and this stigma is not likely to fade away in the near future.

In a world where transgender and gender diverse individuals face considerable stigma and might be averse to having a diagnosis related to this aspect of their life, its inclusion in their medical chart could potentially cause harm, no matter the terminology used. This potential for harm stems from the fact that the transgender and gender diverse community is heterogeneous, and at least some community members will not agree with whatever diagnostic term is chosen.¹¹ As long as a patient must have a diagnosis in order to be reimbursed for care related to gender identity and expression, that nontraditional gender identity will remain stigmatized, and the diagnosis will face ethical challenges.

Next Steps

In light of the potential risks and benefits of diagnosis, what can clinicians do to help patients avoid feeling pathologized? For one thing, clinicians should be aware that it might not be appropriate to diagnose patients with gender incongruence, which, as mentioned, is the term used in the newest *ICD* guidelines.¹² Patients should always be asked whether they would like such a diagnosis in their chart, and, if not, the clinician should work with patients to determine what an alternative and appropriate diagnosis would be. Examples of alternative diagnoses that might still warrant treatment if patients are exhibiting symptoms could be anxiety, depression, or adjustment disorder, although there is stigma attached to these mental health diagnoses that the patient might want to avoid as well. While alternative diagnoses were used in the days before reimbursement could be secured for diagnoses such as gender dysphoria, it is still important to discuss the option of an alternative diagnosis with patients, given the stigma of any diagnosis, even though gender incongruence can now be used to secure payment.⁵ By working with the patient to come up with a treatment plan—including the

diagnosis that enables reimbursement for their care—the clinician can promote a more patient-centered approach to treatment.

Clinicians can also serve their patients by advocating for alternative diagnoses, such as anxiety and depression exacerbated by untreated gender incongruence, being used to bill and reimburse for hormonal or surgical therapy without the requirement that gender incongruence itself be in the chart. While patients with these diagnoses might be able to secure funding for certain services related to gender identity, such as counseling, they are not always eligible for the hormonal or surgical therapies that they seek, and they thus might be forced to make a difficult decision between eligibility for limited treatment with an alternative diagnosis and accepting the diagnosis of gender incongruence to receive hormonal or surgical treatment. Additionally, just because a diagnosis of gender incongruence might make a patient eligible for hormonal or surgical therapies does not mean that the **patient's insurance** will cover the said procedures in all cases, so additional discussion with patients on whether access to care would actually improve from having this diagnosis on their charts might be warranted.

Finally, clinicians can promote a more accepting culture by using the newest terminology that seeks to destigmatize and depathologize transgender and gender diverse identities. As mentioned, the newest term, *gender incongruence*, is intended to be neutral and allow for increased flexibility in treatment options, although some might also find it stigmatizing. By staying informed of updates to terminology, clinicians can aid in the quest to destigmatize transgender and gender diverse identities and expressions and promote a more accepting environment for patients. They can also make efforts to include more transgender and gender diverse individuals in further discussions on the terminology used in this area.

Conclusion

There are both benefits and risks to having an all-encompassing diagnosis for individuals seeking treatment related to their gender identity. While there might be scenarios in which it is appropriate to use the most up-to-date terminology—in this case, *gender incongruence*—to describe an individual's reason for treatment, there might also be cases in which another diagnosis would be of more benefit to a patient. Ultimately, the decision of what diagnosis to use should be made jointly by a patient and a team of clinicians, with the team's acknowledgement that patients can perceive gender-based terminology as both empowering and limiting, depending on the scenario.

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