

## Patient-Centered Transgender Surgical Care

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## AMA Journal of Ethics®

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### FROM THE EDITOR

#### Ethically Navigating the Evolution of Gender Affirmation Surgery

Kelsey Mumford

Gender affirmation surgery has come a long way since it was introduced 90 years ago in Europe. During its first 50 years of existence, gender affirmation surgery went from being a rarely performed procedure in Europe with variable outcomes to an accepted treatment for medical diagnoses in Europe and America. Throughout those years, there was a hard fight to bring this type of surgery out of the shadows and into the public eye as the major techniques of the field were being developed, and it was even offered as an experimental treatment option for the new diagnosis of gender identity disorder in the third edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-III)* in 1980.<sup>1</sup>

The first recorded “sex reassignment surgery,” as it was referred to at the time, took place in Berlin, Germany, at the Institute for Sexual Science in 1931.<sup>1</sup> During the first half of the 20th century, it was common to label gender-nonconforming individuals as pathologic and treat them exclusively for “mental imbalance” without considering the possibility of hormone or surgical therapy.<sup>2</sup> When surgery was performed, it was done for the purpose of completely reassigning a person from one sex to the other, as gender was understood in a binary context.<sup>1</sup>

It was not until 1952 that gender affirmation surgery would become internationally recognized following the well-publicized sex reassignment surgery of World War II American veteran Christine Jorgensen, previously known as George Jorgensen Jr, in Denmark.<sup>3</sup> Following this event, gender affirmation surgery demand spiked in Denmark, with individuals traveling from across the world to undergo the procedure.<sup>3</sup> More than a decade after Jorgensen’s surgery, in 1966, Johns Hopkins University opened its Gender Identity Clinic and became the first US academic institution to begin performing gender affirmation surgeries.<sup>4</sup> Over the course of the following decade, more than 1000 Americans underwent gender affirmation surgery at the hands of surgeons at major American university clinics.<sup>1,3</sup> Although the Hopkins clinic closed in 1979 due in part to public controversy surrounding a study published by the clinic’s director that apparently showed a lack of **subjective improvement in patients** who had undergone surgery and that was later found to be heavily biased, private practitioners rose up to fill the void.<sup>1</sup>

The year 1979 also saw the publication of the first edition of the Standards of Care (SOC) by the Harry Benjamin International Gender Dysphoria Association, which later

became known as the World Professional Association for Transgender Health (WPATH).<sup>5</sup> The SOC were created to better standardize care following the closure of the Hopkins Gender Identity Clinic and to provide guidelines for when to offer surgical therapy.<sup>6</sup> The addition of gender identity disorder in *DSM-III*, while pathologizing and stigmatizing, did increase access to the health care system for these procedures.<sup>5</sup> By the mid-1980s, all of the major techniques for performing genital reconstruction had been established, with intestinal vaginoplasty being invented in 1974 and radial forearm free flap phalloplasty in 1982.<sup>7</sup>

As the turn of the millennium approached, policy makers set their sights on destigmatizing and depathologizing the treatment for gender incongruence, as gender affirmation surgery continued to grow and become an accepted treatment modality. The WPATH published 7 editions of the SOC between 1979 and 2012, the terminology for transgender and gender diverse identities was changed numerous times, new surgical advancements were made, and regulations were adopted to require health insurance companies to cover surgical treatments for gender incongruence.<sup>8</sup> Transsexualism, as gender identity disorder was then called, was removed from the mental health disorders section of the World Health Organization's *International Classification of Diseases* in 2018, and a government appeals board ruled that Medicare must cover gender affirmation surgeries in 2014.<sup>6</sup> These changes happened as research studies validated the beneficial effects of gender affirmation surgery and the Endocrine Society and other national organizations published clinical practice guidelines, all of which developments contributed to the practice's acceptance as the official standard of care.<sup>9,10,11,12,13,14</sup>

We have now reached a tipping point in the field of gender affirmation surgery wherein the focus has largely shifted from fighting for its acceptance as a treatment modality and increasing patients' access to it toward ethical stewardship of this now-validated and accessible set of procedures, although challenges remain, as access to surgical and medical care for adolescents remains politically fraught.<sup>15</sup> This issue of *AMA Journal of Ethics* considers these challenges for the field and offers views of clinicians and advocates as protectors of patient autonomy and patient-centered, inclusive care.

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**CASE AND COMMENTARY: PEER-REVIEWED ARTICLE**

**How Should a Transgender Patient's History of Deep Vein Thrombosis and Smoking Influence Gender-Affirming Health Decision Sharing?**

Rebkah Tesfamariam and Joshua D. Safer, MD

**Abstract**

This commentary on a case considers a transgender patient's mental health and risk for deep vein thrombosis (DVT) in ethical decision making about feminizing gender-affirming hormone therapy (GAHT). Key considerations when beginning GAHT include recognizing that venous thromboembolism risk may only be modest and can be easily mitigated and that a transgender patient's mental health status should not weigh in a treatment decision about hormone therapy any more than it would for someone who is not transgender. Because the DVT risk of the case patient, who has a history of smoking and DVT, will only be increased modestly if at all by estrogen therapy and can be decreased through smoking cessation along with other DVT prevention methods, the patient should receive gender-affirming hormone therapy.

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**Case**

K is 34 years old and is transgender. They present to an endocrinology clinic to meet Dr J and, hopefully, begin desired hormone therapy. Dr J is most concerned about K's suffering deep vein thrombosis (DVT) 3 years ago and 10-pack-per-year smoking history, especially since K is not currently on anticoagulation therapy and continues smoking. K has also seen a therapist regularly for 15 years to augment medical management of depression and anxiety.

Dr J asks K to talk more about what they hope to achieve with hormone therapy, and K responds with a list of long hoped-for changes. Dr J notes that some physical changes that K hopes for could be better achieved surgically. Dr J outlines how to mitigate K's DVT risk, although some thromboembolism risk would remain, even with anticoagulants and smoking cessation. Dr J explains that, in order to better understand and quantify estrogen therapy risks, results of laboratory tests on K's blood draws from today's visit will be needed, too. K emphasizes that they would like to start hormones as soon as possible. K is eager to start anticoagulation therapy if that would make it easier for them to start hormone therapy with Dr J. Dr J also advises K to consider whether they can

commit to a smoking cessation program. K schedules a follow-up appointment next week but feels daunted about quitting smoking and discouraged about not having an estrogen regimen prescribed yet.

### Commentary

Dr J is tasked with managing K's gender-affirming estrogen regimen in an ethical way. The goal is to treat K's health risks equitably, commensurate with the care of any other patient. Dr J is concerned about minimizing K's risk of DVT, prescribing gender-affirming **hormone therapy** (GAHT) safely, and providing appropriate mental health intervention when needed.

K's medical history, including smoking and DVT history, should be the focus of treatment. K's treatment as a transgender person should not differ from that of any other patient with a similar medical history seeking hormone therapy. Put differently, although K's patient experience must be highlighted and valued, K's being transgender is not likely to change their treatment regimen. If K chooses to explore other methods of gender-affirming care, such as surgery, Dr J can adjust the treatment plan to K's long-term goals.

### Assessing DVT Risk

With regard to treatment options, K's DVT risk is an important factor to weigh, given K's smoking history and that their prior DVT increases the likelihood of recurrent thromboembolism.<sup>1</sup> Other factors, such as age above 35 (K is 34), weight, hypertension, and co-occurring illnesses such as HIV, must be included when assessing DVT risk.<sup>2</sup> Since degree of the DVT risk with GAHT cannot be definitively determined, forms of estrogen that increase venous thromboembolism risk should not be prescribed.<sup>3</sup> Regardless of K's GAHT, Dr J must encourage K to quit smoking and to minimize DVT risk by taking therapeutic anticoagulants and wearing compression stockings.<sup>4,5,6</sup> K's willingness to both start anticoagulation therapy and commit to a smoking cessation program shows promise for their safe use of estrogen.

Before prescribing estrogen, clinicians must review the literature on the dosage and method of estrogen administration. Low-dose exogenous estrogens have been shown to increase risk of blood clots.<sup>7</sup> If patients, such as K, are already at risk of DVT, they may need to take anticoagulant medications independently of their plans to take exogenous estrogen. Estrogen treatment is thus a secondary factor in assessment of K's DVT risk, and it is critical to address the primary factor—a prior DVT—in isolation.

In K's case, there are various available options for estrogen therapy that minimize the associated health risks. For example, transdermal estrogen may pose less risk for DVT than oral estrogen.<sup>8</sup> More specifically, transdermal estrogen, unlike oral estrogen, does not increase proinflammatory cytokines and procoagulant factors in transgender women.<sup>2,9</sup> Nevertheless, it is unclear if the lower DVT risk of transdermal estrogen is due to dosage or route of administration.<sup>3</sup>

Although research on DVT risk of estrogen therapy for transgender patients (other than individual case studies<sup>10</sup>) is sparse, oral ethinyl estradiol has been shown to be associated with venous thromboembolism in transgender women<sup>11</sup> and should not be prescribed, as there are safer and equally effective alternatives available. Additionally, hormone therapy with a combination of lower doses of estrogen and adjunct androgen-lowering or androgen-inhibiting agents might decrease DVT risk. In Europe, cyproterone

acetate and gonadotropin-releasing hormone (GnRH) agonists have been the preferred agents in conjunction with estrogen.<sup>12</sup> In Israel, spironolactone or GnRH agonists as well as cyproterone acetate are used as estrogen adjuncts.<sup>13</sup> An Israeli research team reported that spironolactone and GnRH do not elevate prolactin as cyproterone acetate does, suggesting that the observed elevation of prolactin in transgender women may be due to factors besides estrogen.<sup>13</sup> Ultimately, the use of forms of estrogen other than estradiol as GAHT poses a small risk for DVT.<sup>11</sup> By addressing K's other health problems, their DVT risk can be further lowered. Most importantly, Dr J should inform K that knowledge of the risk of DVT with GAHT is limited in scope due to a lack of data.

Estrogen is a commonly prescribed medication; K should receive estrogen since the benefits of estrogen therapy to K's quality of life outweigh the minimal risks. Note that, in parallel cases, a patient with ovaries and a history of DVT and tobacco use is not automatically denied hormonal birth control or menopausal hormone therapy. In fact, taking exogenous estrogens, a history of immobilization postsurgery, and other common factors have lower DVT risk than pregnancy,<sup>9</sup> which can increase a person's postpartum risk of venous thromboembolism 22- to 84-fold relative to women who are not pregnant or postpartum.<sup>14</sup> It has also been shown that the DVT risk for combined oral contraceptives—the most commonly used estrogen product and one that often includes the thrombogenic estrogen, ethinyl estradiol—is lower than the DVT risk for pregnant and postpartum patients.<sup>9</sup> While exogenous estrogen may have a non-zero risk of harm, its small risk is outweighed by its potential benefit in supporting K's needs.

#### **Assessing Mental Health Risk**

Dr J and K's health care team must also support K's mental health by encouraging K's continued therapy and consistent follow-up care in addition to GAHT. Transgender patients seeking GAHT are often labeled as suffering from **gender dysphoria**. Gender dysphoria is defined in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* as significant distress related to a desire to be another gender, but clinical dysphoria is not exclusive to transgender or gender diverse people.<sup>15</sup> The eleventh version of the *International Classification of Diseases* signaled that gender identity-related health conditions are not mental disorders by moving the relevant categories to the chapter titled "Conditions Related to Sexual Health."<sup>16</sup> While K presents with a "list of long hoped-for changes" in relation to their gender identity, this detail alone does not constitute evidence of a mental health concern. Thus, it would be inappropriate to interpret K's desire for GAHT as a desire to relieve dysphoria. Rather, the prescription of GAHT represents a patient-centered treatment that respects K's autonomy in choosing medical care that will most benefit their health and well-being. Additionally, unless mental health complications arise that might interfere with treatment or put K at risk for mental health instability, K's 15-years of therapy to manage depression and anxiety is not relevant to the decision to prescribe K estrogen therapy. There is no evidence to suggest that K's use of estrogen would increase their depression and anxiety. In fact, multiple studies show that transgender people's depression and anxiety significantly improve following GAHT,<sup>17</sup> which could be anticipated to have a positive outcome in K's treatment as well. In addition to regularly scheduled appointments to assess the effectiveness of GAHT, Dr J may also revisit the conversation annually to ensure that the treatment is not negatively interfering with K's mental health.

## Conclusion

K should receive GAHT with appropriate follow-up care and discussion about potential risks and outcomes. While K has important lifestyle modifications to consider, their well-being as a transgender person remains the priority. Dr J should provide updated information as it becomes available to allow for **well-informed decision making** with K. In addition, Dr J must approach such conversations with trauma-informed knowledge, inclusive language, and thoughtful advice on how to proceed with K's care safely.

K's being transgender does not mean that the risks and benefits of estrogen therapy should be assessed differently for K than for cisgender women. By educating K about minimizing their DVT risk and quitting smoking and by encouraging follow-up with a mental health professional, Dr J shows support for K, whose willingness to take anticoagulants and make lifestyle changes justifies prescribing appropriate GAHT.

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#### Editor's Note

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*The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

**CASE AND COMMENTARY: PEER-REVIEWED ARTICLE**

**How Should Surgeons Approach Gender-Affirming Surgery Revisions When Patients Were Not, Perhaps, Well Informed in Prior Counseling?**

Lee C. Zhao, MD, Gaines Blasdel, Augustus Parker, and Rachel Bluebond-Langner, MD

**Abstract**

Surgeons often encounter patients with realistic goals yet who desire unrealistic means of achieving them. This tension is compounded when surgeons consult with patients eager to revise a prior gender-affirming procedure completed by another surgeon. Two key factors of ethical and clinical relevance are that (1) a consulting surgeon's job is complicated when a population-specific evidence base is lacking and (2) a patient's marginalization is exacerbated by their having suffered the downstream effects of compromised initial access to comprehensive, realistic surgical care. This case commentary about revision of gender-affirming phalloplasty canvasses the pitfalls of a limited evidence base and focuses on strategies surgeons can use to help guide consultation. In particular, informed consent discussion may need to reframe a patient's expectations about clinical accountability for irreversible interventions.

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**Case**

T is a 32-year-old transgender man who presented to Dr D, a reconstructive urologist. Five years ago, he underwent an abdominal phalloplasty and scrotoplasty, along with partial colpocleisis and hysterectomy, in a different state, and now he wishes to pursue urethral lengthening to the tip of the penis, which was previously constructed without a urethra. Dr D recognizes urethroplasty in abdominal phalloplasty (UAP) as a revision procedure with high risk for complications, which is why a radial forearm flap phalloplasty (RFFP) is the typical recommendation for patients desiring urethral lengthening.

On further discussion with T, T clarifies that he was never told about the relative advantages of RFFP or the broad consensus that abdominal phalloplasty was incompatible with urethral lengthening. T tells Dr D that he has always wanted urethral lengthening as a goal but that he does not recall discussing this with the surgeon prior to the first phalloplasty. T is dismayed by the information from Dr D, but after

contemplation of the risks and burdens of treatment presented still wishes to proceed with urethral lengthening while avoiding any additional donor sites, such as would be required for RFFP. Dr D mentions that other phalloplasty patients have had skin grafting procedures to reconstruct the urethra after phalloplasty. On examination, Dr D believes that the revision surgery would be unsafe for T and would fail to reach his expectations. Considering T's unfortunate past experiences, Dr D knows that he must approach his recommendations both sensitively and scientifically, providing continued care with multidisciplinary support.

### Commentary

Given Dr D's previous experiences with UAP and knowledge of the literature and analogous procedures, he feels that the revision surgery would not achieve the patient's goals. Considering the less robust blood supply after local tissue transfer and decreased pliability of the abdominal tissue, Dr D suggests that an additional donor site, such as the forearm, is needed and believes that urethral lengthening on the abdominal phalloplasty would result in an unacceptably high rate of stricture and fistula above the already high rate expected in standard procedures such as RFFP.<sup>1</sup>

First, Dr D should clarify the goals of surgical treatment with T. Potential goals that can be addressed without urethroplasty to the tip of the phallus should be elucidated, such as creating the appearance of a urethral meatus<sup>2,3</sup> or closure of the vaginal canal.<sup>4</sup> If T desires these non-urologic changes in addition to standing micturition, treatments to meet these goals should also be discussed. For the specific goal of standing micturition, we would recommend that Dr D offer T a free flap phalloplasty using the radial forearm. In this option, T's existing penis would be disassembled and could potentially be repurposed as the skin envelope of the penis.<sup>5</sup> Alternatively, T could forgo surgery and use an assistive device to stand to urinate. Both options require T to compromise, either by undergoing much more extensive surgery than originally anticipated or by not achieving his goal of urinating from the tip of the penis. To best support T in moving forward, the surgeon must honestly face the disappointment intrinsic to this compromise.

We begin this commentary by describing preliminary scientific evidence and our own clinical experience with gender-affirming surgery generally; we do not perform UAP revision surgery routinely. Realistic expectations for treatment outcomes with UAP must then be communicated to the patient. A shared decision-making process can begin once the patient understands the potential outcomes, thereby ensuring autonomous and maximally **informed consent**.

### Synthesizing Preliminary Evidence and Clinical Experience

Although access to gender-affirming care has been increasing, case volume remains too low and procedures too heterogeneous to perform statistically powered studies for many of the interventions included in phalloplasty.<sup>6</sup> Tools like the IDEAL (idea, development, exploration, assessment, long-term) framework for surgical innovation adapt traditional hierarchies of **evidence quality** to surgical care and can maximize the utility of preliminary evidence for informing clinical decision making.<sup>7,8</sup> Based on the limited available evidence, UAP has a high rate of urethral complications.<sup>9,10</sup> When surgeons are faced with immediate clinical questions and insufficient evidence, they can supplement data on the techniques under consideration by extrapolating from research on analogous procedures, such as a 2-stage Johansson urethroplasty described in T's request for urethroplasty, and clinical experience.

Dr D has limited options that he would feel comfortable offering the patient, and this information must now be communicated. We recommend that Dr D remain grounded in what is known rather than addressing the unknowns inherent in the initial request: the patient's anatomy differs from the majority of urethroplasty patients from our own practice and in the literature, as UAP relies on collateral blood supply rather than a robust vascular pedicle.<sup>10,11,12</sup> Although the exact outcome of such a surgery is debatable, what Dr D knows is that UAP is not as safe and reliable as urethral lengthening after other types of phalloplasty.

Guiding patient decisions based on limited research and clinical experience has multiple ethical implications. Although the surgeon may estimate that the likelihood of adverse outcomes is too high to justify the benefits and thus that proceeding with surgery would violate the principle of nonmaleficence, multiple frames of reference for risk acceptance must be considered in surgery. Cisgender individuals living with a condition that could require reconstructive treatment have been shown to be more risk tolerant than surgeons offering the operation.<sup>13</sup> The role of the surgeon is to guide clinical decision making by offering greater knowledge and experience. Even if T had the same professional knowledge and experience as Dr D, he might still judge the potential benefits to outweigh potential risks.

Ethical principles, such as centering T's autonomy, help to guide decision making but do not inherently compel the surgeon to act in accordance with the patient's wishes.<sup>14</sup> Consistent with the concept of "surgical buy-in," or relational autonomy of patient and surgeon as described by Schwarze et al, surgeons conceptualize themselves as taking accountability for all steps of clinical care necessary to help patients reach their surgical goal.<sup>15</sup> In T's case, Dr D believes that T's surgical goal is unachievable, so T should be encouraged to consult with other surgeons who may have differing clinical experience or risk acceptance. In suggesting a second opinion, Dr D should recommend other surgeons who he specifically believes are best equipped to offer expert guidance and clarify that he is open to seeing T again for further discussion if he decides to pursue additional consultations. Connecting the patient to trans-affirming mental health clinicians for decisional support would provide an additional source of professional guidance, although perpetuating the history of mental health clinicians' gatekeeping for gender-affirming surgery must be avoided.<sup>16</sup> Neuropsychiatric evaluation might be required for patients with a questionable capacity to consent.

### **Setting Realistic Expectations**

It will be difficult for T to learn that his current outcome might have been prevented with more thorough counseling, and Dr D must acknowledge this circumstance without assuming that the original surgeon was ill-intentioned or neglectful in order to establish a therapeutic relationship with T. The initial clinical documentation could elucidate what information was provided to T, enabling Dr D to assess whether T understood and recalled it. In T's case, the initial discussion of the risks and benefits of alternative treatments and a request for urethral lengthening were not documented.

To help T set realistic expectations, Dr D might wish to assess the veracity of T's nonclinical information sources, as one small survey found that 94% of transgender respondents reported receiving surgical information from the internet.<sup>17</sup> In addition, some patients and clinicians lack access to reliable information due to a legacy of exclusion from academic medicine, which is important for understanding the historical context of current injustice in health care. T's prior residence and health plan may also

have contributed to his seeking a revision procedure, as a lack of trained surgeons and barriers to insurance coverage have led some patients to access care that may be less comprehensive.<sup>18,19</sup> Dr D has potentially encountered these downstream effects of social marginalization as experienced by T and other transgender patients. Although Dr D cannot single-handedly reverse the unjust distribution of research attention and medical resources, he can acknowledge their maldistribution to build an alliance with his patient.

Alternatively, the first surgeon may have counseled T that future urethroplasty would be ill-advised but T did not retain this information<sup>19</sup> or may have misunderstood his goals. For patients like T who initially lacked a realistic understanding of outcomes, surgeons like Dr D who are considering revision must carefully reset patient expectations. To communicate surgical risk, we recommend that surgeons use the Best Case/Worst Case framework, which involves detailing the best possible, worst possible, and most likely outcomes for each potential treatment using storytelling to illustrate the burdens of treatment (ie, catheterization on the scale of weeks or months until urethroplasty is complete), the expected negative consequences (such as additional scarring to the donor site), and a full picture of the end state if realized.<sup>20</sup> The Best-Case outcome of standing micturition after free flap phalloplasty still includes the potential lifelong need for specialized urological care, as strictures can occur years after surgery.<sup>21</sup>

Discussion of undesired trade-offs of a desired intervention may be one of the most difficult parts of the consultation for patients, as it requires them to surrender how they had imagined their future. Although balancing sensitivity and compassion with a scientific, clinical rationale can be difficult, both are crucial to providing the best possible counseling. In T's case, Dr D should continually validate the legitimacy of T's current treatment priorities by expressing that T's desire for urethroplasty is due to T's real understanding of the potential benefits and that he would offer it to T if it were safe. Dr D should then explain that the method T has requested has too great a potential for adverse outcomes; with presently available techniques, urethroplasty with his current penis is not possible though another treatment option might provide a viable solution.

### **Sharing Surgical Decisions and Informed Consent**

In T's case, we would hesitate to book any surgical revision of phalloplasty immediately after the consultation. Given the emotional gravity of resetting T's expectations, Dr D should offer the opportunity for additional consultation to reach a final, **shared decision**. Such caution is valuable, as an overly confident surgeon and an overly optimistic patient can together reach a shared, yet poor decision.

Furthermore, informed consent is not a rigid, final destination on a checklist; it is an ongoing and iterative process that should center what the individual patient most values.<sup>22</sup> Although the practice of maximally informed consent is still limited by many practical factors, there is a minimum acceptable standard for a surgeon to meet when proceeding with irreversible treatments.<sup>23</sup> Gender-affirming surgery aims to improve quality of life, so it is patient satisfaction, rather than externally observable endpoints such as nonrecurrence of cancer, that is the arbiter of success. Given a lack of patient-directed research on gender-affirming surgery outcomes,<sup>24</sup> however, surgeons may not have immediate access to information requested by patients to best predict their own satisfaction.<sup>25</sup>

Although the surgeon is accountable for establishing informed consent, information that contributes to consent does not only come from the surgeon. In addition to recommending that T consult mental health professionals, Dr D might offer to connect T with other patients who have had a complete revision of phalloplasty with a new free flap, as this is a uniquely challenging experience. T's further contact with primary care and mental health professionals who have been provided with information described in the Best Case/Worst Case scenario framework may also help T to manage his expectations regarding further surgery.

### Conclusion

Patient autonomy is an important ethical tenet, but it does not compel surgeons to perform interventions they deem unsafe. Communicating surgical risk to patients seeking revision must be done sensitively, acknowledging the potential for prior medical trauma. Best Case/Worst Case scenario storytelling can help the surgeon to establish more robust informed consent, along with multidisciplinary care coordination and connections to other patients who have previously faced the same decisions.

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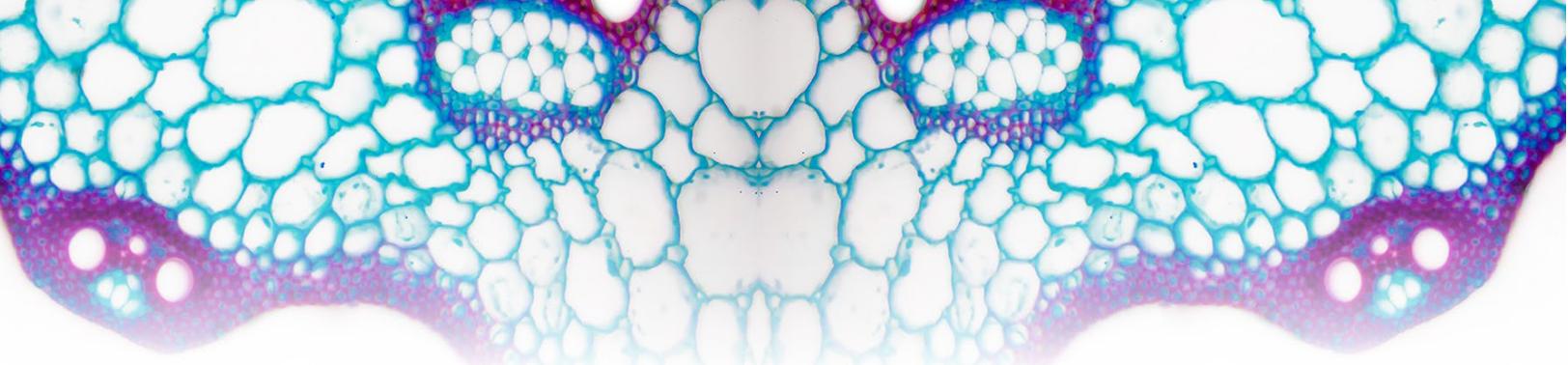
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## AMA Journal of Ethics®

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### IN THE LITERATURE: PEER-REVIEWED ARTICLE

#### Patient-Centered Approaches to Using BMI to Evaluate Gender-Affirming Surgery Eligibility

Whitney Riley Linsenmeyer, PhD, RD, LD and Sarah Garwood, MD

##### Abstract

Body mass index (BMI) cutoffs are routinely used to assess eligibility for gender-affirming surgeries (GAS), yet they are not empirically based. The transgender population is disproportionately affected by overweight and obesity due to clinical and psychosocial influences on body size. Strict BMI requirements for GAS are likely to cause harm by delaying care or denying patients the benefits of GAS. A patient-centered approach to assessing GAS eligibility with respect to BMI would utilize reliable predictors of surgical outcomes specific to each gender-affirming surgery, include measures of body composition and body fat distribution rather than BMI alone, center on the patient's desired body size, and emphasize collaboration and support if the patient genuinely desires weight loss.

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##### Assessing Eligibility

The number of transgender patients seeking gender-affirming surgery (GAS) has dramatically increased in recent years.<sup>1</sup> Body mass index (BMI) cutoffs are routinely used to assess eligibility for GAS due to concerns about adverse surgical outcomes.<sup>2,3,4</sup> Results from the National Surgical Quality Improvement Program revealed that the effect of BMI on surgical outcomes presents the greatest risk to patients with morbid obesity (BMI  $\geq$  40). Commonly cited concerns include increased risk of surgical site infection; cardiovascular risks, such as cardiac arrest and myocardial infarction; and pulmonary complications, such as pneumonia, reintubation, and prolonged ventilator support.<sup>5,6</sup>

Risks associated with delaying or denying access to GAS are also salient. Gender-affirming medical interventions, including hormone therapy (HT) and GAS, are associated with improved quality of life and decreased levels of anxiety, depression, **gender dysphoria**, and suicidal ideation.<sup>7,8,9</sup> The eighth version of the World Professional Association of Transgender Health guidelines characterize GAS as “medically necessary” for some patients to alleviate gender dysphoria.<sup>10</sup> Thus, surgeons must consider not only

the risks of the surgery itself, but also the risks to a patient’s health and well-being when GAS are delayed or denied.

The purposes of this article are (1) to review the existing research on BMI as a predictor of GAS outcomes using a mapping review; (2) to discuss weight disparities among the transgender population; and (3) to advance discussion of how to evaluate patients’ eligibility for GAS with particular attention to their body size in light of calls for a “multimodal, human-centered approach” to addressing risk factors for GAS.<sup>2</sup>

### Results of a Mapping Review

Table 1 provides brief definitions of various chest and genital GAS.

<b>Table 1. Brief Definitions of Gender-Affirming Surgeries</b>	
<b>Surgical Procedure</b>	<b>Definition</b>
<b>Masculinizing Surgery</b>	
Hysterectomy	Removal of the uterus
Implantation of erection prosthesis	Addition of a penile implant, often as part of a phalloplasty
Mastectomy or chest reconstruction	Removal of breast/chest tissue
Metoidioplasty	Creation of a penis using existing genital tissue
Ovariectomy or oophorectomy	Removal of one or both ovaries
Phalloplasty	Creation of a penis
Scrotoplasty	Creation of a scrotum
Vaginectomy	Removal of all or part of the vagina
<b>Feminizing Surgery</b>	
Augmentation mammoplasty	Increase in breast/chest size
Clitoroplasty	Creation of a clitoris
Orchiectomy	Removal of one or both testicles
Penectomy	Removal of a penis
Vaginoplasty	Creation of a vagina using existing genital tissue
Vulvoplasty	Creation of a vulva

To review existing research on BMI as a predictor of GAS outcomes, we conducted a mapping review of the available literature published through July 1, 2022. A mapping review is ideal to categorize existing literature, identify gaps, and guide further research.<sup>11</sup> We searched the Scopus database using queries with keywords: the name of the surgical procedure (eg, mastectomy) AND body mass index OR obesity OR body weight AND transgender. Studies were screened to remove those that reported BMI or weight status in the sample population but did not evaluate the role of BMI in predicting GAS outcomes.

Table 2 presents a summary of the articles retrieved from our search. In total, 11 studies explored the role of BMI in predicting chest and genital GAS outcomes.

**Table 2.** Summary of Studies That Investigated the Role of BMI on Predicting Breast/Chest and Genital GAS Outcomes

Surgical Procedure	Studies	Study Design	Results
<b>Masculinizing GAS<sup>a</sup></b>			
Mastectomy, chest reduction, or musculoplasty	Cuccolo (2019) <sup>12</sup>	Retrospective chart review of 755 patients	Obesity was more prevalent among patients who underwent breast/chest reduction compared to those who underwent a mastectomy, but complication rates did not differ between the two cohorts.
	Knox et al (2017) <sup>13</sup>	Retrospective chart review of 101 patients	Concentric circular technique presented greater risk of complications compared to free nipple graft technique in patients with a BMI > 27 kg/m <sup>2</sup> and additional factors.
	Pittelkow (2020) <sup>14</sup>	Retrospective chart review of 145 patients	Postoperative infections were significantly increased in patients with morbid and super obesity, but not in patients with obesity.
	Rothenberg (2021) <sup>15</sup>	Retrospective chart review of 948 patients	There were no significant differences in complications or revisions between patients with obese versus those with a normal BMI.
	Stein (2021) <sup>16</sup>	Retrospective chart review of 97 patients	Minor and major complication rates did not differ between patients with obesity and those without obesity
Hysterectomy	Ferrando (2021) <sup>17</sup>	Retrospective chart review of 67 patients	BMI was not associated with increased incidence of intraoperative endometriosis or heavy bleeding.
Metoidioplasty	Watershoot (2021) <sup>18</sup>	Retrospective chart review of 74 patients	BMI was not a predictor of complications.
<b>Feminizing GAS<sup>b</sup></b>			
Vaginoplasty	Buncamper (2016) <sup>19</sup>	Retrospective chart review of 475 patients	BMI was not associated with complications.
	Gaither (2018) <sup>20</sup>	Retrospective chart review of 330 patients	BMI was not associated with complications.
	Ives (2019) <sup>21</sup>	Retrospective chart review of 101 patients	BMI was not associated with delayed revision urethroplasty or complications.
<b>All GAS</b>			
Procedure type not specified	Scott (2022) <sup>1</sup>	Analysis of American College of Surgeons NSQIP Data	BMI was positively associated with an increased risk for having at least one complication.

Abbreviations: GAS, gender-affirming surgeries; BMI, body mass index; kg, kilograms; m, meters; NSQIP: National Surgical Quality Improvement Program

<sup>a</sup> No studies retrieved on ovariectomy/oophorectomy, phalloplasty, vaginectomy, scrotoplasty, or implantation of erection and/or testicular prostheses.

<sup>b</sup> No studies retrieved on clitoroplasty, vulvoplasty, augmentation mammoplasty, penectomy, or orchiectomy.

Five studies focused on masculinizing chest surgeries, such as mastectomy, breast reduction, or musculoplasty.<sup>12,13,14,15,16</sup> An obese BMI ( $\geq 30$ ) did not increase the risk of complications in 4 of the 5 chest reconstruction studies.<sup>12,14,15,16</sup> Pittelkow et al found that postoperative infection risk was higher in mastectomy patients with morbid obesity (BMI  $\geq 40$ ) and super obesity (BMI  $\geq 50$ ).<sup>14</sup> BMI was not associated with complications in studies of hysterectomy,<sup>17</sup> metoidioplasty,<sup>18</sup> and vaginoplasty.<sup>19,20,21</sup> Among all forms of gender-affirming surgery, BMI was associated with a very slight increased risk for complications in Scott et al's study that relied on American College of Surgeons National Surgical Quality Improvement Program data, although the findings were not reported by BMI classification, type of gender-affirming surgery, or the nature of the complication.<sup>1</sup>

The studies identified in this literature review have several limitations. Because existing research is limited to 4 common GAS, future research should address BMI as a predictor of outcomes in all forms of gender-affirming surgery. A second limitation is that because BMI cutoffs were routinely used to determine GAS eligibility when some of the studies were performed,<sup>2,4</sup> patients with higher classes of obesity might not have been included in the study samples. Thus, further research should explore BMI as a predictor of GAS outcomes in patients with class I, II, and III obesity, similar to the work of Rothenberg et al<sup>15</sup> and Pittelkow et al,<sup>14</sup> and in patients with an underweight BMI ( $< 18.5$ ).

### **Weight-Related Inequity**

A patient-centered approach to evaluating GAS eligibility with respect to BMI requires consideration of multiple influences on body weight and obesity risk. Transgender individuals are more likely to be affected by overweight and obesity than nontransgender individuals secondary to clinical and psychosocial factors.<sup>22,23,24,25</sup> For example, masculinizing and feminizing HT result in estimated increases in body weight of 1.7 kg and 1.8 kg, respectively,<sup>26</sup> with case reports of up to 27.3 kg of weight gain.<sup>27</sup> Anticipated weight gain with HT increases the likelihood that a patient's BMI would exceed predetermined limits for GAS. In addition, the transgender population is disproportionately affected by nutrition-related conditions, such as **food insecurity** and eating disorders,<sup>28,29,30,31,32</sup> both of which are associated with an increased obesity risk in certain population groups.<sup>33,34,35</sup> The transgender population is also significantly less physically active than the cisgender population due to fear of being "outed" as transgender, "passing" as male or female, and body dissatisfaction, among other factors.<sup>36,37,38,40,41,42,43,44</sup> Although obesity is a complex disease, physical inactivity is a known risk factor.<sup>25</sup>

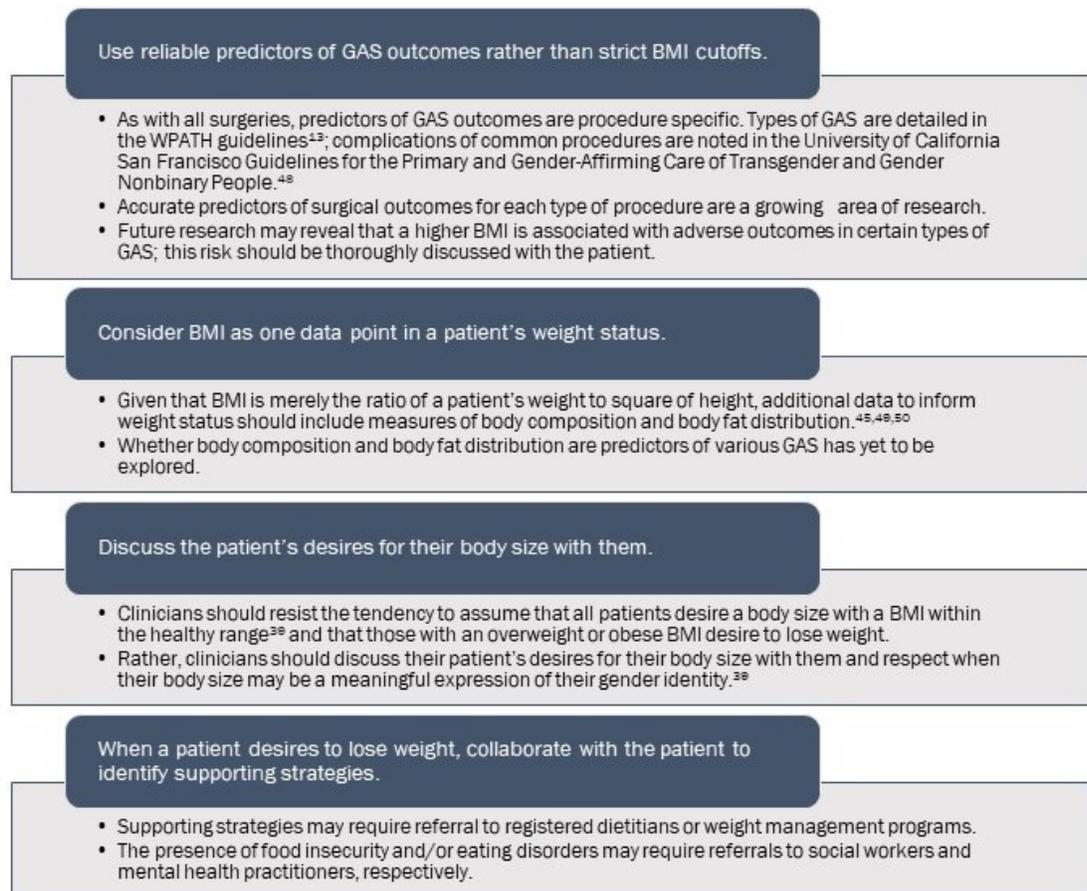
### **A Patient-Centered Approach**

Although the terms *obese* and *obesity* have been used throughout this paper when describing the results of existing research reliant on Centers for Disease Control and Prevention BMI ranges, we recognize that obesity as a medical diagnosis lacks sensitivity to body size diversity. Strict BMI requirements for GAS and routine weight loss recommendations also neglect a fundamental consideration: the patient's own desire for their body size. The hegemonic assumption is that all patients desire a body size that is within the "healthy" BMI range of 18.5-24.9 as defined by the Centers for Disease Control and Prevention,<sup>39</sup> despite the known limitations of BMI as a predictor of adiposity and health outcomes.<sup>45</sup> Whether the patient with a BMI classified as overweight or obese genuinely desires a smaller body size, however, is not routinely considered. Notably, the patient's desire for their own body size does not change the risks associated with GAS, but it is relevant to the provision of patient-centered care.

Body size and shape may be an expression of a patient’s authentic gender identity. The first author (W.L.) and a colleague have related the narrative of a transgender man who genuinely desired a larger body size—which he described as “having more of a presence,” “filling out my space,” and “going from invisible to visible”—when he decided to transition.<sup>46</sup> Although clinicians would label his body as obese, his larger body size was an expression of his masculinity.<sup>46</sup> Importantly, emerging research suggests that prescribing weight loss for patients seeking GAS is not only ineffective but also may cause harm by propagating weight cycling and weight stigma.<sup>2,47</sup> Thus, while many patients with overweight or obesity may genuinely desire a smaller body size, the reflexive assumption that all patients are dissatisfied with their body size lacks sensitivity to patients’ goals and gender expression.

A patient-centered approach to assessing GAS eligibility with respect to BMI would be empirically driven and center on the patient’s goals for their body. Toward this end, clinicians can employ the strategies depicted in the Figure.

**Figure.** Patient-Centered Approach to Use of Body Mass Index in Evaluating Gender-Affirming Surgery Eligibility



Abbreviations: BMI, body mass index; GAS, gender-affirming surgery; WPATH, World Professional Association for Transgender Health.

## Conclusion

The use of BMI cutoffs to determine GAS eligibility is an oversimplified and unsubstantiated practice. Given that transgender individuals are disproportionately affected by obesity, strict BMI requirements for GAS are likely to harm a significant number of patients by delaying or denying the benefits of GAS. A patient-centered approach to assessing GAS eligibility with respect to BMI would utilize reliable predictors of surgical outcomes specific to each gender-affirming surgery, include measures of body composition and body fat distribution rather than BMI alone, center on the patient's desires for their body size, and emphasize collaboration and support if the patient genuinely desires weight loss. Further research is needed to determine reliable predictors of various GAS.

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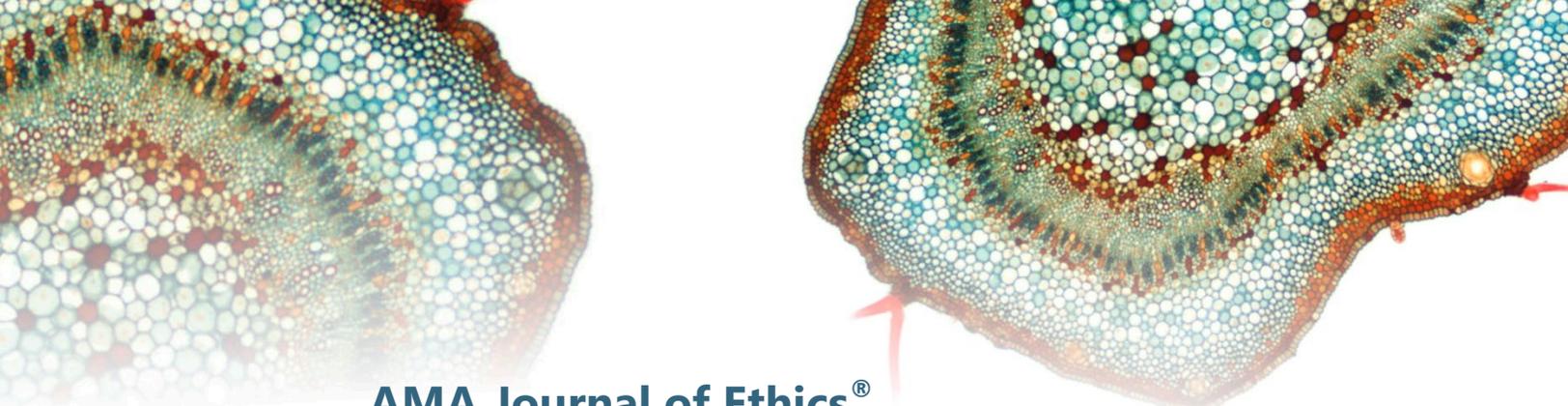
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### HEALTH LAW: PEER-REVIEWED ARTICLE

#### Gender-Affirming Care, Incarceration, and the Eighth Amendment

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##### Abstract

As outlined in *Estelle v Gamble* (1976), the 8th Amendment to the US Constitution requires that states provide adequate care for people who are incarcerated—but what constitutes “acceptable” care under professional guidelines is frequently at odds with the standard of care used by clinicians outside of carceral facilities. Outright denial of standard care runs afoul of the Constitutional prohibition on cruel and unusual punishment. As the evidence base that undergirds standards of care in transgender health has evolved, people who are incarcerated have sued to expand access to mental health and general health care, including hormonal and surgical interventions. Carceral institutions must transition from lay administrative to licensed professional oversight of patient-centered, gender-affirming care.

*The American Medical Association designates this journal-based CME activity for a maximum of 1 AMA PRA Category 1 Credit™ available through the AMA Ed Hub™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.*

##### Transgender Care in Carceral Settings

Transgender people, especially those who are Black, Indigenous, and people of color, are disproportionately incarcerated, with 16% of all respondents in a 2011 national survey of transgender people reporting having a history of incarceration in jail or prison; the rate for Black respondents was 47% compared to a general population rate of 2.7%, although the latter figure is limited to state and federal prison systems.<sup>1</sup> It is estimated that there are nearly 5000 transgender people residing in US state prisons<sup>2</sup> and that another 1200 are incarcerated in the federal system.<sup>3</sup>

In the United States, no unified policy exists for the housing of and the delivery of health care to transgender and nonbinary prisoners in carceral settings. Variation can be found in state policies pertaining to where transgender and nonbinary prisoners are housed and with whom, what medical care they can access, and under which circumstances they are eligible for said care.<sup>4</sup> The policies governing jails and detention centers also vary by agency and county. Although policies vary, clinicians’ ethical imperative to advocate for stronger protections for transgender people who are incarcerated and for best practices with respect to their care does not. In this paper, we seek to establish that, for transgender people who experience significant distress related to their inability

to access gender-affirming hormonal and surgical therapy while incarcerated, legal protection under the Eighth Amendment provides remedy. We also show that the United States regularly fails to meet the needs of transgender people who are incarcerated notwithstanding this legal standard and that remedy requires a lengthy judicial process to which few people who are incarcerated have access.

### **Standards**

The state's responsibility to provide health care to people who are incarcerated rests largely on the Eighth Amendment prohibition on cruel and unusual punishment.<sup>4,5</sup> The judicial standard underpinning this claim was established in *Estelle v Gamble* (1976), which held that the state has a legal obligation to provide medical care for people who are incarcerated that is "reasonably commensurate with modern medical science" and guidelines and of "a quality acceptable within prudent professional standards."<sup>6</sup> Proof of violation of the Eighth Amendment under *Estelle* requires 2 criteria to be met: that the care be medically necessary and that failure to provide such care constitutes "deliberate indifference" by a prison administration that is aware of the suffering resulting from that lack of treatment.<sup>4,5,7</sup>

The World Professional Association for Transgender Health (WPATH) has published widely accepted standard of care guidelines for the medical treatment of gender minorities.<sup>8</sup> While it is recognized that not all transgender people experience **gender dysphoria**, or "the distress that may accompany the incongruence between one's experienced or expressed gender and one's assigned gender,"<sup>9</sup> many do suffer from such distress until they receive treatment. Access to gender-affirming care is associated with increased quality of life and decreased rates of self-harm, including 44% and 73% lower odds of suicidality in transgender adults<sup>10</sup> and youth,<sup>11</sup> respectively, compared to cohorts who do not receive gender-affirming-care. WPATH,<sup>8</sup> the American Medical Association,<sup>12</sup> and the American Academy of Family Physicians,<sup>13</sup> among other organizations, have recognized that gender-affirming mental health care, hormone therapy, and gender-affirming surgical procedures are medically necessary interventions that can relieve the distress of gender dysphoria. For some, gender-affirming surgery may be the only effective treatment.

Deliberate indifference, the second criterion that must be demonstrated in Eighth Amendment cases, requires awareness on the part of the prison officials that their conduct or lack of intervention will cause significant harm or risk of harm to a prisoner. While medical necessity of care is often fairly simple to prove, deliberate indifference is a subjective assessment that represents a much higher legal hurdle.

### **Why Gender Affirmation Doesn't Happen in Carceral Settings**

There are many barriers to gender affirmation in carceral settings. The first is staff bias and a lack of training. Qualitative studies of both correctional and clinical staff<sup>14</sup> and transgender people with a history of incarceration<sup>15</sup> show that lack of staff competency regarding gender-affirming care presents a barrier to access, resulting in inadequate or complete denial of care. In particular, clinical staff report a lack of training and unfamiliarity with transgender care,<sup>14</sup> a finding replicated in other institutional settings such as the military.<sup>16</sup>

Housing is the second barrier to gender affirmation. Although under the federal Prison Rape Elimination Act (PREA), prisoners are legally entitled to be housed in a prison in accordance with their gender identity regardless of their anatomy,<sup>17</sup> in reality this

practice is concerningly rare. A 2020 survey found that only 15 of 4890 transgender people were housed according to their gender identity in state prisons.<sup>2</sup> Many state prisons rely on a binary system of classification that rests largely on genital morphology, seeking to house only transgender prisoners who have had genital surgeries in accordance with their gender.<sup>18,19,20</sup> Yet data show that transgender women who are incarcerated in men's prisons have a vastly heightened risk for sexual assault than prisoners as a whole.<sup>21</sup> Conversely, transgender women housed in women's facilities have substantially lower rates of victimization than transgender women housed in men's facilities.<sup>19</sup> Prison administrators have responded to violence against transgender people by remanding them to "protective" custody (ie, solitary confinement), but this practice is notorious for exacerbating isolation, psychological distress, and exclusion from prison programming. This practice is not only legally precarious but also highlights an ethical failing of states that do not readily provide gender-affirming care. For if prisoners are only eligible for transfer to facilities in accordance with their gender upon achieving specific milestones in transition, and if housing in accordance with gender—not anatomy—is a predictor of violence against transgender people in prison, then the decision to provide or not provide gender-affirming care ultimately determines whether or not the state takes decisive action to mitigate some of the worst harms associated with incarceration for gender minority prisoners.

The third barrier to gender affirmation in prison settings is lack of medical and surgical intervention. *Estelle v Gamble* established that by neglecting essential medical care, prisons inflicted punishment beyond society's penological interests.<sup>6</sup> Prisoners, who must rely on the state for their medical needs, should receive adequate treatment. However, in *Maggert v Hanks* (1997), the prison psychiatrist disputed the very diagnosis of gender dysphoria, and the US Court of Appeals for the Seventh Circuit stated: "except in special circumstances that we do not at present foresee, the Eighth Amendment does not entitle a prison inmate to curative treatment for his gender dysphoria."<sup>22</sup> There was concern that if gender-affirming therapy became the norm in prisons, transgender people would purposely commit crimes in order to receive said treatment. Several legal challenges to carceral institutions' denial of gender-affirming hormone therapy have resulted in gender-affirming care being extended to people who are incarcerated. The decision of the US Court of Appeals for the Seventh Circuit in *Meriwether v Faulkner* (1987) recognized gender dysphoria as a serious medical condition constituting a valid Eighth Amendment claim as established in *Estelle* but emphasized that the plaintiff, a transgender woman denied estrogen, was entitled to "some" kind of medical intervention meeting minimal standards of adequacy though not necessarily the intervention she was requesting.<sup>23</sup> It was not until the landmark case of *Fields v Smith* (2011), in which the US Court of Appeals for the Seventh Circuit struck down a 2005 Wisconsin law barring all access to gender-affirming hormones or surgeries for people in the custody of the Department of Corrections as a violation of the prohibition of cruel and unusual punishment, that courts began to rule favorably for transgender plaintiffs.<sup>24</sup> In 2015, the Department of Justice's statement of interest in *Diamond v Owens* issued a directive to all state prisons to evaluate all persons seeking hormone therapy and to continue the hormone regimen they were on at the time of incarceration.<sup>25</sup>

In several other court cases, the Eighth Amendment argument has been extended to include gender-affirming surgeries.<sup>26,27,28,29</sup> As previously noted, some transgender people experience severe dysphoria even after counseling, nonmedical affirmation, and hormone therapy. Prisoner access to gender affirmation surgery remains extremely rare, although blanket bans on these procedures have been ruled unconstitutional under

Eighth Amendment claims.<sup>30</sup> The handful of successful petitioners have had their surgical requests fulfilled only after expressions of extreme self-harm and only after extensive litigation.<sup>27,29,30,31</sup> The plaintiff in *Kosilek v Spencer* filed her first claim in 1992, but the decision of the district court ordering the commissioner of the Massachusetts Department of Corrections to provide her with surgery didn't come until 2014.<sup>26</sup> This decision was immediately reversed by the First Circuit,<sup>26</sup> and the Supreme Court declined to hear her appeal.<sup>32</sup> She didn't receive surgery until 2021, after *Kosilek* was heavily scrutinized in the landmark case, *Edmo v Corizon* (2019),<sup>29</sup> a full 27 years after *Kosilek* initially sought remedy. Other people who are incarcerated who have sought gender affirmation surgery have lost their cases on a variety of grounds, including disagreement over WPATH guidelines representing standard of care,<sup>28</sup> safety considerations for other prisoners,<sup>27</sup> and prison-hired medical experts denying the necessity of the plaintiff's surgery.<sup>33</sup>

### Removing Barriers

Despite legal advances, structural barriers to adequate gender-affirming care remain for transgender people who are incarcerated. Under *Estelle*, correctional institutions have an obligation to deliver gender-affirming care if “medically necessary” to transgender people who are incarcerated in accordance with “professional standards,”<sup>6</sup> such as the WPATH guidelines, which are widely accepted as representing the current medical and scientific consensus.<sup>34</sup> Even when this obligation is acknowledged, however, artificial administrative delays can prevent timely and adequate treatment,<sup>35</sup> effectively blocking access to appropriate care. Often, prisoners must meet a certain threshold (ie, a “serious” condition) to be eligible for medical intervention.<sup>36</sup> In order to gain access to gender-affirming care, prisoners have resorted to extreme measures to make their cases known, including self-surgery, such as autocastration.<sup>5,7</sup>

We hold that gender-affirming care for transgender and gender nonconforming people—which is required under the prevailing legal standard if it is medically necessary for alleviation of gender dysphoria—should be **patient-centered**. In light of the barriers noted above, patient-centered gender-affirming care within carceral institutions requires a multifaceted approach. Specifically, there are 3 foci that jails, prisons, and detention facilities must address to ensure a standard of care comparable to that available in the community: affirmation, custodial policy, and clinical competence.

Establishment of gender affirmation in jails, prisons, and detention centers should be formal and explicit, with medical and custodial staff receiving competency training. Custodial policy includes housing assignments, which, under PREA standards, shall be decided on a case-by-case basis with serious consideration given to the transgender person's views on their safety.<sup>17</sup> The use of solitary confinement for purported protection must end. This practice has always been a dangerous and inhumane solution, which can be avoided with adequate attention to the safety of transgender people. Other practices, including custodial staff conducting strip searches to determine genital status, should not be performed or should be performed in accordance with the person's gender, such as name and pronoun use and access to appropriate commissary items.<sup>37</sup> Carceral staff are often outwardly hostile to transgender people, exacerbating the distress they already experience from unjust housing assignments and lack of medical care.<sup>38</sup> Protocols must be established for managing staff who continue to violate the human rights of people who are incarcerated.

Finally, **clinical competence in gender-affirming care** is as crucial as it would be for any other medical presentation. On-site staff should receive training to fill in gaps or correct practices that create barriers to care for transgender people.<sup>39</sup> In institutions with inadequate or unsuitable staff, outside care should be obtained, just as it would be for other forms of specialized medical care.<sup>40</sup> The use of nonclinical staff for “gender identity disorder review panels” must end, with external medical professionals, not prison officials, leading the process. Clinical guidelines produced by a professional entity, such as WPATH<sup>8</sup> or the University of California, San Francisco,<sup>41</sup> should be used to guide care. As these guidelines for medical and surgical interventions are widely used in community practice and are lifesaving and effective, their use should not be limited in carceral institutions.

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**HEALTH LAW**

**What's Wrong With Criminalizing Gender-Affirming Care of Transgender Adolescents?**

Scott J. Schweikart, JD, MBE

**Abstract**

Gender-affirming care (GAC) includes hormonal and surgical interventions. In recent years, many states have criminalized GAC for adolescent patients. This article canvasses states' legal prohibitions and challenges to them and considers consequences for clinicians and patients.

**Gender-Affirming Care**

Gender-affirming care (GAC) is a “supportive form of health care” for transgender people that “consists of an array of services that may include medical, surgical, mental health, and non-medical services.”<sup>1</sup> Such care is critical for the “overall health and well-being” of transgender adolescents, as it helps patients in “aligning their outward, physical traits with their gender identity”<sup>1</sup> and thereby overcome the discomfort or distress caused by the misalignment of the two that defines gender dysphoria.<sup>2</sup> GAC is well established, and “every major US medical association recognizes that gender-affirming health care is medically necessary treatment for dysphoria.”<sup>2</sup> Surgical treatment is “essential” for some transgender people experiencing gender dysphoria, as “relief ... cannot be achieved without modification of their primary and/or secondary sex characteristics to establish greater congruence with their gender identity.”<sup>3</sup> More common than surgery is hormone therapy, a form of GAC that—like surgery—is necessary treatment for some patients suffering from gender dysphoria. Hormone treatment may “provide significant comfort to patients who do not wish to make a social gender role transition or undergo surgery.”<sup>4</sup> Both these methods of GAC—surgery and hormone treatment—are facing growing scrutiny across the United States with regard to their application to **adolescent patients**.

**Effectiveness of GAC**

Evidence has shown that surgical GAC can be effective for some minor patients. One study found that top surgery for transmasculine youth reduced chest dysphoria (discomfort with breasts) and concluded that “professional guidelines and clinical practice should consider patients for chest surgery based on individual need rather than chronologic age.”<sup>5</sup> Surgery is an important option for some adolescent patients and “may be performed on older adolescents who have shown a consistent and persistent gender identity, are stable with respect to their mental health, and have parental

support.”<sup>6</sup> Deciding surgical intervention on a case-by-case or individual basis is key; sometimes surgery may be necessary in light of the “benefit to the adolescent’s overall health.”<sup>7</sup> Physicians who provide GAC, including surgery, to transgender youth perform such interventions thoughtfully and on an individualized basis. One surgeon explains that she approaches such “decisions about treatment carefully over time, with input from an interdisciplinary team, together with youth and their caregivers, and by established guidelines.”<sup>8</sup> By criminalizing physicians for “practicing evidence-based medicine,” any new state law “nullifies their expertise” while also interfering with the patient-physician relationship.<sup>9</sup>

### **Criminalization of GAC**

The criminalization of GAC for adolescents is emergent in multiple US states. In the last 2 years, “25 US states have introduced bills to restrict access to gender affirming medical care for minors.”<sup>10</sup> For example, in 2021, Arkansas became the first state to outlaw physicians from providing GAC (both hormonal and surgical) to minor patients<sup>11</sup> via an override of the governor’s veto of the bill.<sup>12,13</sup> In 2022, the Alabama legislature passed<sup>14,15</sup>—and the governor signed into law<sup>16</sup>—a bill known as the Alabama Vulnerable Child Compassion and Protection Act prohibiting physicians from providing GAC (both hormonal and surgical) to minors.<sup>17</sup> Often the motivation behind such bills is political, a new front on the culture war targeting transgender citizens. For example, in January 2020, the South Dakota House of Representatives passed a bill criminalizing provision of GAC treatment (both hormonal and surgical) to transgender youth under the age of 16, shortly after the legislature’s failure to pass a “bathroom bill.”<sup>18</sup> Proposed GAC restrictions coming after failure of bathroom bills are not unique and are evidence of political animus. As recently noted in the *Harvard Law Review*: “The shift from the stigmatization and vilification of trans youth in the bathroom bills to the victimization narrative embodied in the gender-affirming care bans illustrates how opponents of trans identity are adapting their rhetoric in response to changing legal and social attitudes towards transgender children.”<sup>2</sup>

Although the South Dakota bill is intended as a way for the state government to protect children from harmful medical intrusion, critics note that legislators often are not “using actual evidence” and are “not listening to any health care providers” and are instead “advancing something that’s very dangerous to make a statement.”<sup>18,19</sup> With regard to similar restrictions in Texas, the Endocrine Society explains that “medical evidence, not politics, should inform treatment decisions” and that medical professionals should not “be punished for providing evidenced-based care that is supported by major international medical groups.”<sup>20</sup>

### **Legal Challenges**

The legality of these restrictions is now coming under judicial scrutiny, and laws are being tested in a number of courts. For example, the Alabama law was enjoined by a federal district court, which ordered a preliminary injunction to block the law in part—enjoining Alabama from enforcing the ban on medication treatment but allowing the state to continue blocking surgical treatments.<sup>21,22,23</sup> The court determined that “the imminent threat of harm to Parent Plaintiffs and Minor Plaintiffs [seeking treatment]—ie, severe physical and/or psychological harm—outweighs the harm the State will suffer from the injunction” and reasoned that “enjoining the Act upholds and reaffirms the ‘enduring American tradition’ that parents—not the States or federal courts—play the primary role in nurturing and caring for their children.”<sup>23</sup> The federal district court clearly recognized the harms in blocking youth from receiving GAC. However, the court did limit

its decision (without clear analysis or explanation) to hormonal therapy, leaving the part of the law banning gender-affirming surgeries for youths to remain in effect. While the court may have limited its injunction to only allowing hormonal-based GAC treatments because the plaintiffs were only requesting access to hormonally based GAC and not surgery,<sup>24</sup> the limited injunction is meaningful, as it could also imply that the district court accepted the plaintiff's concerns that surgical treatment is a more severe option to be "avoided"<sup>24</sup> compared to hormonal-based GAC treatments for minor patients.

### **Unlawful Discrimination and Equal Protection**

Recent years have seen a rapid rise in transgender constitutional rights litigation.<sup>25</sup> Many of these cases have been successful in recognizing constitutional protections for transgender citizens. Indeed, "some courts have held that transgender status is a protected class in its own right, while others have found that antitransgender discrimination is sex discrimination."<sup>2</sup> Much of the success has stemmed from equal protection arguments. Katie Eyer explains:

During the last five years, there has been a wave of decisions in the lower courts developing a jurisprudence of transgender equality: that transgender individuals should be considered a suspect or quasi-suspect class (and thus discrimination against them should be subject to heightened scrutiny), that anti-transgender discrimination should be considered sex discrimination (and thus under established law should receive intermediate scrutiny), and that discrimination against the transgender community is irrational. Collectively these case law developments represent a fundamental shift in the lower courts' approach to the equality rights of the transgender community.<sup>25</sup>

This trend in litigation is extending to the promotion of rights for transgender youth, as there is concern that GAC restrictions for transgender youth are a violation of the US Constitution's Equal Protection Clause. The Department of Justice (DOJ) joined with the plaintiffs in challenging Alabama's and Arkansas's laws restricting GAC for adolescents. The DOJ argues that such restrictions are a violation of the Fourteenth Amendment's Equal Protection Clause and believes that such restrictions are discriminatory on the basis of gender identity.<sup>26,27</sup> In its complaint for the Alabama case, the DOJ states that GAC restrictions discriminate "on the basis of sex and on the basis of transgender status," depriving citizens of equal protection under the Constitution.<sup>28</sup>

As of the end of 2022, the case challenging Alabama's law is still playing out and being heard by the 11th Circuit Court of Appeals.<sup>29</sup> Alabama maintains that it possesses a rational basis to prevent the "sterilization of children" and that the "risks of gender-affirming treatments, which can include loss of fertility, outweigh any benefits," while the DOJ argues that the "law discriminates on the basis of sex by prohibiting certain treatments only for one sex" (eg, prohibiting prescribing testosterone treatment for "children assigned female at birth").<sup>29</sup>

### **Impact of Restrictions**

These laws are poor public policy, as they create a significant conflict between physicians' adherence to the law and adherence to their professional code of ethics and civil law tort duty not to commit medical malpractice. The traditional standard of care with regard to medical malpractice requires that "medical care for a given patient and health care provider is the quality of care that would be provided to any patient in a similar clinical situation, by the average provider in a similar location."<sup>30</sup> In some specific cases, adolescent GAC treatment, including surgery, may be necessary in order for a physician to practice in line with the legal standard of care (thus avoiding malpractice)

and also to satisfy their professional ethical duty to offer safe and effective medical care that promotes the patient's well-being.<sup>31</sup>

As Kraschel et al explain: “these statutes would transform their [physicians'] fiduciary duty into a criminal act.”<sup>10</sup> Similarly, Lepore et al argue that the laws are untenable, as they “require that health care workers act against current evidence-based guidelines” such that they are legally mandated to violate their duty to “do no harm.”<sup>32</sup> The same tension between professional and legal obligations is observed in new abortion laws being enforced post-*Roe v Wade*, wherein the professional ethical duties of physicians are put in direct conflict with criminal law, forcing physicians to choose between upholding their ethical duties or violating the law.<sup>33</sup> Hence, these new laws prohibiting GAC treatment for minors (including gender-affirming surgery) center on the government's unwillingness to let the medical profession self-regulate—via oversight from state medical boards—or allow civil tort law to regulate physician practice as it does in most other cases.

### Conclusion

The recent trend criminalizing GAC for transgender youth is politically motivated and not tethered to evidence-based medicine. The consequences of legally blocking this critical treatment are dire and have life-threatening implications. Many leading medical associations around the country—such as the American Academy of Child and Adolescent Psychiatry, the American Academy of Pediatrics, and the American Medical Association—all agree that GAC is critical lifesaving care for certain transgender youths and that “[b]locking access to timely care has been shown to increase youths' risk for suicidal ideation and other negative mental health outcomes.”<sup>34</sup> Additionally, such bans serve to **discriminate against transgender patients**, raising serious concerns about constitutional equal protection violations. A further consequence of laws that criminalize health care is the undermining of trust in patient-physician relationships, which promotes a chilling effect that harms the practice of medicine more broadly. Ultimately, physician judgment in consultation with the patient and their family should be valued and prioritized. Any potential harms to patients are already mitigated via professional regulation and tort law, and allowing physician judgment to prevail helps strengthen patient autonomy without government discrimination or the injury that may result from restricting vital medical care.

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**STATE OF THE ART AND SCIENCE: PEER-REVIEWED ARTICLE**

**Patient-Reported Outcome Measures in Gender-Affirming Surgery**

Manraj Kaur, PhD, MSc, Shane Morrison, MD, MS, Andrea Pusic, MD, MHS,  
and Anne Klassen, DPhil

**Abstract**

Patient-reported outcome measures (PROMs) are questionnaires that assess how patients feel and function. PROMs should be developed and validated using a mixed methods, multistep approach with extensive patient input to ensure that they are easy to understand, comprehensive, and relevant. PROMs that are specific to gender-affirming care (including surgery), such as the GENDER-Q, can be used to educate patients, align patients' goals and preferences with realistic expectations about the surgical procedures' purposes and outcomes, and conduct comparative effectiveness research. PROM data can contribute to evidence-based, shared decision making and just access to gender-affirming surgical care.

**The Importance of Asking Patients**

Gender-affirming surgery includes a range of individualized and medically necessary procedures that are performed to align an individual's physical characteristics with their gender identity. Demand for gender-affirming surgery has grown exponentially in recent years,<sup>1</sup> with 25% of transgender and gender diverse (TGD) individuals reporting in a 2015 survey that they had undergone some type of gender-affirming surgery.<sup>2</sup> In parallel, there has been an upsurge in gender-affirming surgical options and technical variations.<sup>3,4</sup> Gender-affirming surgeries are often complex, as they can involve multiple specialties, and might be irreversible. They are also associated with high costs to the health care system and the patient (eg, copays).<sup>5,6</sup> Consequently, to provide the highest-quality and evidence-based care, it is crucial to measure and longitudinally evaluate outcomes of gender-affirming procedures and to conduct comparative effectiveness research.

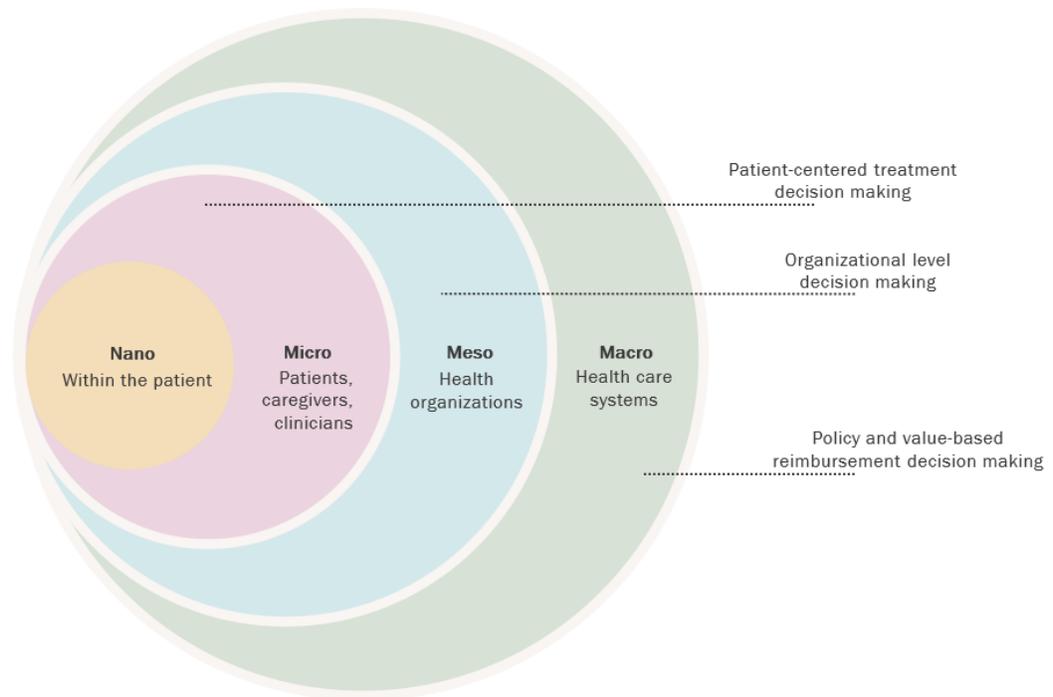
To date, the measurement of outcomes in the gender-affirming surgery literature has largely focused on the clinician perspective (ie, clinical judgment or interpretation of a patient's observable signs or physical manifestations of a condition). These clinician-reported outcomes are impairment focused and include, for example, wound healing, bleeding, nerve injury, and flap loss. However, only collecting and reporting clinician-reported outcomes overlooks the impact of gender-affirming surgeries and related complications on patients and their health-related quality of life. Patient-reported

outcomes (PROs) are unobservable or latent outcomes known only by the patient and cannot be assessed using clinical observation or physical examination. PROs are symptom and function focused and may include physical symptoms (eg, pain, fatigue), functions (eg, activities of daily living, sleep, work), psychosocial well-being, and sexual well-being. These outcomes are measured using standardized and validated questionnaires (also called scales, surveys, or instruments) without the data being interpreted by a health care professional or anyone else and are called patient-reported outcome measures (PROMs).<sup>7</sup> PROMs, including for **gender-affirming care**, have a number of benefits and should be developed and validated using a mixed methods, multistep approach with extensive patient input to ensure that they are easy to understand, comprehensive, and relevant.

### PROMs Benefits

At its core, the use of PROMs allows for systematic and meaningful inclusion of patient voice in treatment decision making and enhances patient-centered care. However, collecting and utilizing PROM data may have a multilevel impact on how health care is planned, organized, delivered, and reimbursed (see Figure).<sup>7,8,9</sup>

**Figure.** Multilevel Uses of PROMs Data



Previous studies have shown that completing a PROM can result in patients' improved awareness of their health status or treatment-related effects and provide patients with relevant terminology (nano level), enabling them to better communicate with their health care team.<sup>10,11,12</sup> At the level of patients and health care professionals (micro level), PROM data can be used to set expectations or align a treatment approach with the preferences of the patient, educate the patient, facilitate clinician-patient communication, identify pre- or postoperative concerns, prioritize health outcomes, and measure changes in health over time.<sup>13</sup> At the level of a health care organization (meso

level), systematically or routinely collected PROM data can be used to assess health outcomes over time. More specifically, patient data can be used to predict health outcomes for clinical and sociodemographic subgroups and to evaluate the comparative clinical effectiveness of treatment interventions. The PROM data also can be used to evaluate clinician performance and for peer benchmarking.<sup>14,15</sup> The organization may use these data to evaluate program effectiveness and efficiency as well as quality assurance and improvement initiatives and to identify gaps in health care services. Lastly, PROM data are useful to health care systems (macro level) in comparing health outcomes across different organizations or jurisdictions for the purpose of informing health care reimbursement and policy decisions, ultimately providing the basis for value-based reimbursement.<sup>16,17</sup>

### **PROM Design**

Broadly, there are 2 main types of PROMs: (1) generic PROMs that measure overall health or well-being or general aspects of health status and (2) condition- or treatment-specific PROMs that measure symptoms and symptom interference for a specific condition or treatment. Both generic and condition- or treatment-specific PROMs are required to meet PROM development and validation guidelines that have been put forth by the US Food and Drug Administration (FDA),<sup>18</sup> COSMIN (Consensus-based Standards for the selection of health Measurement Instruments),<sup>19</sup> the Professional Society for Health Economics and Outcomes Research (ISPOR; formerly, the International Society for Pharmacoeconomics and Outcomes Research),<sup>20,21</sup> and similar organizations.<sup>22,23</sup> At a minimum, the guidelines recommend that the development of a PROM should begin by defining the construct, target population, and context of use. As part of this process, extensive qualitative input should be sought from the people who experience the construct—and for whom the measure is intended—to establish the PROM's face validity (what the PROM appears to measure from patients' perspectives). Additionally, patient data should be used to develop questions (ie, items) for the PROM. The items should include words used by patients as much as possible, and any double-barreled, technical, or value-laden terms should be avoided. Once the items are developed, appropriate response options, recall duration, and instructions should be defined. The PROM should be piloted among patients using cognitive debriefing interviews, and expert feedback should be sought to establish the PROM's content validity (ie, comprehensibility, comprehensiveness, and relevance). A field test study should be conducted with a large, heterogeneous sample of patients to assess the PROM's reliability (ie, internal consistency, measurement error), construct or criterion validity (whether the PROM measures what it intended to measure), as well as its responsiveness (whether the PROM captures change over time in health status or condition).<sup>19</sup> Scoring algorithms should be established based on the theoretical approach guiding PROM development and validation. Following this process, the PROM should be made available for clinical care and research. The PROM may be translated into other languages and culturally adapted for increased uptake using ISPOR's best practice guidelines.<sup>24</sup>

### **PROM Data Collection and Implementation Considerations**

PROM data collection should always start with W5H questions—why, who, what, when, where, and how (see Table). Establishing concordance between what matters to the target population (the construct of interest) and what the PROM is intended to measure is of utmost importance for a successful PROM data collection program. A core team of key stakeholders—patients, clinicians, researchers, payers, regulators, and, where applicable, caregivers, hospital administrators, or community organizations—should be established and their feedback integrated into the planning, design, implementation,

and evaluation of the program. The feasibility (ease of implementation, practicality, integration with information technology such as electronic health records, and scalability) and acceptability (face validity, content validity, ethics, burden, opportunity cost) of the PROM(s) should be examined in a pilot study prior to scaling PROM data collection at the meso and macro levels.<sup>25,26</sup>

**Table.** Questions Informing Patient-Reported Outcome Measures Data Collection

Question	Explanation
<b>Why</b>	Establish a clear purpose for PROM data collection and how the data will be used. <ul style="list-style-type: none"> <li>• Diagnose, prescribe, predict, or evaluate.</li> </ul>
<b>What</b>	Define the construct of interest and identify a suitable PROM. <ul style="list-style-type: none"> <li>• Ensure that the construct of interest is aligned with what matters to patients who are seeking or receiving gender-affirming surgery.</li> <li>• The PROM should have content and face validity, in addition to established reliability and validity in the target population.</li> <li>• Other considerations when choosing a PROM include available translations and fees to use the PROM.</li> </ul>
<b>Who</b>	Define the target population in which data will be collected. <ul style="list-style-type: none"> <li>• Ensure that all relevant subgroups are accurately represented and that the data collection procedures are accessible and equitable.</li> </ul>
<b>When</b>	Establish the timing and frequency of data collection. <ul style="list-style-type: none"> <li>• These parameters predominantly should be dictated by the purpose of data collection and the clinical research question.</li> <li>• Ensure accessibility and prevent research fatigue.</li> </ul>
<b>Where</b>	Collect remotely or at the point of care (eg, prior to a clinic visit). <ul style="list-style-type: none"> <li>• Ensure accessibility and reasonable privacy for patients completing PROMs.</li> </ul>
<b>How</b>	Develop and pilot the plan for data collection. <ul style="list-style-type: none"> <li>• Data may be collected via paper, electronic (desktop or portal) devices, telephone (eg, automated voice recognition software) or a combination thereof.</li> <li>• Data may be collected before or during clinic visits.</li> <li>• Consider administrative burden, cost, accessibility, and real-time use of PROM data for clinical care.</li> <li>• Consider information technology-related requirements.</li> </ul>

Implementation of PROMs in gender-affirming surgery at the hospital, program, system, or national level should be grounded in implementation science frameworks (deterministic and evaluative) with a focus on intersectionality (eg, the Consolidated Framework for Implementation Research<sup>27,28,29</sup> enhanced for intersectionality<sup>30</sup>). Prior to implementation, extensive input should be sought from all stakeholders on factors that affect implementation success and scalability, including barriers to and enablers of PROM data collection, such as staff and organizational preparedness. The clinic workflows should be refined to ensure minimal logistical burden to clinic staff and patients, and the clinic staff should be trained on the collection, interpretation, and use of PROM data. Information technology-related resources (eg, data reporting, analytics) should be harnessed or developed to ensure accessible and equitable data collection. An iterative feasibility evaluation should be conducted to ensure that the preset quality indicators (eg, program fidelity, PROM completion rates) are met and that there are no

gaps in the efficient and effective scaling of the PROM data collection program. Elements of PROM programs that have been linked to long-term success include identifying clinical champions, dedicated staff members and resources, ensuring stakeholders' commitment to integrate and use PROM data, accessibility of PROM data for clinical care, and actionable feedback to patients and clinicians based on PROM data.<sup>31</sup> Guidance is available for planning PROM implementation and selecting PROMs,<sup>22,32,33,34</sup> implementing and evaluating PROM initiatives,<sup>29</sup> integrating PROMs into electronic health systems,<sup>35</sup> and visualizing PROM data.<sup>36,37</sup>

### **Patient-Facing Policy**

A key consideration in gender-affirming surgery is that PROs research, as it expands, should aim to reduce health- and health care-related disparities at the policy level. Efforts should be taken at the micro, meso, and macro levels to ensure that PROMs are designed and implemented in fully accessible ways and without the unintended exclusion or inundation of patient subgroups. PROMs should be made available in languages spoken by patients, require no more than a sixth-grade reading level,<sup>38,39</sup> and employ hybrid modes and methods of data collection (eg, during a clinic visit or remotely, on mobile devices or on paper). The environment in which PROMs are administered or used should foster inclusiveness by ensuring that the staff are culturally competent, by providing accessible spaces (eg, gender-neutral washrooms), and by using intake forms that include a variety of gender and sexual identities. Data collected at the hospital system (meso) or jurisdiction (macro) level should be analyzed to identify ways to improve care quality and cost effectiveness to promote value-based health care. The analysis, use, and dissemination of PROM data at all levels should thoroughly and thoughtfully consider the impact of the data on extant health policies that fund and regulate access to gender-affirming care.

### **PROMs in Gender-Affirming Surgery**

Although PROMs have been used to assess gender-affirming surgery outcomes for the last few decades, recently the shortcomings related to the development and psychometric properties of existing PROMs have been called to attention. Converging evidence from recent systematic reviews<sup>40,41,42</sup> on PROMs used in gender-affirming surgery highlight 4 key issues. First, most PROMs identified in the literature were developed to be used for a specific study and therefore lack validation. Second, several PROMs that are used in the gender-affirming care literature were developed to evaluate outcomes in cisgender groups and have not been rigorously validated in gender diverse individuals (eg, the Female Genital Self-Image Scale, the International Prostate Symptom Score).<sup>40,41,42</sup> Third, the number of PROMs used in the gender-affirming surgery literature are limited by their content or by failing to follow international guidelines for PROM development. Lastly, PROMs that comprehensively assess outcomes of specific types of treatment interventions or procedures (eg, scrotoplasty, labiaplasty) or a single body part or region (eg, forehead, jaw, facial hair) are lacking. An urgent need for a comprehensive, rigorously designed, and validated PROM to assess outcomes of gender-affirming care was identified. Our international team of clinicians, quality-of-life researchers, and psychometricians responded to this call to action by developing the GENDER-Q—a PROM for assessing outcomes in gender-affirming care.<sup>43</sup>

The GENDER-Q consists of a comprehensive set of unidimensional scales (questionnaires) that assess the domains of appearance (hair, face, neck, body, breasts, chest, genitals, donor site), health-related quality of life (physical, psychosocial, sexual, voice, practices), the experience of care (health professional, clinic, preoperative

information, and outcome), and devices (catheter, testicular implants, erectile devices).<sup>43,44</sup> To develop the GENDER-Q, our team followed international guidelines for PROM development.<sup>18,19,20,21,22,23</sup> We conducted in-depth interviews with 84 TGD individuals from 4 countries (Canada, Denmark, the Netherlands, and the United States) who were seeking or had undergone gender-affirming treatment(s).<sup>44</sup> The data were used to create the preliminary versions of a set of independently functioning scales. The scales were shown to 7 to 14 TGD individuals (depending on the scale) and 50 clinicians and research experts and iteratively refined, resulting in the field test version of the scales.<sup>44</sup> The field test version was piloted in a sample of 602 English-speaking TGD individuals from 28 countries who were recruited using an online crowdsourcing platform.<sup>44</sup> An international field test study to establish the measurement properties of the GENDER-Q is underway. The data collected will be used to refine the scales, assess their reliability and validity, and develop a common scoring algorithm for each scale for international use. Once the field test is completed, the scales and scoring will be made available for not-for-profit clinical research and care at no charge.

The GENDER-Q represents a positive ethical shift in the measurement of PROs for gender-affirming surgery, as it lays the foundation for a patient-centered health care culture that promotes the notion of “nothing about us without us,” as opposed to the current, fundamentally flawed practice of using PROMs in gender-affirming surgery that were developed for the cisgender population.

### Conclusion

Empirically and systematically integrating rigorously developed and validated gender-affirming surgery-specific PROMs (eg, GENDER-Q) that capture what matters to patients are indispensable to patient-centered, shared treatment decision making; improving care quality; and expanding access to and funding of surgical procedures.

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GENDER-Q was co-developed by Drs Anne Klassen, Manraj Kaur, and Andrea Pusic; Brigham and Women's Hospital and McMaster University own copyright. Dr Klassen could receive license revenue when GENDER-Q is used in investigations. Dr Pusic co-developed Q-PROM portfolio measures and could receive royalties when they are used in clinical trials. Dr Morrison had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

**MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE**

**Should Uterus Transplantation for Transwomen and Transmen Be Subsidized?**

Timothy F. Murphy, PhD and Kelsey Mumford

**Abstract**

Success in uterus transplantation (UTx) among ciswomen suggests that transwomen and some transmen will also likely have interest in this intervention. It does not seem likely, however, that all parties interested in UTx will have the same standing when it comes to federal subsidies or insurance coverage benefits. This analysis describes the comparative moral strength of claims for financial support for UTx that different parties might make.

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**Costs of Uterus Transplantation**

Gestation of a child following uterus transplantation (UTx) in cisgender women with absolute uterine infertility factor has proved successful in the United States.<sup>1</sup> Given the success of UTx that relies on both living and deceased donors, interest in the procedure is likely to extend beyond cisgender women.<sup>2</sup> Among those likely to be interested in UTx are transwomen who want to gestate their own children, transwomen who want uterus transplants to consolidate their identities but not to gestate children, some transmen who want to gestate their own children, and cisgender men wanting to gestate children of their own. Transwomen and cisgender men will not have been born with a uterus, and transmen might have had female-typical bodies in the past but lacked a uterus for reasons of disease or disorder. Here, we understand transgender people to be those who meet American Psychiatric Association or World Health Organization standards for gender dysphoria or gender incongruence respectively.<sup>3,4</sup>

In one possible economic arrangement, all parties wanting UTx for any reason would rely entirely on their own resources or philanthropy to pay all costs. However, because the costs are significant, it is likely that all parties interested in UTx will look to both private insurance and government providers for help covering costs. The Swedish researchers involved in the initial successful uterus transplants resulting in live births estimate the average cost per successful gestation to be €74 564—including in vitro fertilization (IVF) and medical care (€55 400) and paid sick leave (€19 164).<sup>5</sup> In the United States, the costs of UTx have been estimated to run between \$100 000 and \$300 000, and these

costs are typically paid by institutions themselves or through research grants supporting clinical trials.<sup>6</sup> A few institutions offer UTx to cisgender women paying out of pocket, although these women's insurance might cover some of their expenses that would ordinarily be paid by health insurers for pregnancy and childbearing.

No reliable estimates exist on how many transwomen, transmen, or cismen might be candidates for or want UTx, and even a rough estimate of what the individual cost might be for such people can only be speculative, especially since no UTx has been reported in such parties. However, the overall total financial cost of UTx for these parties would likely be smaller than the overall total cost for cisgender women because of the comparatively smaller number of transpeople and the even smaller subset likely to be interested in this intervention. In this analysis, we consider the comparative moral strength of transwomen's and transmen's claims for financial support.

### **Ethical Considerations**

Any system for subsidizing health care costs involves a mix of ethical and civic considerations. Ethical considerations typically focus on the importance of health as a good unlike any other. Health is good in itself, and it also serves as a means of access to other goods that confer meaning and value in life. Many governments offer some support for health care costs to ensure equity among their citizenry, but political opinion is divided over the rationale for and the extent of government responsibility to pay for health care. For their part, employers offering health insurance may understand insurance as a competitive tool in the marketplace—as a way to attract and retain the employees they want. Certain ethical considerations are of course taken into account by both government and private providers to ensure, among other things, that like cases are treated alike.

The strength of claims for subsidy of UTx will vary according to ethical rationales for covering costs in the first place. One might claim, for example, that UTx is important as a matter of health in restoring a compromised capacity that is the cause of pain and suffering.<sup>7</sup> Or one might claim that UTx is important as a matter of access to a good that is fundamental to social status equality. Some subsidies by private and government payers rely not on health, properly speaking, but on notions of well-being, and one might claim that UTx is essential to well-being.<sup>8</sup> Or one might claim that, as a transplant procedure, UTx ought to be eligible for the subsidy that governments provide for other transplantations.<sup>9</sup> When it comes to private insurance, one might argue that coverage for UTx is contractually implied in private insurance policies to the extent that these policies provide fertility coverage—as happens, for example, in states that require health insurers doing business in their state to provide a certain degree of subsidy for IVF.<sup>10</sup> In general, IVF and other interventions in fertility medicine are not subsidized by government or private insurers in the United States. With this background in place, let us review the various parties who might come forward with a claim for subsidy for UTx.

*Transwomen who want to gestate children.* Even though there has been no uterus transplant to date in transwomen that we know of, some clinicians have maintained that there are no absolute barriers in anatomy, hormones, and obstetric considerations that would rule out the possibility of successful UTx in transwomen.<sup>11</sup> Transwomen wanting to gestate children can plausibly justify subsidy of UTx on a number of grounds, as mentioned above. Transwomen lack a trait (the ability to bear children) that may cause them to experience psychological dissonance in a way that undermines their health and well-being. The lack of a uterus also closes off the prospect of gestating a child in a way

that is available to women as a class. It follows that lack of a uterus is an obstacle to full participation in the social goods attached to women's identity.

Such women might also note that because some insurance coverage is available in the United States for IVF, it is inconsistent that only some kinds of infertility treatment are subsidized. Moreover, just because no pregnancy has been achieved by UTx in a transwoman, some commentators have argued that the government has some responsibility to support research on methods to achieve that goal on the grounds that government has a responsibility to help secure equity in the social goods important to human well-being.<sup>8,12</sup> However, the counterargument might be raised that other options for having children are available, such as through adoption, thereby limiting government responsibility for that kind of research. Nevertheless, transwomen might point to values of gestation that cannot be offset by adoption and to obstacles that sexual and gender minorities sometimes face in adoption.<sup>13</sup>

*Transwomen who want to consolidate identity.* Some—but not all—of this rationale also applies to transwomen who want UTx not to have a child but to consolidate their identity. They may experience dissonance at not having a uterus but, in this case, UTx is not sought to remedy lack of access to the goods of gestation and childbearing. This interest in UTx might be judged to be less important than other kinds of medical interventions wanted by transwomen. For example, some transwomen seek subsidies for facial feminization because they exhibit a “masculine” face in an otherwise “feminine” presentation of self.<sup>14</sup> Their masculine-typical appearance can elicit harm, threats of harm, and social discrimination. Facial feminization can significantly diminish that adversity. Genital modification can also be important in helping people secure relationships consistent with their gender.

In contrast, UTx offers no comparable outward benefit, which is not to say that it is of no value, only that it might be evaluated as less important than other health care interests, especially if the risks of the intervention are not offset by a sufficiently important gain. It is also an open question whether carrying out UTx for one person's identity consolidation would close off the option for another person to secure UTx in order to have a child, in which case questions of justice would necessarily be involved, involving competing claims on limited resources. Moreover, UTx as currently practiced involves only temporary placement, whereas a uterus might be wanted indefinitely, thus exposing the individual to much longer-term risks of immunosuppression. Third-party payers might, again, reasonably judge a transient medical intervention less important and riskier than others, especially since for private insurers and governments alike resources will be limited.

*Transmen who want to gestate children after gender-affirming surgery.* Transmen start life with female-typical bodies but modify their bodies to align with male-typical traits to varying degrees. Some transmen have children prior to any body modifications that interfere with gestation. Others do not and have their uterus removed to conform their bodies to a certain gender ideal. Some transmen have transitioned in gender but retained their uterus and gestated children. This precedent triggered interest in UTx among transmen, especially if they did not retain their uterus or store gametes prior to their transition.<sup>15</sup> Transmen's justifications for subsidies will differ from those of transwomen in that transmen cannot claim that they lack a capacity characteristic of men that compromises their health or that compromises status equality with other men. Unless one wants to argue that all people have a fundamental interest in gestating, it is

not clear that men lack a capacity they ought to expect as a matter of reproductive justice.

Moreover, other means of having children are available to them, no less than to other adults facing infertility of one kind or another. One might make the case for some transmen, however, that their fertility was compromised by failure on the part of clinicians and institutions to incorporate the prospect of retaining a uterus until such time as they decided definitively not to gestate children. As a matter of restorative justice, some transmen might have a stronger case for subsidies than others. This claim would be undercut, of course, by informed consent processes that advised about this option.

### Conclusions

As UTx is clinically safe and effective in principle,<sup>16</sup> we might expect transwomen and some transmen to join with ciswomen in seeking subsidies for the procedure from government and private payers. In the United States, private insurers are free to offer coverage largely (but not entirely) as they choose. Some may be expected to resist coverage should UTx become possible for transwomen and transmen, especially employers that use their closely held businesses to express religious views.<sup>17</sup> By contrast, some employers offering health insurance may not want to discriminate against any actual or potential employees and thus may extend coverage of UTx to those parties. Federal and state providers of health insurance are also ultimately free to decide what medical interventions they wish to cover and for what reasons (whether for “health” in a limited sense or “well-being” in a more expansive sense). At present, some states require private insurers doing business in their jurisdiction to pay for certain IVF services, but most do not.<sup>18</sup> For its part, the federal government does not subsidize fertility treatment except under very limited circumstances.<sup>19</sup>

Certain moral considerations apply in the provision of health care by both private insurers and the state since the purpose and importance of health care services vary. We have offered scenarios involving stronger and weaker moral grounds for subsidy of UTx. Morally stronger claims for coverage point to the significance of UTx for protecting health, comparable coverage for **other fertility services**, and securing a gender-characteristic capacity as a matter of equity and access. Morally weaker cases involve claims grounded in personal interests unrelated to having children or achieving other kinds of status equality and involve relatively greater risk than benefit.

Even if we were to accept that some transpeople are morally entitled to subsidies for UTx, not all will be subsidized. Third-party payers are entitled to offer coverage in light of certain factors, especially medical criteria such as general health, age, and life expectancy. Not all transpeople will be positioned to benefit from UTx; some will simply not be healthy enough to undergo UTx, and, regardless of the reason they want UTx, third-party payers could justifiably decline reimbursement. Other parties will have stronger claims to UTx subsidies for reasons related to health and well-being—benefits that justify the risks. Bayefsky and Berkman have set out criteria for the allocation of uteruses from dead donors, including the prospect of success, medical eligibility, and age, among others.<sup>20</sup> Bruno and Arora have suggested further criteria, such as lower priority for parties who have already given birth.<sup>21</sup>

We suggest that governments and private insurers rely on similar kinds of **guidelines** to set out exclusion criteria for UTx, such that even when payers cover the costs for some,

they would retain the moral right to exclude coverage of UTx for other parties. Even if there are limits on subsidies, the case could be made that no moral obstacle stands in the way of justifying subsidies for UTx for some transwomen and transmen, just as there seems to be no fully persuasive argument against gestating a child via UTx.

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**MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE**

**How Should Clinicians Navigate Decision Making About Genital Reconstructive Surgeries Among Intersex and Transgender Populations?**

Frances Grimstad, MD, MS, Jessica Kremen, MD, Elizabeth R. Boskey, PhD, MPH, LICSW, and Hannah Wenger, MD

**Abstract**

Genital reconstructive surgeries (GRS) are available for a variety of indications and populations, including transgender and gender diverse (TGD) individuals and those with intersex traits/differences in sex development (I/dsd). Despite the common outcomes of GRS for TGD and I/dsd individuals, decision making about this surgical care differs between these populations and across the lifespan. Sociocultural perspectives on sexuality and gender dominate the ethics of GRS, and reform is needed within clinical ethics to center the autonomy of TGD and I/dsd individuals in informed consent processes. Such changes are necessary to ensure justice in health care for all sex and gender diverse individuals across the lifespan.

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**Introduction**

For transgender and gender diverse (TGD) individuals and for those with intersex traits/differences in sex development (I/dsd)—an umbrella term used to describe a constellation of congenital variations in sex traits—genital reconstructive surgeries (GRS) have analogous aesthetic and functional outcomes that contribute to sexual, gender, and reproductive health.<sup>1,2</sup> Candidacy for GRS among sex and gender diverse populations has historically varied based on age. GRS for TGD populations is primarily accessible to adults, usually those who have reached the legal age of majority.<sup>1</sup> In contrast, individuals with I/dsd are often considered for GRS in infancy and childhood.<sup>3</sup> The ethics of **decision making about GRS** in these respective populations has evolved in parallel with clinical norms, such that considerations of beneficence and nonmaleficence in GRS—which are steeped in dominant societal notions of sexuality and gender—supersede considerations of respect for autonomy and justice.

After describing sociocultural norms of sexuality and gender, we examine historical and contemporary ethics of decision making about GRS that are influenced by these norms. Based on our collective history and extensive discussions with clinicians, community

members, and advocates, we assert that GRS across the lifespan is ethically sound when the autonomy of sex and gender diverse individuals is centered in decision making and when these individuals are active participants in informed consent processes. We also identify and problematize divergent approaches to informed consent that do not consistently empower sex and gender diverse individuals as decision makers—either in adulthood or in adolescence, a period in the lifespan when both TGD individuals and those with I/dsd may seek GRS.

### **Influence of Sociocultural Norms on GRS**

Sociocultural norms about sexuality and gender in the United States inform “standard” expectations for GRS procedures and associated surgical goals and outcomes. For example, people with 46 XX chromosomes who have virilizing congenital adrenal hyperplasia (CAH) are routinely considered for clitoral recession procedures because they have female sex organs (ovaries, uterus, and vagina) and gender identity (often reared from birth as female). Clinicians are less likely to expect that these patients will want metoidioplasty and urethral lengthening to create a more prominent phallus. It is assumed in these cases that societal norms and individual preferences will favor external genitalia typical of an endosex female (whose sexual traits are aligned with what is expected of “female” sexed bodies). We use the term *endosex* and explicitly name the majority category to avoid the implicit othering of minority individuals that occurs when framing minority status as being in opposition to “normal.”

Notably, there is some evidence that girls with virilizing CAH are more likely to identify as non-cisgender than girls without CAH and that some 46,XX CAH children may do well when raised male.<sup>4</sup> As such, the threshold for parental consent for GRS to “correct” I/dsd variations—typically, for clitoroplasty in a child with CAH—is lower than the threshold for parental consent for GRS to affirm gender identity—eg, for metoidioplasty in an adolescent with CAH—because the former aligns with normative societal expectations, while the latter does not. As a result of such norms, TGD individuals across the lifespan also encounter clinicians who are hesitant or reticent to perform GRS when projected surgical outcomes do not aesthetically or functionally align with binary endosex standards. For example, vaginal sparing phalloplasty is a “nonstandard” GRS procedure that creates a phallus and preserves a functional vagina.

### **Historical and Medical Context for GRS**

*I/dsd populations.* It is estimated that individuals with I/dsd compose up to 2% of the global population.<sup>5</sup> GRS in individuals with I/dsd is medically indicated to treat or normalize genital aesthetic and functional variance.<sup>2</sup> For example, urogenital sinus mobilization separates urethral and vaginal openings to achieve average, endosex female anatomical genital appearance and to promote future sexual and reproductive capacity, including tampon insertion, penile-vaginal intercourse with effective insemination, and the capacity for vaginal delivery.<sup>6</sup> Originating in the 1930s, GRS for individuals with I/dsd made possible the alteration of infants’ genitals in order to align their gross anatomy and functionality with that of endosex individuals’ genitalia.<sup>7</sup> Throughout the history of GRS for individuals with I/dsd, medical and ethics academics have endorsed—and clinicians have consistently upheld—guardians as the most appropriate decision makers regarding their children’s sexual, gender, and reproductive health.<sup>7</sup> Prevailing ethical norms and legal standards continue to empower guardians to decide for or against infant or childhood GRS for individuals with I/dsd.

Since the 1990s, some individuals with I/dsd have shared lived experiences of early GRS as negatively affecting their sexual function and reproductive potential.<sup>8</sup> These stakeholders have also voiced concerns about genital anatomical modifications in infancy or early childhood that could conflict with an individual's future gender identity and embodiment goals.<sup>8</sup> Their advocacy has invoked the principle of respect for autonomy and the right to an open future—the right of the child to self-determination, including the ability, upon achieving maturity, to make decisions about gender identity, sexual anatomy, and sexual and reproductive function—as guideposts of ethical decision making about GRS. Accordingly, clinicians and guardians in contemporary US health care settings have been called upon to postpone GRS until individuals with I/dsd can participate in informed consent processes.<sup>9</sup> However, GRS in infancy and early childhood remains the **standard of care** for I/dsd populations at most US medical institutions.<sup>2</sup>

*TGD populations.* While global prevalence estimates are difficult to establish, TGD individuals compose around 0.6% of the US population, although the percentage is higher among adolescents (1.4%).<sup>10</sup> Up to two-thirds of members of the TGD population in the United States may, during their lifetime, desire GRS to treat or relieve gender incongruence or dysphoria—distress arising from a mismatch between their gender and their sense of their physical, psychological, and emotional self.<sup>11</sup> In its nascence, GRS for TGD individuals encompassed procedures common to GRS for individuals with I/dsd but the procedures were performed only on adults. Initial surgeries modified postpubertal genital anatomy according to aesthetic standards of endosex individuals of the “opposite” sex, and therefore surgical outcomes achieved select aspects of genital functionality per standards of heterosexuality.<sup>12</sup> Despite differing medical indications, GRS in TGD and I/dsd populations shared similar periprocedural complications and postprocedural sequelae related to fertility and sexual function.<sup>1,3</sup>

Historically, TGD individuals received nominal direction from clinicians regarding medical interventions of relevance to their sexual, gender, and reproductive health and thus sought GRS at their own discretion.<sup>13,14</sup> In contrast to candidacy for GRS for individuals with I/dsd, eligibility for GRS for TGD individuals was often contingent on presurgical psychological evaluations intended to assess TGD individuals' readiness for GRS and to protect clinicians from ethical and legal scrutiny. This legacy reverberates in contemporary insurance and institutional requirements for GRS for TGD individuals in the United States.<sup>1,12,15</sup> Notably, GRS is not widely accessible to TGD individuals in the United States before the legal age of majority, even with guardians' consent.<sup>16</sup> This age-related criterion for GRS reflects the international gold standard for TGD medical care set by the World Professional Association of Transgender Health (WPATH), which specified, until its most recent guidance update in 2022,<sup>17</sup> that GRS should not be undertaken until the age of majority in any given country and, unlike with chest surgeries, WPATH did not provide alternate eligibility criteria for adolescents.<sup>1</sup>

### **Inconsistencies in Decision Making**

Informed consent manifests the ethical principle of respect for an individual's autonomy in decision making about medical care; upholds personal values of self-determination, sovereignty, authenticity, and best interest; and realizes intentional, collective, and relational decision making among individuals and other stakeholders.<sup>18</sup> While clinicians are habitual stakeholders, guardians become stakeholders when individuals do not meet legal and clinical standards of competence and capacity. Importantly, in childhood and adolescence, guardians are stakeholders with legal authority to make decisions for

the child,<sup>19,20</sup> which is relevant to the ways in which decision making about GRS occurs for individuals with I/dsd.

*I/dsd populations.* Because GRS for individuals with I/dsd is most often performed in infancy and early childhood when the future preferences of individuals with I/dsd are unknowable, the locus of informed consent is the guardian. At this life stage, an individual with I/dsd's assent is unobtainable. Neither legal competence nor decision-making capacity are present. As such, guardians rely upon their own values, those of clinicians, and the perceived values of society writ large to make a decision about GRS that they believe is in the best interest of the individual with I/dsd. In the context of clinical counseling, these stakeholders may be influenced by assumptions not associated with high-quality scientific evidence—specifically, the assumption that children with endosex genitalia will have better psychosocial outcomes than children with intersex genitalia in maturity.<sup>7</sup> In addition, decisions about surgery may reflect culturally determined assumptions, including that a child with I/dsd will mature as heterosexual and desire aesthetically and functionally normative genitalia. Acceptance of a right to an open future prioritizes the as-yet-unknown values of an individual with I/dsd during childhood and can guide the guardian's determination of the individual's best interest regarding early GRS.<sup>19</sup>

*TGD populations.* In contrast to individuals with I/dsd, TGD individuals are central to decision making about GRS. Legal competence, as primarily defined by attainment of the legal age of majority, is ethically requisite. Consequently, informed consent for GRS most often occurs during adulthood, and the individual's preferences and conception of quality of life are considered essential but insufficient for informed consent. Many clinicians and Global North societies view age as a proxy for psychological and cognitive maturity and dispute TGD adolescents' ability to conceptualize their preferences about GRS.<sup>1,20,21</sup> As such, societal obligation to the welfare of children is often considered to preclude GRS for TGD adolescents, even if they seek to assent and consent is given by their guardian(s). Importantly, many TGD adolescents have a strong sense of self-determination, authenticity, and their own best interest, although these values are rarely given substantive consideration or factored into professional guidelines concerning decision making about GRS for TGD adolescents.<sup>20</sup>

Despite the growing acceptance of gender diversity in Global North societies, ethical standards for decision making about GRS continue to incorporate the assumption that TGD individuals' original genitalia are "normal" and "healthy" and to posit regret as a significant risk of surgery.<sup>17</sup> Psychological evaluations are often required to corroborate an individual's preferences and decision-making capacity, an insurance- and clinician-driven criterion that TGD and medical advocates identify as excessively restrictive and medically unnecessary.<sup>21</sup> Desired genital alterations in GRS are diverse (see Table), and individuals whose preferences do not align with binary endosex norms can also experience regret if they do not undergo GRS.<sup>22</sup>

**Table.** Examples of GRS in I/dsd and TGD Populations

Procedure	Used in I/dsd <sup>a</sup>	Used in TGD <sup>a</sup>	Effects on Fertility
Clitoroplasty	Yes	Yes	None
Gonadectomy <sup>b</sup>	Yes	Yes	Removal is sterilizing if gonads are functional
Hysterectomy	Yes	Yes	Sterilizing
Excision of mullerian remnants <sup>b</sup>	Yes	Yes	Risk of impaired fertility
Labioplasty	Yes	Yes	None
Penectomy	No	Yes	None
Phalloplasty	No	Yes	None
Scrotoplasty	No	Yes	None
Urethral lengthening or shortening	Yes	Yes	Lengthening may facilitate penile-vaginal sex if performed in a sperm-producing individual with I/dsd <sup>c</sup>
Urogenital sinus mobilization	Yes	No	May address issues that affect fertility of individual with I/dsd during penile-vaginal sex <sup>c</sup>
Vaginectomy	No	Yes	None
Vaginoplasty	Yes	Yes	Sterilizing if testes of TGD individuals removed; may address obstructive issues that affect fertility of I/dsd individuals during penile-vaginal sex <sup>c</sup>

<sup>a</sup> Refers to typical usage. The use of any type of surgery in both populations does not assume the same surgical techniques.

<sup>b</sup> Not technically genital surgery.

<sup>c</sup> Facilitating penile-vaginal intercourse and/or improving the structural connection between vagina and uterus can improve the fertility potential of penile-vaginal intercourse, which may or may not be considered as altering baseline fertility.

As of February 2023, 28 US state governments have introduced or passed legislation banning GRS and other **gender-affirming care for TGD minors**, even with guardian consent.<sup>23</sup> In some states, this legislation subjects to criminal liability any clinicians who provide GRS or guardians who consent to such care for TGD adolescents.<sup>23,24</sup> While eliminating the rights of guardians of TGD adolescents to consent to GRS actively desired and sought by their minor offspring, these mandates often incorporate explicit GRS exemptions for guardians of I/dsd infants and children and tacit permission for gender-affirming care among cisgender adolescents, such as breast augmentation or gynecomastia repair, with guardian consent.<sup>25</sup> Such laws and policies reify an “ethics of normativity” in decision making about GRS. They also empower state governments as an implicit stakeholder, one with autonomy disproportionate to that entrusted to individuals, clinicians, and guardians and that tends to enforce sexual and gender uniformity as defined by dominant Global North societies.<sup>7</sup> An ethics of normativity undermines respect for autonomy and defines beneficence and nonmaleficence solely in terms of the expectations of these societies. This reality precludes ethically sound informed consent for GRS in adolescence.

### Working With I/dsd and TGD Populations

We recommend reform of clinical ethics to prioritize the autonomy of TGD adolescents and those with I/dsd irrespective of dominant sociocultural expectations regarding GRS. We propose the following key considerations to guide decision making and practice:

1. *GRS must be considered within an ethical context that understands sex and gender diversity to be normal, not pathological, states.* Within such a decision-making framework, clinicians and other stakeholders champion the autonomy of TGD youth and those with I/dsd by emphasizing their self-determination, sovereignty, authenticity, and best interest. Ethically sound informed consent for GRS—especially concerning the rights of guardians to consent to these procedures for children and adolescents—warrants that the individuals who would be undergoing the procedure be considered active stakeholders and that their rights be given precedence when appropriate, based on their decisional capacity.
2. *The right to an open future must be prioritized in decision making about GRS for children and adolescents.* Reproductive and sexual health are universal human rights.<sup>26</sup> Decisions about fertility and sexuality are to be driven, to the extent possible, by the individuals that they most directly affect. Furthermore, all GRS must explicitly direct their primary benefit to the individual, as opposed to the guardian, the clinician, or other stakeholders.
3. *Assessment of adolescents' decisional capacity using best practices is imperative to decision making about GRS for adolescents.*<sup>27</sup>

Health care justice for TGD individuals and those with I/dsd requires explicit acknowledgment of dominant societal expectations so that they may be intentionally factored into decision making. Within this evolved ethics of GRS, justice is promoted by centering respect for the individual's autonomy in decision making, seeing beneficence and nonmaleficence as principles that must derive from the locus of individual autonomy, and prioritizing the present and future rights of the individual over those of other implicit and explicit stakeholders.

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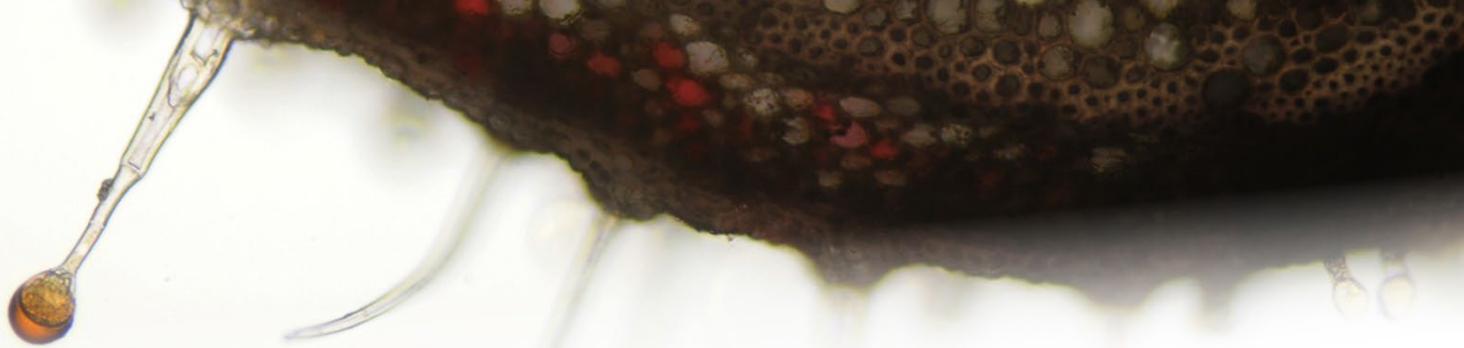
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## AMA Journal of Ethics®

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### HISTORY OF MEDICINE: PEER-REVIEWED ARTICLE

#### 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.<sup>1</sup> 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.<sup>2</sup> 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.<sup>2</sup> 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.<sup>3</sup> 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.<sup>3</sup>

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.<sup>4</sup> 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.<sup>4</sup> 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.<sup>5</sup>

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.<sup>6</sup> The fifth edition of *DSM* in 2013 also opted to use the term *gender dysphoria* in an effort to depathologize its terminology.<sup>7</sup> 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.<sup>2</sup> 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.<sup>8</sup>

*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.<sup>9</sup> 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.<sup>9</sup>

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.<sup>10</sup> 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.<sup>11</sup> 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.<sup>12</sup> 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.<sup>5</sup> 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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### VIEWPOINT: PEER-REVIEWED ARTICLE

#### More Lessons for Health Professionals From a Transgender Patient

Ryan K. Sallans, MA

##### Abstract

Over the past decade, ways of defining self in relation to gender identity and forms of expression have widely expanded. Along with this expansion of identifying language, there has been an increase in medical professionals and clinics specializing in providing gender care. Yet many barriers to providing this care still exist for clinicians—including their comfort with and knowledge about collecting and retaining a patient's demographic information, respecting the name and pronouns a patient goes by, and providing overall ethical care. This article shares one transgender person's numerous health care encounters over 20 years as both a patient and a professional.

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##### Lessons to Explore

Over the course of my professional career, I have had the great honor and privilege to observe how current institutions provide **gender care** and to share my perspective on what works well and what creates further confusion or potential for harm. The following lessons complement my 2016 publication in the *AMA Journal of Ethics*,<sup>1</sup> with additional guidance from past and present research.

*Lesson 1: Understanding transgender health means understanding needs of transgender people.* Accessing health care for transition-related reasons or other needs can be difficult for transgender patients. A 2015 survey of nearly 28 000 transgender respondents found that 55% were denied coverage for transition-related surgery, 23% did not see a doctor for fear of being mistreated, and 33% reported avoiding doctors due to inability to afford care.<sup>2</sup> The risk of suicide and substance use is also disproportionately higher among transgender people than in the US population as a whole, with 40% of transgender people and 4.6% of Americans reporting having attempted suicide at least once in their lifetime and 3 times as many transgender people as people in the US population using illicit drugs or drugs not prescribed to them.<sup>2,3</sup>

In order to better advocate for patients' access to care and coverage, it is important for health professions students and professionals to have awareness of the factors that exacerbate patient vulnerabilities, such as pervasive social and cultural discrimination and lack of employment or insurance coverage.

*Lesson 2: Allow space for—but do not force—patients to share information about sexual orientation and/or gender identity at each health care visit.* It is now recommended to routinely collect demographic information related to a patient's sexual orientation (SO) and gender identity (GI), otherwise referred to as SO/GI.<sup>4,5,6</sup> There are many opportunities to allow for patient self-disclosure—including the name one goes by and one's pronouns, sex, gender, and orientation—during a health care visit. Self-disclosure begins with the initial paperwork and extends to the exam room. Demographic information may be collected through self-reporting at intake or registration, reporting by caregivers, or conversations with clinicians.<sup>7</sup>

While health care organizations and agencies recommend completing these fields in the electronic health record to improve access to and quality of care,<sup>6</sup> it is important to allow the option to disclose or not. In addition, there are practical barriers to data collection that stem from clinicians' discomfort with and lack of training in collecting and interpreting information and from patients' hesitancy to disclose.<sup>5,6,7</sup> Another factor to consider is the impact and influence of minority stress—including the patient's expectation of rejection, identity concealment, and internalized stigma<sup>8</sup>—and whether it is appropriate to collect information about SO/GI based on the reason for the patient's health care visit.

*Lesson 3: Take care not to “out” patients who aren't “out” to everyone; ask patients what information to document in their health records and preserve confidentiality.* It is not uncommon for transgender patients to avoid sharing information about their identity and medical history with health care professionals due to past negative experiences in health care settings. Having paperwork and electronic health records set up for patient self-disclosure may help eliminate the potential for an awkward exchange. Ensuring that patients can list their gender pronouns and the name they go by rather than their legal name may be a source of comfort for patients who are anxious about misgendering. Other patients may choose not to list pronouns and may find it uncomfortable or not genuine if asked.

An option I strongly caution against is having staff directly ask about demographic information related to SO/GI at the time of front-desk registration. Information about any patient's gender or sexual orientation can be highly private. Openly asking a patient this information may “out” them to people they have not informed or to strangers in the room, causing confusion or unnecessary discomfort. For example, while I was working as a consultant for a large hospital network, it was shared that a parent and child were checking in with the front desk staff. The staff asked the child's gender identity, at which the child turned to her mom and cried while saying, “They think I am a boy?!”

It is also important for health care professionals and staff not to complete demographic fields in the electronic health record based on assumptions or without a patient's permission. I recently visited a health care setting for my yearly physical and lab work associated with my ongoing use of testosterone. When looking through the chart, I saw my sexual orientation was listed as heterosexual. I did not complete that field, nor am I

heterosexual. Assuming identity based on relationship status can cause clinicians to overlook screening for certain health behaviors and health risks.

Professionals who show sensitivity to transgender patients' risks and needs can increase patients' trust. When patients trust you as a health care professional and come out as transgender, express respect for their trust. Showing respect includes discussing what should and should not be placed in health records, particularly correspondence to other clinicians or third-party payers. For all future visits, note paperwork in case patients change or update information.

*Lesson 4: Not all transgender patients are alike, self-identify with the same language, and need the same things from health care.* Each transgender patient has a different story and different needs—including for general health care—that are unrelated to their transition status. Regarding medically assisted components of a transition, some transgender patients seek numerous interventions, others want only some interventions, and still others seek no medical assistance for their transition.<sup>9</sup> Transgender identities and needs exist on a spectrum, and attempting to classify, generalize, or routinize them is not always helpful.

When serving transgender patients, be mindful that more than half the total number of publications ever printed on transgender issues have been published since 2010.<sup>10</sup> Another literature review on articles published between January 1997 and March 2017 noted that 32% of the studies were published in 2016 and 80.5% were published after 2011.<sup>8</sup> All were conducted in major cities, thereby underrepresenting patients outside of urban locations.

Relying on guidance from research conducted largely within the last 5 years in major cities limits historical and contemporary representation, as well as the **gender language** used. For example, current literature often uses terms such as *transgender* and *nonbinary* to identify patients who seek either transition or forms of expression outside male and female genders while noting that the words *transsexualism* and *transexual* are outdated and potentially offensive. For people who identify as transexual, this messaging stigmatizes their lived experience. When I share my medical history, I state that I am a transexual man in order to clarify that I've crossed my sexed body from female to male. Contemporary gender terms are still being explored and require further ethical consideration.<sup>11</sup> Placing transgender people in binary (male and female) or nonbinary (outside of male and female) categories potentially creates further confusion.<sup>12</sup> For example, I have a personal identity of being either transgender or transexual, but I do not identify as being binary. For me, binary is related to a structured system, not an individual's sense of self. A suggested umbrella term is *gender diverse*.<sup>11</sup>

*Lesson 5: Advocacy for changing how we diagnose and treat transgender patients will continue to decrease stigma and misperceptions.* How health care professionals code a patient's health care visit might impact that patient's current and future care and others' perceptions. In 2022, the *International Classification of Diseases* version 11 (*ICD-11*)<sup>13</sup> replaced the diagnostic categories "transsexualism" and "gender identity disorder of children" with "gender incongruence of adolescence and adulthood" and "gender incongruence of childhood," which made coding inclusive of the wide range of identities and unique needs of patients exploring or undergoing a form of gender transition.<sup>14</sup> It also moved the gender incongruence diagnostic categories from the chapter on mental health to the chapter on sexual health to further decrease

stigmatization of transgender people.<sup>13</sup> Ending the practice of classifying and coding patients with gender identity disorder in the *ICD* aligns with the removal of this language from the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* in 2013.<sup>15</sup> These are welcome changes, but one point of contention remains: for years, transgender patients and advocates have been requesting that coding and classification related to gender identity be removed from the *DSM* completely and that gender incongruence solely be included in the *ICD* to shift the focus on gender identity from mental illness to medical needs.<sup>16</sup>

Like any area of medicine, standards of care and best practice guidelines are continually being updated. In 2022, the World Professional Association for Transgender Health (WPATH) announced the release of Standards of Care, version 8 (SOC-8),<sup>9</sup> which expanded guidance for care of transgender adolescents and patients with gender diverse identities. In 2011, I attended the WPATH conference where SOC-7 was introduced.<sup>17</sup> Being someone that transitioned under SOC-6,<sup>18</sup> I welcomed the changes introduced. During my time of transitioning, clinicians could require a patient to undergo a year living as the gender they identified with to complete the “real life experience” before beginning administration of hormone therapy.<sup>18</sup> After a year of consistent administration of hormone therapy, a patient could then seek surgical care. The release of SOC-8 thus further addresses the diverse needs of transgender patients.

*Lesson 6: Transgender health literacy requires clinicians’ ongoing education and training.* Opportunities to explore gender through social and medical transition options have rapidly expanded as information technology has increased transgender visibility.<sup>19</sup> There has also been an increase in acceptance and awareness of identities that venture beyond our understanding of male and female.<sup>11</sup> Yet medical schools and health service organizations recognize that there is little training for clinicians on how to work with patients in relation to sexual orientation and gender identity.<sup>20</sup>

By following the American Medical Association (AMA) *Code of Medical Ethics*, clinicians can ensure that patients receive appropriate medical care. The *AMA Code* recommends that physicians meet patients where they are at, “present the medical facts accurately ... to make recommendations for management in accordance with good medical practice,” and “help the patient make choices from among therapeutic alternatives consistent with good medical practice.”<sup>21</sup> Gender-affirming care begins when one first enters a facility and sees oneself reflected in imagery, forms, and how one is addressed. Clinicians who show knowledge of transgender health and are comfortable in discussing patients’ specific needs will have a positive impact on the mental health of transgender patients,<sup>22</sup> specifically in the form of decreased depression, anxiety, and suicidality.<sup>8</sup>

Opportunities to increase transgender health literacy among clinicians include consultation,<sup>23</sup> conferences,<sup>24</sup> webinars,<sup>25</sup> books, and articles focused on transgender health care. It’s also critical for health care professionals to listen closely to individual patients’ stated needs to further grow their knowledge when serving transgender patients.

## **Conclusion**

These lessons have hopefully offered insight into unique issues that transgender patients confront when seeking health care services. Clinicians who practice cultural humility by listening to patients’ needs and by holding respectful conversations create safer environments that will hopefully deepen patients’ trust and lead to better care.

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**LETTER TO THE EDITOR**

**Response to “Science and Ethics of ‘Curing’ Misinformation”**

Jamaji C. Nwanaji-Enwerem, MD, PhD, MPP

In their article, “[Science and Ethics of ‘Curing’ Misinformation](#),” Freiling et al recognize scientific evidence as one of several factors that inform answers to public health policy questions and guidance on individual and social behavior. From this perspective, evaluating interactions between science and other policy-informing factors is likely pivotal for tackling misinformation and improving how sound scientific evidence is received. In this letter, I emphasize interpersonal trust as one of the most important conditions for science to beneficially contribute to societies—especially those that are democratic. Nevertheless, efforts to improve social trust might seem arduous. For instance, Freiling et al assert that rebuilding trust requires addressing underlying etiologies, such as structural inequities, and not simply symptoms. Here, I highlight [participatory methods](#) (ie, iterative cycles of co-creation, co-action, and co-learning that empower communities to create meaningful and sustainable change)<sup>1,2</sup> as a root cause-focused strategy that scientists and public health practitioners can employ in the near term to build trust and improve the impact of their science and interventions.

It is worth reflecting on the social conditions that best position science, among other factors, to maximally benefit democratic societies. Freiling et al argue that evidence-based claims that do not connect with social preferences and values or align with how people “make sense of information” are less likely to be adopted. Nevertheless, trust might transcend these other conditions, and efforts to build trust could avert the ethical pitfalls of social engineering strategies to [combat misinformation](#) (eg, inoculation and nudging) that the authors emphasize.

For example, an international analysis of countries’ resilience to COVID-19, defined as “the nationwide decay rate of daily cases or deaths from peak levels,” reported a significant, positive correlation between interpersonal trust and country-level pandemic resilience,<sup>3</sup> suggesting the importance of social trust in policy and science for public health success.<sup>4,5</sup> While building trust in society and institutions is a difficult task, often requiring long-term investments, scientists and public health practitioners can implement *daily* changes in their work that contribute to these broader efforts. Using participatory action methods in research and project implementation is one such approach. Stadnick et al engaged underserved community members in decisions about research projects aimed at improving COVID-19 testing and vaccine uptake.<sup>6</sup> In their work, involving community advisory boards at every step of the project—from framing of research aims and study design to program development—helped build trust with

communities, improved the likelihood of success of public health interventions, and bolstered the impact of the science.<sup>6</sup> Such lessons can be applied more generally.<sup>7</sup>

Overall, shifting the paradigm of “just follow the science” to “collectively do the science” would help foster relationships that build trust while maximizing the value and utility of science in policy-relevant processes.

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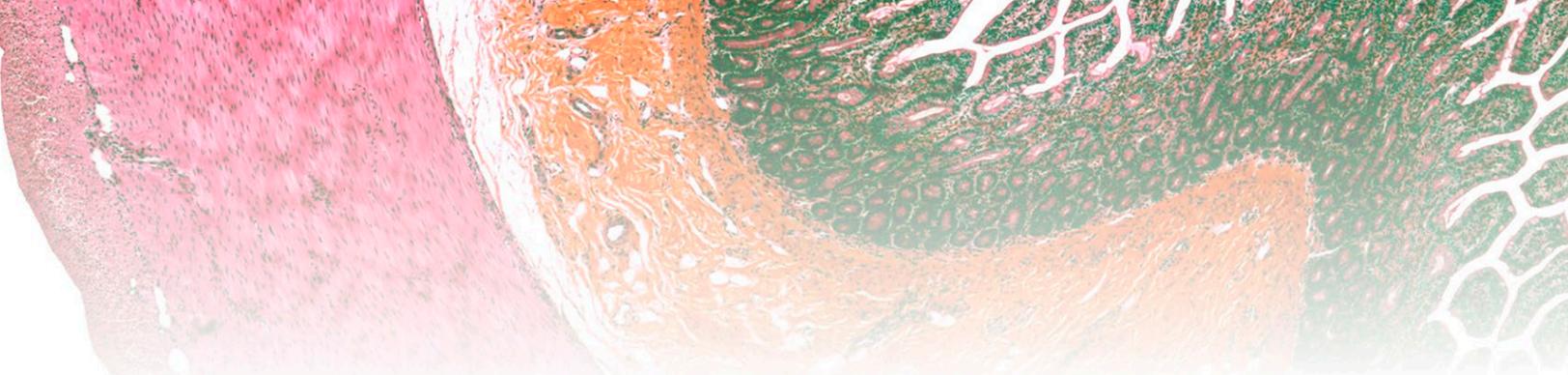
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### LETTER TO THE EDITOR

#### Healthy Conversation About Meat?

Jessica Pierce, PhD, Marc Bekoff, PhD, Hope Ferdowsian, MD, MPH, Barbara J. King, PhD, and L. Syd M. Johnson, PhD

We write in response to the journal's inclusion of Temple Grandin's "Answers to Patient, Student, and Clinician Questions About How Animals Are Slaughtered and Used for Food" in the April 2023 issue.

Grandin claims that, because cortisol levels in cattle are the same on a ranch and in a slaughterhouse, the animals are not stressed. This is not an evidence-based assertion. Cortisol levels are considered a rough and misleading measure of stress,<sup>1,2</sup> and "at a ranch" could refer to any number of possible environmental conditions.

Moreover, Grandin says that because cattle walking up a chute to be slaughtered behave in the same way as cattle walking up a chute to be vaccinated, animals in a slaughterhouse aren't aware they are going to die—which could be taken as ethical support for killing them. The scientific inference is mistaken, as is the moral logic. Her discussion of carbon dioxide stunning methods is equally unsettling, as if deceiving animals about what's happening to them (moving pigs with their group so that they feel "calm and excellent") makes that practice ethically acceptable. It is now widely acknowledged that human and animal behavior vary considerably in response to stress and trauma.<sup>3</sup> It is also widely acknowledged that animals have an interest in their own lives, seeking not merely the absence of pain and distress but also opportunities to flourish.<sup>4,5</sup>

Grandin claims that grazing cattle "can improve soil health and regenerate the land." In fact, grazing as currently practiced has negative impacts on the land.<sup>6,7</sup> It is curious that she doesn't talk about concentrated animal feeding operations, which are where nearly all our meat supply comes from,<sup>8</sup> and which are an environmental and public health disaster.<sup>8,9</sup>

The fact that Grandin has a conflict of interest is noted at the bottom of her article, and this conflict infuses all corners of her perspective—from the way she presents science to the way she presents ethics. The essay does a great disservice to patients, students, clinicians, and animals by offering a scientifically and ethically misleading apology for the meat industry. Publishing her essay in this forum is irresponsible from a clinical and public health point of view, as well as in light of the profound threat of climate change, and it carries serious negative implications for animal well-being.

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### LETTER TO THE EDITOR

#### Response to “Healthy Conversation About Meat?”

Temple Grandin, PhD

This letter responds to “Healthy Conversation About Meat?” It criticized my article, “Answers to Patient, Student, and Clinician Questions About How Animals Are Slaughtered and Used for Food.” The main focus of my article is conditions in slaughterhouses. On the cortisol issue, I did not state that the animals were not stressed. I said that animals’ stress levels at slaughter were similar to those during handling on a ranch.

There are 2 basic ethical schools of thought on the use of animals for food. One view is that using animals for food is wrong. The other view is that using animals for food can be done ethically.<sup>1</sup> I have spent a major part of my career improving conditions in slaughterhouses. In the 1970s and throughout the 1990s, conditions in some slaughterhouses were terrible. Today they are not perfect, but they have greatly improved.<sup>2</sup>

It was beyond the scope of my article to discuss the many problems with concentrated animal feeding operations. There are some serious animal welfare problems on some large farms.<sup>3</sup> Some of these problems will be more difficult to fix than slaughterhouses’ problems. The 2 species that have the greatest welfare issues with highly restrictive housing are pigs and laying hens. Farms and slaughterhouses that submit to regular inspections by large supermarket and restaurant buyers have better conditions.<sup>4</sup> The worst places are not inspected by buyers. The letter also contained a reference that supported regenerative grazing for soil health.<sup>5</sup> I have visited ranches where the land was improved with rotational grazing.<sup>6</sup> I have also observed land damaged by overgrazing. When rotation is done right, it can be beneficial for the land.

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**Temple Grandin, PhD** is a professor of animal science at Colorado State University in Fort Collins. She specializes in livestock handling and welfare.

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Dr Grandin reports doing paid consulting work on animal handling and welfare for major meat companies and restaurants.

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